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# Tales from the Crypt: Scientific, Ethical, and Legal Considerations for Biohistorical Analysis of Deceased Historical Figures

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# Tales from the Crypt: Scientific, Ethical, and Legal Considerations for Biohistorical Analysis of Deceased Historical Figures

Jordan Paradise, J.D.\* and Lori Andrews, J.D.<sup>+</sup>

"Blest be the man that spares these stones, and curst be he that moves my bones."
-- William Shakespeare's epitaph

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### I. INTRODUCTION

In June 2004, forensic scientists began digging up forty-nine graves housed in crypts beneath the Chapel of Medici located directly under the larger Chapel of San Lorenzo in Florence, Italy. The head researcher, paleopathologist Dr. Gino Forniciari, is no ghoulish vampire, but a professor of forensic anthropology and director of the Pathology Museum at Pisa University. He is disintering members of the Medici family, whose dynasty ruled Florence from the 13<sup>th</sup> century to the mid 16<sup>th</sup> century. The project is one of the largest exhumation studies ever undertaken. Researchers are exhuming a number of important historical figures spanning over ten generations reportedly buried within the Medici crypt, including: Grand Duke Cosimo I, the Grand Duke of Tuscany (1519-1574); Duchess Eleonora di Toleda, wife of Grand Duke Cosimo I (1522-1562); Grand Duke Francesco I, the second son of Grand Duke Cosimo I (1541-1587); and Giovanni delle Bande Nere, husband of the granddaughter of Lorenzo the Magnificent (1498-1526).

The goal of the Medici exhumations is to use methods of molecular biology and genetics to answer questions that have arisen throughout history, such as whether the Medici family had genetic predispositions to suffer from conditions such as gout, whether several of the members of the Medici family were in fact murdered rather than died of natural causes, and specifically whether Francesco I died of malaria or was poisoned. Recent reports have proclaimed that initial samples of Francesco's liver reveal a lethal dose of arsenic. The study also aims to determine if members of the Medici family were genetically inclined to suffer from various other diseases

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<sup>&</sup>lt;sup>1</sup> Nicole Winfield, Renaissance Glitterati to be Unearthed, MSNBC NEWS, Dec. 24, 2003, http://www.msnbc.msn.com/id/3802926/.

<sup>&</sup>lt;sup>2</sup> *Id*.

<sup>&</sup>lt;sup>3</sup> *Id*.

<sup>&</sup>lt;sup>4</sup> *Id*.

<sup>&</sup>lt;sup>5</sup> Thomas H. Maugh II, *Mining Myths of the Medicis*, L.A. TIMES, Mar. 11, 2005, at A5.

<sup>&</sup>lt;sup>6</sup> Rossella Lorenzi, Genetics to Reveal Secrets of the Medicis, DISCOVERY NEWS, Jan. 12, 2004, http://www.abc.net.au/science/news/stories/s1024266.htm.

<sup>&</sup>lt;sup>7</sup> For example, it had been recorded that the predecessor of Grand Duke Francesco I, who ruled Florence from 1574 until 1587, had been crippled by gout. One Medici was even known as Pietro il Gottoso (Peter the Gout). However, visual and radiological examination of the remains has shown some of this to be false. "In fact, [the forensic experts and] paleopathologists have established that he suffered from a form of arthritis called diffuse idiopathic skeletal hyperostosis, or Forestier's disease." John Hooper, *Tales from the Crypt that Bury Medici History in Ever Deeper Mystery*, THE GUARDIAN, Mar. 21, 2005, at 13, *available at* http://www.guardian.co.uk/international/story/0,3604,1442146,00.html.

<sup>&</sup>lt;sup>8</sup> Lorenzi, *supra* note 6

<sup>&</sup>lt;sup>9</sup> Maria Sanminiatelli, *Scientists May Have Found Medici Murder*, ASSOCIATED PRESS, Jan. 3, 2007, http://www.msnbc.msn.com/id/16453497; Francesco Mari, et. al., *The Mysterious Death of Francesco I de' Medici and Bianca Cappello: An Arsenic Murder?*, 333 BRIT. MED. J. 1299, 1301 (2006).

such as rheumatoid arthritis, cancer and obesity.<sup>10</sup> The Learning Channel filmed the first stages of the exhumation and analysis for a documentary, *Mummy Detective: Crypt of the Medici*, which aired in October 2004.<sup>11</sup>

While fascinating in theory, these studies are not without controversy, raising questions regarding what scientific, ethical, and legal concerns can (and should) override the desire to answer "historic questions." For example, a descendant of the Medici family living in Rome strongly opposes the exhumations and has hired a lawyer, arguing that the researchers have not obtained his permission to exhume his ancestors. He says, "'[i]f they went into your chapel, in your tomb, and opened your family's graves, how would you feel?""<sup>13</sup>

These biohistorical studies are being undertaken for myriad reasons, such as identification and authentication of remains, investigation into alleged criminal behavior, investigation into medical or psychological conditions, and even for purposes of commercialization. This type of research is underway in a number of disciplines, yet the justifications for biohistorical research are often based on insufficient historical or scientific evidence, as well as potentially inappropriate financial considerations. Due to the biological nature of much of this testing, biohistorical analysis can reveal personal and genetic information that a deceased public figure never shared with anyone or sometimes never knew. As a result, findings generated from biohistorical analysis can have a more profound impact on the image of that public figure and on his living relatives than the more traditional means of historical analysis, such as biographical and psychological studies. Biohistorical investigations can be unusually invasive, including disinterment of the dead or the release of private medical information regarding the historical figure, sometimes for dubious societal gain. Often a single researcher or hobbyist can obtain access to a strand of hair or spot of blood from a historical figure and undertake a biohistorical analysis.

Although we acknowledge that the promotion of research and knowledge is important, there are other considerations that may warrant limitations on this type of research. For this project, we analyzed potentially applicable federal statutes, case law, and codes and guidelines from twenty-six professional organizations and societies informative to the field of biohistory. We surveyed the field, identified deficiencies in oversight and guidance, investigated prior biohistorical studies, and concluded that greater consideration of a variety of scientific, ethical and legal issues is needed. The article uses legal and ethical precedents to propose ways to avert abuses in five key areas we identified as important: (1) promotion of research; (2) access to samples or artifact; (3) scientific integrity and dissemination of results; (4) informed consent and rights of participants; and (5) avoidance of conflicts of interest. Throughout, we make suggestions for averting key abuses in these five areas, anchored on the utilization of Biohistorical Review Boards specifically

<sup>&</sup>lt;sup>10</sup> Lorenzi, supra note 6.

<sup>&</sup>lt;sup>11</sup> Mummy Detective: Crypt of the Medici (The Learning Channel television broadcast Oct. 17, 2004); *see also* Mark Rose, Medici Mystery, Archaeology, Oct. 12, 2004, http://www.archaeology.org/online/reviews/medici.html (reviewing the televised documentary).

<sup>&</sup>lt;sup>12</sup> Alan Feuer, Where the Bodies Are Buried, Modern-Day Medici Feud, N.Y. TIMES, May 4, 2004, at A4.

<sup>&</sup>lt;sup>13</sup> *Id*.

informed of the biohistorical nature and metholodogy of the study.

Part II introduces the field of biohistorical analysis, identifying relevant terms, presenting concerns that have arisen in the conduct of biohistorical research, and highlighting a number of key research endeavors in the field. Part III explores the lack of legal limitations and professional guidance in this area, focusing in on the five key areas, drawing examples mainly from federal regulations, relevant case law and professional codes and guidelines, but also utilizing recent biohistorical studies as well. Throughout, we identify critical questions, concerns, and considerations for biohistory. We conclude with suggestions for development of guidance in this area.

### II. "BIOHISTORICAL ANALYSIS": TERMS, METHODS, AND CASE STUDIES

Developments in science and technology have given researchers new means to undertake research on historical figures and historical artifacts. Biohistorical analysis involves using historic specimens of human remains or human material extracted or derived from historical artifacts (including complete or nearly-complete human corpses and partial human remains, such as blood, tissue, and hair) to gather evidence about specimens that are *identifiable* or specimens that are at least *attributed* to a historic figure at the time of the research. This excludes large-scale exhumations of unmarked graves, burial sites, or disaster sites involving unidentified or unidentifiable specimens.

Techniques of bioanalysis commonly used in medicine, paternity, forensics, and criminal cases -- such as DNA testing or biochemical assays -- are now being applied to answer historical questions. As this area of research is gaining momentum, it is beginning to catch the attention of the mainstream media and society. Since 2000, numerous films and books have portrayed this research, including *Beethoven's Hair* (both a book and a short documentary 14), *Digging Up Butch and Sundance*, 15 *Possessing Genius: The Bizarre Odyssey of Einstein's Brain*, 16 *Voice for the Dead*, 17 and *Abraham Lincoln's DNA and other Adventures in Genetics*. 18 Fascination with more personal souvenirs from deceased historical figures and even living celebrities such as hair clippings and chewed gum is becoming more widespread.

Biological testing and analytic techniques of these specimens include chemical or biochemical analysis (including toxin or trace metal analysis), skeletal analysis (both physical and anthropological), blood analysis, microscopical analysis, and DNA analysis. This "bioanalysis" of historical artifacts and remains is being proposed for several reasons, including (1) authentication, (2) investigation, and (3) commercialization.

### 1. Authentication

Authentication studies involve the use of biohistorical analysis to confirm the

<sup>15</sup> ANNE MEADOWS, DIGGING UP BUTCH AND SUNDANCE (Univ. of Neb. Press 2003).

<sup>&</sup>lt;sup>14</sup> RUSSELL MARTIN, BEETHOVEN'S HAIR (2005).

 $<sup>^{16}</sup>$  Carolyn Abraham, Possessing Genius: The Bizarre Odyssey of Einstein's Brain (2002).

 $<sup>^{17}</sup>$  James Starrs, A Voice for the Dead: A Forensic Investigator's Pursuit of the Truth in the Grave (2005).

 $<sup>^{\</sup>rm 18}$  Philip R. Reilly, Abraham Lincoln's DNA and other Adventures in Genetics (2000).

authenticity of a historic specimen. These include testing to determine whether a particular object contains human biological material, such as the cloak worn by Mary Todd Lincoln and allegedly soaked with the President's blood on the night of his assassination. Testing has also been undertaken to determine whether human remains are rightly attributed to a particular historical figure, such as Nicholas Copernicus or the Romanov family.

### Copernicus

In early 2006, Polish archeologists claim to have found the skull of Nicholas Copernicus, the 16<sup>th</sup> century astronomer who was the first to demonstrate that the earth orbited the sun. 19 The remains, found under an altar of Frombork Cathedral on Poland's Baltic coast, consisted of a skull with a broken nose, a feature commonly attributed to Copernicus in contemporary portraits.<sup>20</sup> Researchers with the Central Forensic Laboratory of the Polish national police reconstructed the facial image using the skull, developing a computer-generated image of an old man with stringy white hair, bushy eyebrows and a prominent nose.<sup>21</sup> Researchers want to initiate DNA tests on the skull, proposing an excavation to look for the remains of Copernicus's uncle, Lucas Waczenrode, the former bishop of Warmia to provide a genetic reference sample. Although believed to be buried in Frombork Cathedral, Waczenrode's specific burial site is unknown,<sup>22</sup> meaning that locating his body underneath the cathedral floor could take years and could disinter numerous others in the process--assuming it is there at all. Another impediment to the project plan is that Soviet soldiers in World War II burned most of Frombork and looted the cathedral on their way to Germany.<sup>23</sup> Excavations have yet to begin,<sup>24</sup> but despite a complete lack of knowledge as to the location of the relevant grave and past lootings of the site, researchers are clamoring for the opportunity.

### Abraham Lincoln

The Chicago Historical Society's (CHS) internationally renowned Lincoln and Civil War holdings include the most comprehensive collection of artifacts relating to Abraham Lincoln's assassination, including a stained cloak attributed to Mary Todd Lincoln on the night of the assassination.<sup>25</sup> To date, various proposals to test the blood stain on the cloak have been submitted to the CHS, which has carefully considered legal and ethical issues in making repeated determinations to reject the proposals.<sup>26</sup>

In 1999, CHS convened a conference of historians, scientists, and museum

<sup>&</sup>lt;sup>19</sup> Craig Whitlock, *It Could Be the Head Of Nicholas Copernicus; Breakthrough in Search for Remains Forces Reckoning in Poland*, THE WASH. POST, Feb. 26, 2006, at A12.

<sup>&</sup>lt;sup>20</sup> *Id*.

<sup>&</sup>lt;sup>21</sup> *Id*.

<sup>&</sup>lt;sup>22</sup> Craig Whitlock, *Polish Dig Unearths Probable Remains of Copernicus, and a Small Nationality Problem*, THE IRISH TIMES, Feb. 27, 2006, at 11.

<sup>&</sup>lt;sup>23</sup> Andrew Curry, *Copernicus Unearthed*, SMITHSONIAN, May 2006, at 22, 22-24.

<sup>&</sup>lt;sup>24</sup> *Id*.

<sup>&</sup>lt;sup>25</sup> Chicago Historical Society, Wet with Blood, http://www.chicagohistory.org/wetwithblood/index.htm (last visited Nov. 29, 2007). Other alleged Lincoln assassination relics held by the Chicago Historical Society include bloody bed linens, stained dress fragments, and hair samples. Id.
<sup>26</sup> Id.

professionals to consider DNA analysis of the cloak.<sup>27</sup> Participants determined that the request to perform DNA testing would be denied on the grounds that the available analytical techniques would destroy a significant quantity of original material and that there was no established Lincoln genetic profile for comparative analysis.<sup>28</sup> The possibility of future DNA analysis was not ruled out, pending additional historical research, microscopal research, the development of nondestructive verifiable sampling and testing techniques, and the availability of an established Lincoln genetic profile.<sup>29</sup> Currently, the Chicago Historical Society (CHS), now called the Chicago History Museum, is reportedly discussing testing of the cloak with University of Minnesota researchers, who have established a genetic profile of 300 Lincoln descendants through their work with spinocerebellar ataxia type 5, a genetic neurological disorder affecting coordination.<sup>30</sup> Their bank of genetic reference samples from such a large number of descendants is promising, yet details involving the level of destruction to the cloak will likely be the major consideration as discussions progress.

Similarly, the National Museum of Health and Medicine American Forces Institute of Pathology (AFIP) established two panels to review proposals to test blood stains on the cuffs of the coat worn by the surgeon who removed the bullet that killed Lincoln.<sup>31</sup> In May 1991, the first panel looked at ethical, legal, and social questions of conducting genetic testing on human medical samples held by the Museum; in April 1992, the second looked specifically at the feasibility of testing the Lincoln artifacts held by the Museum based on current methodology and scientific understanding.<sup>32</sup> Chaired by Victor A. McKusick, Professor of Medical Genetics at the Johns Hopkins University School of Medicine, they determined that testing would destroy the artifact and opted not to go forward with testing.<sup>33</sup>

Proposals for studies to test alleged blood from Abraham Lincoln on the night of his assassination raise problems with scientific integrity, highlighting inadequacies in scientific methodology because the blood samples cannot be authoritatively identified as belonging to the President. These proposed Lincoln studies also involve scientific integrity issues regarding destruction of artifacts because the blood-stained cloak allegedly worn by Mary Todd Lincoln and the surgeon's coat would have to be damaged in order to utilize the blood sample.<sup>34</sup>

### The Romanovs

A team of researchers led by British scientists Peter Gill and Kevin Sullivan of the Forensic Science Service in England targeted remains unearthed in 1991 from a

<sup>&</sup>lt;sup>27</sup> *Id*.

<sup>&</sup>lt;sup>28</sup> *Id*.

<sup>&</sup>lt;sup>29</sup> *Id*.

<sup>&</sup>lt;sup>30</sup> Andrew Herrmann, DNA Tests Might Find What Ailed Lincoln, CHI. SUN-TIMES, January 28, 2006, at 2. See also Yoshio Ikeda, et al., Spectrin Muations Cause Spinocerebellar Ataxia Type 5, 38 NATURE GENETICS 184, 184 (2006) (describing genetic research of an American family having two major branches that descended from paternal grandparents of President Lincoln).

<sup>31</sup> Glen W. Davidson, Abraham Lincoln and the DNA Controversy, J. ABRAHAM LINCOLN ASS'N, WINTER 1996, at 1, 21-26 (1996).

<sup>&</sup>lt;sup>32</sup> Id.

<sup>&</sup>lt;sup>33</sup> *Id.* at 24-26.

<sup>&</sup>lt;sup>34</sup> Chicago Historical Society, *supra* note 25.

site located in Ekaterinburg, Russia.<sup>35</sup> The remains were purportedly the bodies of Tsar Nicholas II and his family who had been brutally killed by the Bolsheviks in July of 1918.<sup>36</sup> The findings were published in 1994,<sup>37</sup> reporting that DNA-based sex testing and short tandem repeat (STR) analysis confirmed the presence of a family group in the grave and that analysis of mitochondrial DNA showed an exact sequence match between the purported remains of the Tsarina and three of her children and a living maternal relative, Prince Philip, the Duke of Edinburgh.<sup>38</sup> The scientists concluded that they had discovered the Romanovs, a finding accepted and lauded by the Russian government and widely covered in the international press.<sup>39</sup> However, the scientific methodology employed in the study has been attacked by other scientists as inappropriate and the conclusions inaccurate.<sup>40</sup>

### Billy the Kid

Prevailing history declares that William H. Bonney, more commonly known as Billy the Kid, the notorious 19th century outlaw, was killed in Fort Sumner, New Mexico on July 14, 1881, by Lincoln County Sheriff Pat Garrett. 41 However, some believe that Sheriff Garrett and Billy the Kid, friends despite their differing career paths, shot another man and passed off the remains as Billy's in order to allow his escape from law enforcement officials.<sup>42</sup> While many men in the past have come forward purporting to be the real Billy the Kid, one strongly cited legend offers that after his faked death, Billy left New Mexico and fled to Texas, where he assumed the name "Brushy Bill" Roberts and lived until his death in 1950. 43 The sheriff of Lincoln County, New Mexico opened Case No. 2003-274, in an attempt to initiate DNA testing on the remains located in Fort Sumner as a means to authenticate the legend and assure continued recognition of Lincoln County as the resting place of Billy the Kid.<sup>44</sup> The request sought permission to exhume the graves of the man buried in Fort Sumner as Billy the Kid, his mother Catherine Antrim, and "Brushy Bill' Roberts, the man who some people think was the real Billy the Kid, in order to perform DNA analysis to authenticate the remains in Fort Sumner. 45

<sup>&</sup>lt;sup>35</sup> Peter Gill, et al., *Identification of the Remains of the Romanov Family by DNA Analysis*, 6 NATURE GENETICS 130, 130-135 (1994).

<sup>&</sup>lt;sup>36</sup> Richard Stone, Buried, Recovered, Lost Again? The Romanovs May Never Rest, 303 SCIENCE 753, 753 (2004).

<sup>&</sup>lt;sup>37</sup> Gill, et al., *supra* note 35.

<sup>&</sup>lt;sup>38</sup> *Id*.

<sup>&</sup>lt;sup>39</sup> *Id*.

<sup>&</sup>lt;sup>40</sup> A. Knight, et al., *Molecular, Forensic, and Haplotypic Inconsistencies Regarding the Identity of the Ekaterinburg Remains*, 31 Annals Hum. Biol. 129, 129 (2004).

<sup>&</sup>lt;sup>41</sup> Billy the Kid, MICROSOFT ENCARTA, 2004, http://encarta.msn.com/encyclopedia\_761561568921/Billy\_the\_Kid.html.

<sup>&</sup>lt;sup>42</sup> CNN, Statement Recasts Billy the Kid Doubts, Jan 13, 2004, http://www.cnn.com/2004/LAW/01/13/bill.kid.ap/.

<sup>&</sup>lt;sup>43</sup> Alan Boyle, *Billy the Kid's DNA Sparks Legal Showdown*, MSNBC, Nov. 18, 2003, http://msnbc.msn.com/id/3475969/.

<sup>&</sup>lt;sup>44</sup> Billy the Kid Investigation Resurrected, MSNBC, Nov. 8, 2005, http://ori.msnbc.msn.com/id/9974111/.

 $<sup>^{45}</sup>$  Timothy W. Maier, *Digging up the Dead*, INSIGHT ON THE NEWS, November 10, 2003, at 18; Boyle, *supra* note 43.

### 2. Investigation

Bioanalysis has also been used for investigations about the historical figures themselves, including investigations of cause of death, disease, lineage, and behavior. For example, President Zachary Taylor's body was disinterred to determine if he died of gastroenteritis or arsenic poisoning. Forensic officials announced that tests of Napoleon Bonaparte's hair showed a "major exposure to arsenic" which may have led to his death. Albert Einstein's brain tissue was analyzed to determine if he had a genetic predisposition to aneurysm. Samples of Beethoven's hair were analyzed to determine if lead poisoning was the cause of certain behaviors, Albert Einstein's brain tissue was also studied in a number of attempts to investigate the source of his genius and one researcher claimed that genetic analysis indicated that Thomas Jefferson may have fathered a child with his slave Sally Hemings.

### Medici Dynasty

The Medici exhumations focus on specific investigations into cause of death, disease, and family lineage. Increasing difficulties and unexpected findings have arisen for experts and forensic historians, where tests have included DNA sampling of tissue, hair and bones, as well as CAT scans and X-rays.<sup>52</sup> For example, fourteen of the forty-nine bodies uncovered are of uncertain or misattributed identity. Exhumations have revealed the bodies of eight children inside a hidden crypt who had been unaccounted for on the Medici family tree and the body of a one-year old child buried in the coffin of Filippino Medici, the son of Francesco I, who had reportedly died at the age of four years and nine months.<sup>54</sup> The remains of two of Cosimo Medici's children, thought to have met violent deaths, bore no trace of violence<sup>55</sup> and test results on Cosimo Medici's own remains indicate that, contrary to the theory held by many historians that he died of gout, Cosimo was actually afflicted with diffuse idiopathic skeletal hypertosis, otherwise known as Forestier's disease, a form of arthritis.<sup>56</sup>

<sup>56</sup> *Id*.

<sup>&</sup>lt;sup>46</sup> W. R. MAPLES & M. BROWNING, DEAD MEN DO TELL TALES 3 (1994). Hair and tissue analysis did not find traces of arsenic. David Daley, *C-SPAN Series a Lively Look at Presidents*, FLA. TIMES-UNION, December 7, 1999, at C3.

<sup>&</sup>lt;sup>47</sup> Times Wire Service, Arsenic Idea Backed in Napoleon's Death, L.A. TIMES, June 2, 2001, at A8.

<sup>&</sup>lt;sup>48</sup> Scott McCartney, *The Hidden Secrets of Einstein's Brain Are Still a Mystery*, WALL St. J., May 5, 1994, at A1.

<sup>&</sup>lt;sup>49</sup> MARTIN, *supra* note 14.

<sup>&</sup>lt;sup>50</sup> Sandra F. Witelson, et al., *The Exceptional Brain of Albert Einstein*, 353 LANCET 2149, 2149-53 (1999) [hereinafter Witelson, et al.]; Britt Anderson & Thomas Harvey, *Alterations in Cortical Thickness and Neuronal Density in the Frontal Density in the Frontal Cortex of Albert Einstein*, 210 NEUROSCIENCE LETTERS 161, 161-64 (1996) [hereinafter Anderson & Harvey].

<sup>&</sup>lt;sup>51</sup> E.A. Foster, et al., *Jefferson Fathered Slave's Last Child*, 396 NATURE 27, 27-28 (1998) [hereinafter Foster, et al., *Jefferson Fathered Slave's Last Child*]. Subsequently, he added qualifiers to his results in response to criticism of this theory. E. A. Foster, et al., *The Thomas Jefferson Paternity Case*, 397 NATURE 32, 32 (1999).

<sup>&</sup>lt;sup>52</sup> Winfield, *supra* note 1.

<sup>&</sup>lt;sup>53</sup> Medici Tombs to Unveil More Secrets, ANSA ENGLISH MEDIA SERVICE, February 9, 2006.

<sup>&</sup>lt;sup>54</sup> Hooper, *supra* note 7.

<sup>&</sup>lt;sup>55</sup> *Id*.

In tandem with the exhumations, researchers have also performed an examination of Medici relics housed in a Florence museum and discovered that the teeth and lock of hair believed to have belonged to Lorenzo the Magnificent, Florence's legendary ruler and Renaissance art patron and a blood-stained segment of shirt allegedly worn by Lorenzo's brother Giuliano were misattributed.<sup>57</sup> This study raises problems with using a single comparison sample: with only one sample line, the conclusion could be that a particular sample is "misattributed", when actually it is not. Given recent findings, one researcher asserts "it'll take years to sort things out properly."<sup>58</sup> A € 225,000 second phase of Medici research recently began, during which art experts and forensic historians are scheduled to open more tombs to answer some of the lingering questions regarding the location of bodies and other remains.<sup>59</sup>

### Albert Einstein

When Albert Einstein died of a ruptured abdominal aortic aneurysm on April 18, 1955, his family was informed that his entire body had been cremated as originally scheduled. It was later discovered that Dr. Thomas Stoltz Harvey, the pathologist at Princeton Hospital who conducted Einstein's autopsy, removed and kept his brain, slicing it and embedding it in colloid, so the slices could be examined under a microscope. After dividing the pieces of the brain, he distributed samples to several colleagues. These samples have been the subject of numerous research protocols to study brain morphology and potential explanations for his intelligence, all of which have been met with challenges on a variety of grounds, including lack of scientific expertise of research personnel and the lack of a measurable hypothesis.

### Thomas Jefferson

Eugene Foster's much publicized 1998 comparative Y-chromosomal study entitled "Jefferson Fathered Slave's Last Child," was intended to "throw some scientific light" on whether President Jefferson had fathered his slave Sally Hemings' children. Foster studied male-line descendants of two Hemings children and Jefferson's paternal uncle, Field Jefferson. Descendants of Field Jefferson and Hemings' youngest child, Eston, shared a common haplotype, but no match was

<sup>&</sup>lt;sup>57</sup> Medici Tombs to Unveil More Secrets, supra note 53.

<sup>&</sup>lt;sup>58</sup> *Id*.

<sup>&</sup>lt;sup>59</sup> *Id*.

<sup>&</sup>lt;sup>60</sup> Osgood File (CBS Radio broadcast Aug. 21, 1995). The family's wishes were that the whole body be cremated. HARVEY RACHLIN, LUCY'S BONES, SACRED STONES, AND EINSTEIN'S BRAIN: THE REMARKABLE STORIES BEHIND THE GREAT OBJECTS AND ARTIFACTS OF HISTORY, FROM ANTIQUITY TO THE MODERN ERA 329 (1996) [hereinafter RACHLIN]. The family apparently subsequently gave permission for research. Osgood File (CBS Radio broadcast Aug. 21, 1995). However, they wanted it published only in scientific journals and no attempts would be made to sensationalize the findings. RACHLIN, at 330.

<sup>&</sup>lt;sup>61</sup> RACHLIN, supra note 60, at 330-331 (1996). Rachlin refers to these slide specimens as "an exciting scientific treasure." *Id.* at 331.

<sup>&</sup>lt;sup>63</sup> Witelson, et al., *supra* note 50; Anderson & Harvey, *supra* note 50.

<sup>&</sup>lt;sup>64</sup> Carolyn Abraham, My Dad Has Einstein's Brain, THE GUARDIAN, April 8, 2004.

<sup>65</sup> Foster, et al., Jefferson Fathered Slave's Last Child, supra note 51.

<sup>&</sup>lt;sup>66</sup> *Id*.

found for descendants of Hemings' eldest son, Thomas Woodson.<sup>67</sup> Foster concluded that "[t]he molecular findings fail to support the belief that Thomas Jefferson was Thomas Woodson's father, but provide evidence that he was the biological father of Eston Hemings Jefferson."<sup>68</sup> This study has been attacked as using a methodology that could not answer the question at issue--because a Y chromosome study would indicate that any male in the Jefferson family could have fathered the resulting child.<sup>69</sup> Questions remain as to the scientific integrity and appropriateness of the researchers' methodology.

More recently, a genetic researcher at the University of Leicester in England reported that Jefferson's Y chromosome is most common in the Middle East and in eastern Africa, "rais[ing] the possibility that Jefferson had a Jewish ancestor." However, since that genotype is also found in some British males named Jefferson, the study was inconclusive."

### 3. Commercialization

Commercial ventures also use these methodologies in the development of commercial products, raising questions of access, informed consent, and potential conflicts of interest. Companies are advertising jewelry and other products containing DNA from historic figures. Researchers performing biohistorical studies are commonly funded or sponsored by television companies or corporations. For example, Nobel Laureate Kary Mullis founded StarGene, one of the first companies marketing jewelry containing celebrity DNA. StarGene offered to fund genetic analysis of historical artifacts in exchange for the right to replicate any of the DNA in a line of jewelry products termed "biocollectables." Similarly, an Illinois-based company, LifeGem Memorials, recently released plans to manufacture diamonds

<sup>68</sup> Foster did caution that "we cannot completely rule out other explanations of our findings based on illegitimacy in various lines of descent." *Id.* 

<sup>72</sup> Anthony Luversidge, *Kary Mullis - Molecular Biologist – Interview*, OMNI, April 1992, at 69-92; Rick Weiss, *Gene Jewels*, WASH. POST, Sept. 20, 1995, at F01; *see also* Gail Vines, *Genetics: Let the Public Decide*, 314 BRIT. MED. J. 1055 (1997) (noting that StarGene has "teamed up with the owner of one of the world's largest hair collections to manufacture 'celebrity DNA' for the 'collectibles market'").

<sup>&</sup>lt;sup>67</sup> *Id*.

<sup>&</sup>lt;sup>69</sup> See Reed Irvine, Jefferson Was Falsely Fingered but Many Will Never Hear About It - 'Nature' withheld certain information about Thomas Jefferson's alleged paternity of slaves' descendents, INSIGHT ON THE NEWS, Jan. 25, 1999, available at http://findarticles.com/p/articles/mi\_m1571/is\_3\_15/ai\_53677529 (reporting that the scientific journal, Nature, is "suffering acute embarrassment over the articles it published in November claiming that a study based on DNA analysis[, authored by Eugene Foster,] had proved beyond reasonable doubt that Thomas Jefferson had fathered a son by Sally Hemings, one of his slaves).

<sup>&</sup>lt;sup>70</sup> Nicholas Wade, *Study Raises the Possibility of Jewish Tie for Jefferson*, N. Y. TIMES, Feb. 28, 2007, at A12.

<sup>&</sup>lt;sup>71</sup> *Id*.

<sup>&</sup>lt;sup>73</sup> Kary Mullis, a recipient of the Nobel Prize for developing the Polymerase Chain Reaction (PCR) technology for amplifying bits of DNA, had proposed that pieces of celebrity DNA could be cloned and sold to fans as souvenirs. Mullis had chosen Elvis Presley for its first marketing endeavor, aiming to amplify Mitochondrial DNA via PCR from the hair follicles identified as Presley's by comparison with samples from living relatives and placing the DNA sequence on a commemorative card. *Biotechnology for Pleasure and Profit*, NBIAP NEWS REPORT, December 1993, http://64.233.167.104/search?q=cache:zz2AnHwhRncJ:www.isb.vt.edu/news/1993/news93.Dec+%22 biotechnology+for+pleasure+and+profit%22+and+%22mullis%22&hl=en&ct=clnk&cd=1&gl=us.

using six to ten strands of Beethoven's hair bought from a private collector. <sup>74</sup> Catering not only to those who want a piece of a historical figure but also family members and loved ones, LifeGem claims the business of "making diamonds out of the carbon from cremated human remains" within 24 weeks. <sup>75</sup> According to LifeGem's website, it creates "high-quality" diamonds from the carbon of a customer's loved one as a "memorial to their unique life and as a symbol of your personal and precious bond."

Aside from jewelry, functional products have also been marketed that claim to incorporate celebrity DNA. An advertisement from Airline International touts the Krone Limited Edition Abraham Lincoln Pen, allegedly containing crystallized DNA of Lincoln replicated from hair strands of the former President removed on the night of his assassination, set in an amethyst stone.<sup>77</sup>

Others are cashing in beyond the marketing of a DNA-encrusted product. The Discovery Cable Broadcasting station in the United Kingdom has offered to underwrite a substantive genetic investigation of Abraham Lincoln relics in exchange for personal medical information about the President, including whether or not he suffered from Marfan's syndrome. And in the future, museum boards might consider whether they should offer such celebrity analysis of collection artifacts for a fee. The commercial DNA Ancestry Project will, for a fee, compare anyone's DNA to genetic profiles allegedly belonging to Marie Antoinette, Jesse James, and the Romanovs. In fact, individuals from downstate Illinois have recently contacted the CHS to seek permission to check their own genetic profiles against purported DNA on Lincoln artifacts to determine if they are distant relatives.

Even living historical figures are now being faced with issues of commercialization of their bodily tissue and DNA, which exceeds the scope of this article but raises similar ethical and legal questions. In an effort to have a piece of their favorite celebrity, people have forked over thousands of dollars at internet auctions for clippings of Neil Armstrong's hair gathered by his barber, <sup>79</sup> Britney Spears's used pumice stone, <sup>80</sup> Kelly Clarkston's discarded water bottle, <sup>81</sup> and Governor Arnold Schwarzenegger's chewed cough drop. <sup>82</sup> John Reznikoff, a private

<sup>76</sup> LifeGem, *What is a LifeGem?*, http://www.lifegem.com/secondary/whatisLG2006.aspx (last visited Nov. 29, 2007).

 $<sup>^{74}</sup>$  Reuters News Service, *Beethoven's Hair Gets Some Shine*, THE HOUSTON CHRON., May 14, 2006, at A2.

<sup>&</sup>lt;sup>75</sup> *Id*.

<sup>&</sup>lt;sup>77</sup> The online advertisement reads: "The Krone Limited Edition Abraham Lincoln Pen not only captures the 'genetic essence' of America's greatest President, but also embodies the wonders of 20th century science with the artistry of time-honored craftsmanship." Airline International, *Krone—Abraham Lincoln*, http://www.airlineintl.com/krone/krone\_abraham.htm (last visited Nov. 29, 2007).

<sup>&</sup>lt;sup>78</sup> Genebase Systems, *Trace Your Ancestry with DNA—Ancestry Project*, http://www.dnaancestryproject.com/ (last visited Nov. 29, 2007).

<sup>&</sup>lt;sup>79</sup> Mastro Auctions, Neil Armstrong's Hair—The Source of a Media Frenzy and the First Clippings Ever Publicly Offered!, Apr. 9, 2005, http://www.mastronet.com/index.cfm?action=DisplayContent& ContentName=Lot%20Information&LotIndex=52983&CurrentRow=1.

<sup>&</sup>lt;sup>80</sup> Defamer.com, Britney's Pumice Stone: Investing in the Future, Aug. 3, 2005, http://www.defamer.com/hollywood/britney-spears/britneys-pumice-stone-investing-in-the-future-115706.php.

<sup>&</sup>lt;sup>81</sup> Monsters and Critics.com, *Kelly Clarkson's DNA for Sale at Online Auction*, Apr. 9, 2005, *available at* http://people.monstersandcritics.com/article\_6029.php.

<sup>82</sup> Brian Bernbaum, CBS NEWS ONLINE, The Odd Truth: Arnold's DNA on eBay, May 24, 2004,

owner of the largest collection of human hair at 135 different people's locks, <sup>83</sup> purportedly including hair purportedly from Abraham Lincoln, John F. Kennedy, Marilyn Monroe, Albert Einstein, Napoleon, Elvis Presley, King Charles I, and Charles Dickens. <sup>84</sup> Reznikoff describes the hair collection as a "unique card catalogue of DNA of the most famous people in the world," <sup>85</sup> of which he is the custodian.

### III. OVERSIGHT AND MONITORING OF BIOHISTORICAL ANALYSIS

Although this research in the context of authentication, investigation, and commercialization has the exciting potential to unlock secrets of the past, it takes place in murky legal and ethical territories. Thus, acceptance of this research, or lack thereof, is largely influenced by religious and cultural beliefs regarding the treatment of corpses. Biohistorical analysis raises a variety of scientific, legal, ethical, and social concerns. To meet these concerns, biohistorical research should utilize appropriate scientific methodology, avoid conflicts of interest, protect participants and related individuals through informed consent and confidentiality, employ efficient and accurate reporting, and involve responsible dissemination of results. There are important questions as to who has the authority to decide whether research can be undertaken on a deceased individual, how to balance the potential harm to living relatives against the potential benefit to society, how to develop appropriate safeguards for confidentiality of medical and genetic information generated for both the historic figure and family members, how to establish mechanisms for the protection of interred corpses, and how to assure cultural respect for the dead. Existing professional guidelines provide some policy guidelines, and courts are already beginning to face these issues in cases involving requests to exhume bodies allegedly belonging to John Wilkes Booth, Lee Harvey Oswald and Meriwether Lewis for authentication purposes.

Biohistorical analysis exists at the intersection of various disciplines, including genetics, chemistry, history, and anthropology. By its nature, biohistorical analysis deals with an identifiable subject and has the ability to generate information about that figure and often about his or her family. Despite its ability to uncover a wealth of personal, particularly genetic information, biohistorical analysis is a largely unregulated area of human research because existing federal research regulations apply only to federally-funded research on living subjects. Traditional research and entities funded by the federal government must abide by regulations pertaining to institutional review of research provided in federal regulations, such as the Code of Federal Regulations and United States Code. However, researchers not affiliated with an institution are exempt from Institutional Review Board (IRB) review

83 The Scalp Hunter, MAXIM, Feb. 2006, available at http://www.maximonline.com/articles/index.a spx?a\_id=7031.

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http://www.cbsnews.com/stories/2004/05/25/national/main 619515.shtml.

<sup>&</sup>lt;sup>84</sup> Guinness Book of World Records, *Largest Collection of Hair (Historical Figures)*, GUINNESS BOOK OF WORLD RECORDS, Jan. 2001, *available at* http://www.ukhairdressers.com/records.asp.

<sup>&</sup>lt;sup>85</sup> John Christoffersen, From Famous Hair to Kennedy Car, Collector Hunts for Treasures, THE ASSOCIATED PRESS STATE & LOCAL WIRE, June 10, 2005.

<sup>&</sup>lt;sup>86</sup> Department of Health and Human Services, Basic HHS Policy for Protection of Human Research Subjects, 45 C.F.R. §§46.101-103 (2006); Food and Drug Administration, Protection of Human Subjects, 21 C.F.R. §50 (2001).

because they are not federally funded. Likewise, research on deceased individuals does not trigger state or federal human subjects research regulations or privacy regulations, such as the Health Insurance Portability and Accountability Act of 1996.<sup>87</sup>

There are, however, several federal regulations and relevant federal and state case law that may apply to this field. There are a number of federal regulations protecting research on particular groups of people or archeological artifacts that are particularly relevant. Among these are the Native American Grave Repatriation Act (NAGPRA) and the Archeological Resources Protection Act (ARPA). State case law in this area has involved a variety of legal theories, including grave desecration, invasion of privacy, and family rights. Application of federal and state regulations and case law will be discussed below in the context of the five categories that have been identified as important to considerations of biohistorical analysis.

Biohistorical analysis is also not directly addressed at the professional or organizational level in the United States. A researcher, museum, or other

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<sup>&</sup>lt;sup>87</sup>The DHHS has issued regulations called Standards for Privacy of Individually Identifiable Health Information, also known as the Privacy Rule. 45 C.F.R. Parts 160 and 164. These regulations restrict research on individually identifiable health information in the hands of a "covered entity" – a health plan, health care clearinghouse, or a health care provider who transmits any health information in electronic form in connection with a transaction covered by the Privacy Rule. 45 C.F.R. §160.103. According to the Department of Health and Human Services, "genetic information is considered to be health information." DHHS, "What Health Information is Protected by the Privacy Rule," *available at* http://privacyruleandresearch.nih.gov/pr\_07.asp. However, the regulations have a loophole which would appear to allow biohistorical research on identifiable historical figures.

In most instances, biohistorical research will not be undertaken a covered entity. Even if it were, however, even a covered entity is allowed to use or disclose protected health information for research on a deceased person, provided that the covered entity obtains from the researcher:

<sup>(</sup>A) Representation that the use or disclosure sought is solely for research on the protected health information of decedents; (B) Documentation, at the request of the covered entity, of the death of such individuals; and (C) Representation that the protected health information for which use or disclosure is sought is necessary for the research purpose.

<sup>45</sup> C.F.R. §164.512(i)(1)(ii) (2006). The effect of these provisions is to allow any research on a deceased individual given that they are dead, the research relates to them, and the health information is needed to perform the research. There are no requirements for de-identification, time limits, or other limiting factors within the section.

<sup>&</sup>lt;sup>88</sup> 43 C.F.R. § 10 et seq. and 16 U.S.C.S. § 470aa-mm.

<sup>&</sup>lt;sup>89</sup> See infra Part III.1 (discussing various state law approaches to biohistorical research).

It is worth noting that, unlike in the United States, there are rigorous protections in the United Kingdom covering the removal of tissue from the dead. The United Kingdom adopted the Human Tissue Act of 2004 in response to the recent discovery that body parts were removed from dead children before burial at Alder Hey Children's Hospital in Liverpool. BBC News, *Tissue 'Theft' Law Unveiled*, Dec. 4, 2003, http://news.bbc.co.uk/go/pr/fr/-/1/hi/health/3288955.stm. The Act provides that doctors who want tissue from deceased patients must acquire permission from the family or demonstrate that the patient previously agreed to tissue removal prior to death. United Kingdom, Human Tissue Bill, HL Bill 94 (2003), at Part 1, §§ 2-10, *available at* http://www.publications.parliament.uk/pa/ld200304/ldbills/094/2004094.pdf (last visited Nov. 29, 2007). Specifically, where a person has died, anyone using the body or material must get "appropriate consent." *Id.* § 3 Excepted material means material which has "come from the body of a living person" or "come from the body of a deceased person otherwise than in the course of use of the body for the purpose of anatomical examination." *Id.* § 12. Where the activity is not public display or excepted material, appropriate consent can be acquired from a person appointed to deal with issues of consent following his or her death or a person in a qualifying relationship with decedent immediately before he or she died. *Id.* § 3(6).

<sup>&</sup>lt;sup>91</sup> The Appendix provides a brief overview of each of the twenty-six organizations analyzed, including information on the mission and constituency of each organization. Guidelines from the following organizations were analyzed: American Anthropological Association (AAA), American Association of

interested party contemplating DNA analysis on a historical figure's artifact or remains would have difficulty finding clear and definitive guidance among existing professional codes of ethics and practice guidelines. This lack of guidance has resulted in professional confusion and uncertainty. Because the field of biohistory actually utilizes a collection of well-established technologies, it seems most appropriate to develop guidance at the level of individual professional organizations or guidelines that span several disciplines. Concerted regulatory oversight mechanisms should follow, yet the development and promotion of guidance at the professional and scientific level is critical as this field of study grows.

In order to assess the state of professional oversight for biohistorical analysis, we examined twenty-six professional codes and practice guidelines from relevant professional organizations (e.g., organizations made up of professional historians, chemists, sociologists, archaeologists, anthropologists, biologists, etc.), 92 identifying provisions that could possibly apply or could be expanded to apply to the biohistorical enterprise. Analysis of those codes revealed deficiencies in the existing codes and highlighted the need for a new ethics code tailored specifically to biohistorical research. This is to be expected, as these professional and organizational guidelines were developed with a particular discipline in mind and may not have contemplated the field of biohistorical analysis that has emerged in the last few decades. Most codes assume that the way to handle particularly thorny ethical issues is to keep confidential the identity of the research subject. For example, many codes instruct merely to follow existing federal guidelines on living human subjects that operate on the assumption that samples can be anonymized and individuals will remain unidentified. 93 However, in biohistorical analysis, the samples that have either been identified or are attributed to a particular deceased historical figure raise issues that are not covered by federal human subjects guidelines.

Using principles expressed in the twenty-six professional codes, federal and state regulations, and case law we have identified five important issues to consider in creating guidelines for addressing the ethical, legal, and scientific issues underlying biohistorical analysis: (1) promotion of research, scientific discovery, and public knowledge; (2) access to sample or artifact; (3) scientific integrity and dissemination

Museums (AAM), American Board of Forensic Document Examiners (ABFDE), American College of Forensic Examiners (ACFE), American College of Medical Genetics (ACMG), American Cultural Resources Association (ACRA), American Historical Association (AHA), Archaeological Institute of America (AIA), American Institute of Chemists (no acronym used), American Institute for the Conservation of Historic and Artistic Works (AIC), American Medical Association (AMA), Association of Professional Genealogists (APG), American Sociological Association (ASA), American Society for Biochemistry and Molecular Biology (ASBMB), American Society for Clinical Laboratory Scientists (ASCLS), American Society of Human Genetics (ASHG), American Society for Information Science (ASIS), Biotechnology Industry Organization (BIO), College Art Association (CAA), Council of American Survey Research Organizations (CASRO), Human Genome Organization (HUGO), International Council of Museums (ICOM), International Society for Ethnobiology (ISE), National Council on Public History (NCPH), Oral History Association (OHA), and Society of American Archivists (SAA).

<sup>&</sup>lt;sup>92</sup> *Id*.

<sup>&</sup>lt;sup>93</sup> See American Institute for the Conservation of Historic and Artistic Works, Code of Ethics and Guidelines for Practice (1994), http://aic.stanford.edu/pubs/ethics.html (noting that "[t]he conservation professional should be cognizant of laws . . . concerning the rights of artists and their estates, occupational health and safety, sacred and religious material, excavated objects, endangered species, human remains, and stolen property").

of results; (4) informed consent and risks of participants; (5) conflict of interests – Where appropriate, we highlight useful or problematic provisions in the existing codes in an effort to underscore the potential for more targeted guidance for biohistory.

### 1. Promotion of Research, Scientific Discovery, and Public Knowledge

The promotion of research and discovery is a fundamental goal of scientific inquiry. The federal government actively funds scientific research and the Constitution protects the freedom of scientific inquiry. While the promotion of research, scientific discovery, and public knowledge are important considerations, guidelines for biohistorical analysis need to relay that they are not superior to ethical, legal, and scientific concerns. There are limitations and these concerns may outweigh research interests in a given situation. Fourteen of the twenty-six codes and guidelines we analyzed share the aim of promoting research, explicitly guiding members to promote research in some form or another. Four of these instruct members to pass on the general knowledge, experience, and skills they have learned to colleagues, scholars, students, and the public. Five of these instruct members to share research materials and source data (distinct from published results) as a way of promoting research. Two contain general statements about advancing knowledge

[T]he State may not, consistently with the spirit of the First Amendment, contract the spectrum of available knowledge. The right of freedom of speech and press includes not only the right to utter or to print, but the right to distribute, the right to receive, the right to read (*Martin v. Struthers*, 319 U.S. 141, 143 (1943)) and freedom of inquiry, freedom of thought, and freedom to teach (*see Wieman v. Updegraff*, 344 U.S. 183, 195 (1952)) -- indeed the freedom of the entire university community. *Sweezy v. New Hampshire*, 354 U.S. 234, 249-250, 261-263 (1957); *Barenblatt v. United States*, 360 U.S. 109, 112 (1959); *Baggett v. Bullitt*, 377 U.S. 360, 369 (1964). Without those peripheral rights the specific rights would be less secure.

Id

<sup>95</sup> The ICOM Code provides, "[m]embers of the museum profession have an obligation to share their knowledge and experience with their colleagues and with scholars and students in relevant fields." International Council of Museums, *Code of Ethics for Museums* § 3.9 (2006), http://icom.museum/ethics.html. The AIC, NCPH, and AMA codes contain similar statements. American Institute for the Conservation of Historic and Artistic Works, *Code of Ethics and Guidelines for Practice* (1994), http://aic.stanford.edu/pubs/ethics.html; National Council on Public History, *Code of Ethics and Professional Conduct* (2007), http://www.ncph.org/AbouttheCouncil/BylawsandEthics/tabid/291/Default.aspx#Ethics; AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-9.095 (2002).

Ollege Art Association, Code of Ethics for Art Historians and Guidelines for the Practice of Art History (1995), http://www.collegeart.org/guidelines/histethics.html; Oral History Association, Oral History Evaluation Guidelines (2000), http://omega.dickinson.edu/organizations/oha/pub\_eg.html; American Anthropological Association, Code of Ethics of the American Anthropological Association at 3 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf; Archeological Institute of America, Code of Professional Standards at 3 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_StandardsA5S.pdf; American Society of Human Genetics, Report, Statement on Informed Consent for Genetics Research (1996), http://genetics.faseb.org/genetics/ashg/policy/pol-25.htm.

The CAA Code provides, "[a]n art historian has the moral obligation to share the discovery of primary source material with ... colleagues and serious students." College Art Association, *Code of Ethics for Art Historians and Guidelines for the Practice of Art History* (1995), http://www.collegeart.org/guidelines/histethics.html. The CAA also "believes . . . there should be full, free, equal, and nondiscriminatory access to research materials for all qualified art historians." College Art Association *Id.* The CAA draws a distinction between the obligation to share primary source materials and the right

<sup>94</sup> Griswold v. Connecticut, 381 U.S. 479, 482 (1965).

or science. Two of these codes also address providing opportunities for others in the field. 88

Various codes speak to the purpose of research, favoring research that is in the public interest. Three codes articulate or appeal to some notion of common or shared values in this respect. Three codes specifically draw on principles of public trust, public interest, or public good. Three codes address the public educational

not to disclose anything of an interpretive nature. *Id.* 

The OHA instructs members to "arrange to deposit their interviews in an archival repository that is capable of both preserving the interviews and eventually making them available for general use." Oral History Association, *Oral History Evaluation Guidelines*, http://omega.dickinson.edu/organizations/oha/pub\_eg.html. The AAA provides, "anthropological researchers should seriously consider all reasonable requests for access to their data and other research materials for purposes of research." *Code of Ethics of the American Anthropological Association* at 3 (1998), http://www.aaanet.org/committees/ethicscode.pdf.

The AIA contains only a general statement about sharing information useful to others. Archeological Institute of America, *Code of Professional Standards* at 3 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_StandardsA5S.pdf.

The ASHG Report instructs researchers to share unused portions of samples with other researchers, provided the subjects gave consent. American Society of Human Genetics, *Report, Statement on Informed Consent for Genetics Research* (1996), http://genetics.faseb.org/genetics/ashg/policy/pol-25.htm.

<sup>97</sup> College Art Association, Code of Ethics for Art Historians and Guidelines for the Practice of Art History (1995), http://www.collegeart.org/guidelines/histethics.html; American Sociological Association, Code of Ethics at 4-5 (1997), http://www.asanet.org/galleries/default-file/Code% 200f% 20Ethics.pdf.

<sup>98</sup> The AAA Code of Ethics instructs anthropologists to "preserve opportunities for future fieldworkers." American Anthropological Association, *Code of Ethics of the American Anthropological Association* at 3 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf. The AIC Code of Ethics instructs conservation professionals to "provid[e] and promot[e] educational opportunities in the field." American Institute for the Conservation of Historic and Artistic Works, *Code of Ethics and Guidelines for Practice* (1994), http://aic.stanford.edu/pubs/ethics.html.

<sup>99</sup> The AAM Code explains, "[a professional code of ethics] must also rest upon widely shared values." American Association of Museums, *Code of Ethics for Museums* (2000), http://www.aam-us.org/museumresources/ethics/coe.cfm. The ASA Code explains, "[t]his Code of Ethics articulates a common set of values upon which sociologists build their professional and scientific work." American Sociological Association, *Code of Ethics* at 3 (1997), http://www.asanet.org/galleries/default-file/Code%20of%20Ethics.pdf. The ASIS Code offers some actual common values relied upon. "[This Code] recognizes the dedication to the ideals of truth and service [.]" American Society of Information Science & Technology, *Code of Professional Practice* (1961), http://ethics.iit.edu/codes/coe/amer.soc.info.sci.html.

Marrican Association of Museums, Code of Ethics for Museums (2000), http://www.aam-us.org/museumresources/ethics/coe.cfm; American Society for Biochemistry and Molecular Biology, Code of Ethics (1998), http://www.asbmb.org/asbmb/site.nsf/Sub/CodeofEthics?Opendocument; International Council of Museums, Code of Ethics for Museums § 2.0 (2006), http://icom.museum/ethics.html.

The AAM Code provides, "[t]he stewardship of collections entails the highest public trust . . . ." It also provides, "programs promote the public good rather than individual financial gain." American Association of Museums, *Code of Ethics for Museums* (2000) at Programs, http://www.aamus.org/museumresources/ethics/coe.cfm.

The ASBMB provides, "[m]embers are engaged in the quest for knowledge . . . with the ultimate goal of advancing human welfare. Underlying this quest is the fundamental principle of trust." American Society for Biochemistry and Molecular Biology, *Code of Ethics* (1998), http://www.asbmb.org/asbmb/site.nsf/Sub/CodeofEthics?Opendocument. It also provides, "investigators will promote and follow practices that enhance the public interest or well-being." *Id.* 

Finally, the ICOM Code instructs that a main principle that guides the museum professional is that "museums are the object of a public trust . . . ." International Council of Museums, *Code of Ethics for Museums* (2006), http://icom.museum/ethics.html.

role played by an institution, organization, or professional. 101 Five codes define the community role played by an institution, organization, or professional. Other codes speak to various public considerations, including the level of environmental damage from the research 103 and research morally adverse to the pubic interest. 104

Consequently, as evidenced in provisions from existing professional codes, not all research is appropriate. The codes and guidelines we examined consider ethical and social concerns that would harm individuals and society during the course of the research. As biohistorical analysis is the convergence of a multitude of scientific methods and technologies, effective implementation of guidelines should involve

International Council of Museums, Code of Ethics for Museums § 2.7 (2006), http://icom.museum/ethics.html; Archeological Institute of America, Code of Professional Standards at 2 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_StandardsA5S.pdf; Human Genome Organization, Ethics Committee Statement on Human Genome Databases at 1 (2002), http://www.hugo-international.org/PDFs/Statement%20on%20Human%20Genomic%20Databases% 202002.pdf.

The ICOM Code provides, "[t]he museum has an important duty to develop its educational role [.]" International Council of Museums, Code of Ethics for Museums § 2.7 (2006), http://icom.museum /ethics.html.

The AIA Code provides, "professional archaeologists should be actively engaged in . . . educational Archeological Institute of America, Code of Professional Standards at 2 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_StandardsA5S.pdf.

The HUGO code provides, "Individuals, families, communities, commercial entities, institutions and governments should foster the public good." HUGO Ethics Committee, Statement on Human Genome Databases at 1 (2002), http://www.hugo-international.org/PDFs/Statement%20on%20Human%20 Genomic%20Databases %202002.pdf.

<sup>102</sup> International Council of Museums, Code of Ethics for Museums § 2.7 (2006), available at http://icom.museum/ethics.html; American Association of Museums, Code of Ethics for Museums (2000), http://www.aam-us.org/museumresources/ethics/coe.cfm; Archeological Institute of America, Code of Professional Standards (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_ Professional\_StandardsA5S.pdf; American Cultural Resources Association, Code of Ethics and Professional Conduct (1995), http://www.acra-crm.org/Ethics.html; International Society for Ethnobiology (ISE) Code of Ethics (2006), http://ise.arts.ubc.ca/documents/ISECodeofEthics TEXT2006\_000.pdf.

The ICOM, AAM, and AIA Codes call for attracting and reaching wider audiences via public outreach. International Council of Museums, Code of Ethics for Museums § 4.0 (2006), http://icom.museum/ethics.html; American Association of Museums, Code of Ethics for Museums (2000), http://www.aam-us.org/museumresources/ethics/coe.cfm; Archeological Institute of America, Code of Professional Standards at 2 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_ Professional\_StandardsA5S.pdf .

The AAM also calls for maintaining integrity to warrant public confidence. American Association of Museums, Code of Ethics for Museums (2000), http://www.aam-us.org/museumresources/ethics/coe.cfm.

The ACRA Code requires member to "[s]trive to present the results of significant research to the public in a responsible manner." American Cultural Resources Association, Code of Ethics and Professional Conduct, http://www.acra-crm.org/Ethics.html (last visited Nov. 29, 2007).

In contrast to playing a role in the constituent community or the community at large, the ISE Code sees the studied (indigenous) community as playing a vital role in the research process. "This principle recognises the crucial importance of indigenous peoples, traditional societies [,] and local communities to actively participate in all phases of the project from inception to completion, as well as in application of research results." International Society for Ethnobiology, Code of Ethics at 4 (2006), http://ise.arts.ubc.ca/documents/ISECodeofEthics TEXT2006\_000.pdf.

<sup>103</sup> The BIO Statement of Principles promotes environmentally friendly research, providing, "[w]e will strive to optimize the cost efficiencies and environmental advantages associated with using biotechnology while protecting human health and the environment." Biotechnology Industry Organization, Statement of Principles, http://www.bio.org/bioethics/background/principles.asp (last visited Nov. 29, 2007).

<sup>104</sup> The BIO Statement of Principles instructs members to oppose research on germ line therapy, human reproductive cloning, and weapons. Id.

some type of review body to consider concerns regarding the promotion of research and scientific inquiry. This oversight body could also weigh issues of access. scientific integrity, dissemination of results, informed consent, rights of participants, and avoidance of conflicts of interest. In order to provide this review mechanism, institutions should take steps to create a review board made up of an interdisciplinary group of professionals. These review boards should include specialists trained in a number of relevant fields as a means to facilitate comprehensive review. If the project affects a particular vulnerable group, that group should have representation on the review body. Members of such a review body should not be involved in the proposed biohistorical investigation, either in a personal or financial respect. Care should be taken to avoid members who may have a potential or actual conflicting interest, such as an affiliation with an outside individual or entity proposing the biohistorical project at issue. These review bodies would be similar to institutional review boards that review appropriateness of protocols for human subjects research. In some instances, the institution may utilize an existing institutional review board for this purpose.

Individuals not affiliated with an institution, such as people for whom history is an avocation or people who possess a biohistorical artifact, should also perform a similar level of review. This may be done by submitting an analysis proposal to a number of interdisciplinary professionals for review or by using resources of an existing institution. Institutions with review capabilities should be open to reviewing individual proposals submitted to them from outside entities.

Review of a proposal for biohistorical analysis will vary with each individual proposal and should be tailored to reflect the unique investigative question posed. Reviewers should consider the ramifications of a proposal and determine whether the biohistorical analysis should proceed, and, if so, under what circumstances. The reviewer(s) should weigh the ethical, scientific, legal, and social issues when coming to a decision. The review should also consider whether problematic issues significantly outweigh the benefit to society. It is important that reviewers give appropriate attention to the specific social concerns raised by a particular proposal as each proposal will generate unique social consequences. If potential harms to the living are present in a proposal, these should always outweigh more abstract analytical goals.

### 2. Access to Samples or Artifacts

As an initial matter, it is necessary that the investigator or individual proposing the analysis have access to the artifact or specimen. There are many legal cases regarding access issues that have focused on disinterment and disruption of corpses on federal grounds, stewardship of art or paintings in museums, and the right of privacy of individuals whose likeness has been used in some manner. Many people personally possess samples acquired from online auctions or other commercial means; others have knowledge of the location of the resting place of a historical figure. Access in this context involves a variety of components, including how to access the sample when it is owned by another; limitations on what can be done with a sample, such as limits imposed by contract law or statute; and other limitations that may come into play, such as laws regarding testing of genetic samples. Where an investigator does not have access to the artifact or specimen or where he or she will

not be able to legally and ethically obtain it for study, biohistorical research is not even feasible. Where the investigator cannot get documented approval for access or where it is evident that the artifact or specimen was obtained illegally or in an unethical or undisclosed manner, it would seem prudent for institutions to refuse to comply with the researcher's request and for geneticists to refuse to undertake the analysis.

Legal constraints regarding access to biohistorical objects may seem limited. Yet a vast body of legal precedents, generally overlooked by researchers and sometimes ignored by courts, could be used to avert instances of bioanalysis where access is questionable. There is existing legal precedent on relevant topics, such as the duties of museum curators and the handling of bodily materials and corpses, which provides some guidance about the legal and cultural values raised regarding access. Removing tissue without consent, even for research purposes, violates statutes and common law principles about appropriate respect for dead bodies. Tissue removal without consent also violates principles of giving next of kin authority to make decisions that best approximate those the deceased would have made. The provided that the provided is a proximate those the deceased would have made.

When DNA testing of a donated artifact that resides in a museum or other collection is proposed, museum officials most often look to the language of the deed of gift to ascertain whether it contained conditions or restrictions that would limit access for research. Typically a museum's collections management policy defines criteria for the acquisition of collection objects. A deed of gift is usually executed to memorialize the gift and expressly reflects any restrictions or reservations regarding the scope of the gift. Courts will look to this deed when a donor-donee conflict arises.

Cases regarding rights of privacy and use of an individual's likeness in art

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<sup>&</sup>lt;sup>105</sup> See, e.g., Brotherton v. Cleveland, 923 F.2d 477, 481-82 (6th Cir. 1991), reh'g en banc denied, 1991 U.S. App. LEXIS 7107 (6th Cir. 1991) (holding that a widow had a property right in the tissue of her deceased husband); Infield v. Cope, 58 N.M. 308, 314 (1954) (finding that widow was not entitled to damages after undertaker buried her late husband before she had opportunity to view the body); Whitehair v. Highland Memory Gardens, Inc., 174 W. Va. 458, 461-62 (1985) (ruling that individual can bring a cause of action for negligent handling of bodies during disinterment and reinterment during the moving of a cemetery). See also International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.html (establishing ethical guidelines for museums).

Margaret Bowman, The Reburial of Native American Skeletal Remains: Approaches to the Resolution of a Conflict, 13 HARV. ENVTL. L. REV. 147, 152 (1989) (citing PROCEEDINGS: CONFERENCE ON REBURIAL ISSUES 3-15, at 82 (P. Quick ed., 1985) (transcript of conference held at the Newberry Library, Chicago, on June 14-15, 1988; comments of S. Moore)).

<sup>&</sup>lt;sup>108</sup> Marsha S. Shaines & Ildiko P. DeAngelis, Giving to Museums: Legal Basics of Donations of Cash, Objects, and Other Property, SD38 ALI-ABA 209, 212 (1999).

See Society of Mineral Museum Professionals, General Guidelines Regarding Donation of Gems, Jewelry, and Minerals to Museums, Feb. 2000, http://www.agiweb.org/smmp/rept-don-usnm.htm (establishing the process by which the Smithsonian Institution receives gifts of various minerals).
 "By carefully executing a deed of gift, future questions regarding a museum's curatorial and

<sup>&</sup>quot;By carefully executing a deed of gift, future questions regarding a museum's curatorial and conservation obligations, or challenges to title may be avoided." *Id.* 

<sup>&</sup>lt;sup>111</sup> See, e.g., Marshall v. Music Hall Ctr. for the Performing Arts, Inc., 1995 WL 871212 (E.D. Mich. Nov. 2, 1995), at \*1, \*3. (looking to the nature of the gift and finding that when a photographer donated single copies of 37 photographs he had taken of jazz musicians to a local museum, only to have the museum use one of the photographs to advertise an upcoming jazz festival, the museum went outside the scope of the gift because the deed of gift did "not license or otherwise convey any portion of the plaintiff's copyright to the museum").

displays are relevant in access considerations. A number of cases have taken the stance that art falls under the First Amendment as protected free speech and overcomes privacy rights. These cases stand for the proposition that artistic expression does not violate an individual's right to privacy so long as the art contains transformative elements. New York courts have followed this rationale and espoused the position that art is speech, and, therefore, art is entitled to First Amendment protection. 113 For example, where the plaintiff claimed that an artist and museum had infringed on her right of privacy by composing and displaying a collage that included her picture without her permission, she had to prove the "use of [her] name, portrait, picture or voice [was used] for advertising purposes or for the purposes of trade, without consent, within the state of New York."114

The right to privacy can be raised with respect to a state statute, the Constitution, or common law. Looking to the applicable New York state statute, the court determined that the collage was pure "First Amendment speech in the form of artistic expression (with sufficiently transformative elements...) and deserves full protection, even against . . . statutorily protected privacy interests." <sup>115</sup> California courts, on the other hand, have looked to "whether it is the art, or the celebrity, that is being sold or displayed." This line of cases raises interesting questions for commercial enterprises of biohistory.

First Amendment issues also arise with respect to the display of corpses. There are a few cases that offer analogies for biohistory with regard to public sentiment and court determinations on the treatment of corpses. A recent case held that a defendant did not have a constitutionally-protected First Amendment right to photograph corpses at a morgue for artistic purposes. 117 After using corpses as models for his photographic art without the official permission or consent of family members, the photographer was charged with violating an Ohio statute that "prohibits anyone, without authorization of law, 'to treat a human corpse in a way that would outrage reasonable community sensibilities." The photographer claimed that the photographs were a form of artistic expression, and, therefore, the

116 Id. at 349. See also Comedy III Productions, Inc. v. Gary Saderup, Inc., 21 P.3d 797, 799 (Cal. 2001), (applying a balancing test between the First Amendment and the right of publicity based on whether the work in question added sufficient creative elements so as to have transformed the art from merely a likeness or imitation).

<sup>112</sup> See, e.g., Serra v. U.S. Gen. Servs. Admin., 847 F.2d 1045, 1048 (2d Cir. 1988) (noting that a sculpture was a form of free expression); Contemporary Arts Ctr. v. Ney, 735 F. Supp. 743, 744-45 (S.D. Ohio 1990) (enjoining state officials from interfering in the display of an allegedly obscene art exhibit). As one court has observed: "[w]ithout people having the freedom to disseminate ideas, a society is not free. Works of art, including sculptures, convey ideas, just as do literature, movies or theatre. Although a person's right of privacy . . . is also a very significant right, it must fall to the constitutionally protected right of freedom of speech." Simeonov v. Tiegs, 602 N.Y.S.2d 1014, 1018 (N.Y. Civ. Ct. 1993).

Hoepker v. Kruger, 200 F. Supp. 2d 340, 349 (S.D.N.Y. 2002) (citing Simeonov v. Tiegs, 602 N.Y.S.2d 1014 (N.Y. Civ. Ct. 1993)). *Simeonov* held that an artist may make a work of art that includes a recognizable likeness of a person without written consent without violating the person's right of privacy. 602 N.Y.S.2d at 1018. In Simeonov, the court noted that non-verbal expression can be protected by the First Amendment, and that non-verbal expression includes works of art. *Id.* at 1017. 114 *Hoepker*, 200 F. Supp. 2d at 348.

<sup>115</sup> Id. at 350.

<sup>&</sup>lt;sup>117</sup> State v. Condon, 789 N.E.2d 696 (Ohio Ct. App. 2003).

<sup>&</sup>lt;sup>118</sup> *Id.* at 700 (citing Ohio Statutory Rules of Conduct § 2927.01(B)).

manner in which he obtained them was constitutionally immune from prosecution. The court distinguished the case from one in which the corpses were in a place where they were open to public inspection, such as a museum or lending library, stating that "an art museum or gallery does not, for example, abuse a corpse by hanging a picture of it for public display, no matter how grisly or offensive the image." In this case, the court made a distinction between the manners in which a corpse or photograph of a corpse is obtained and the manner in which it is displayed.

Where disinterment and research on a dead body are concerned, courts vary in the protections they provide against research on the dead without consent. Most states recognize a right of relatives to receive the body "in the same condition it was in when death intervened." Even an autopsy, when done without proper authority, is considered an actionable "mutilation." Thus, the pathologist removing Albert Einstein's brain without permission could have faced legal action from the family. Specific to Native American remains, NAGPRA allows decedents to recover their ancestors' remains from researchers and reinter them. 123

In certain cases, courts have held that relatives have property<sup>124</sup> or quasi-property<sup>125</sup> rights in the body. In *Brotherton v. Cleveland*, the United States Court of Appeals for the Sixth Circuit, considered a widow's claim regarding the removal of her dead husband's corneas without consent, acknowledged her property interest in her late husband's body.<sup>126</sup> The court affirmed the lower decision that she had a right to stop the use of his corneas because she felt he would not have wanted them donated for transplantation purposes.<sup>127</sup>

However, a state may mandate an autopsy for the narrow purpose of determining the cause of death, notwithstanding the tradition of protecting dead bodies from disturbance. Most states permit coroners to order or conduct an autopsy only when justice so requires. This exception exists because the state has a compelling

<sup>&</sup>lt;sup>119</sup> *Id.* at 703.

<sup>&</sup>lt;sup>120</sup> *Id.* at 705.

<sup>&</sup>lt;sup>121</sup> Foley v. Phelps, 37 N.Y.S. 471, 474 (N.Y. App. Div. 1896).

<sup>&</sup>lt;sup>122</sup> Gurganious v. Simpson, 197 S.E. 163, 164 (N.C. 1938); Grawunder Beth Israel Hosp. Ass'n, 195 N.E. 221, 221-22 (N.Y. 1935) (per curiam) (mem.).

<sup>123 43</sup> C.F.R. 10 (2003).

See, e.g., Whaley v. County of Tuscola, 58 F.3d 1111, 1115 (6th Cir. 1995) (finding a state law right to possess a relative's corpse created a property interest in the body of the decedent); Brotherton v. Cleveland, 923 F.2d 477, 478 (6th Cir. 1991), reh'g en banc denied, 1991 U.S. App. LEXIS 7107 (6th Cir. 1991) (holding that a widow had a property right in the tissue of her deceased husband). But see State v. Powell, 497 So. 2d 1188, 1193 (Fla. 1986) (ruling that relatives do not have property rights in body parts of the decedent).

<sup>&</sup>lt;sup>125</sup> Fuller v. Marx, 724 F.2d 717, 719 (8th Cir. 1984) ("Under Arkansas law, the next of kin does have a quasi-property right in a dead body.").

<sup>&</sup>lt;sup>126</sup> Brotherton, 923 F.2d at 478.

<sup>&</sup>lt;sup>127</sup> Id. at 482. The Supreme Court of Appeals of West Virginia defined the quasi-property right in the following terms:

<sup>[</sup>T]he quasi-property rights of the survivors include the right to custody of the body; to receive it in the condition in which it was left, without mutilation; to have the body treated with decent respect, without outrage or indignity thereto; and to bury or otherwise dispose of the body without interference.

Whitehair v. Highland Memory Gardens, Inc., 174 W. Va. 458, 461 (1985) (citing Infield v. Cope, 58 N.M. 308, 312 (1954)).

<sup>&</sup>lt;sup>128</sup> Ordinarily, state statutes restrict a coroner's ability to order an autopsy to cases where the death results from a casualty, or a suspicious, unusual, or unnatural manner, and when decedent was in

interest in knowing when a death resulted from a criminal act or other cause that may endanger the health of others and this state interest outweighs the interest (religious, ethical, philosophical, or otherwise) of the family of the decedent who oppose the autopsy. <sup>129</sup>

Medical curiosity alone is not a sufficient reason to mandate an autopsy. As a New York case pointed out, the initiation of an autopsy by a medical examiner "merely to determine whether the decedent died by reason of injury to one vital organ as opposed to another" is insufficient. Private physicians have even less right to satisfy their medical curiosity. Nearly a decade ago, a physician performed an autopsy because "the decedent had a greatly enlarged spleen and it was an interesting case." He removed the heart and spleen, cut them into numerous pieces, and preserved them. The court held that even if the autopsy had been justified, that would provide no authority for the physician to remove and retain organs against the will of the person entitled to the corpse. Again, this case resonates of the acts of Albert Einstein's physician in removing his brain and dividing it into pieces.

When an autopsy violates religious beliefs, the need for the autopsy must be compelling. Six states have enacted statutes which provide that autopsies can never be performed which are contrary to the decedents, or his next of kin's, wishes, absent a "compelling public necessity" or some other heightened level of review. Court cases have protected religious beliefs. In *Begay v. New Mexico*, the mother and siblings of the decedent brought suit for emotional distress because the state did not handle the body "according to traditional Navajo religious beliefs." The New

apparent good health, or is the result of death by violence. *See Coroners*, 18 Am. Jur. 2D Coroners or Medical Examiners § 10 (1985 & Supp. 1997) (overviewing state laws regulating coroners). However, even in these situations, an "autopsy cannot be *justified in the interest of science." Id.* (citing Sandy v. Bd. of Com'rs, 87 N.E. 131 (Ind. 1909)).

<sup>&</sup>lt;sup>129</sup> See 18 AM. JUR. 2D CORONERS OR MEDICAL EXAMINERS § 10 (1985 & Supp. 1997), n.24 (citing Snyder v. Holy Cross Hosp., 352 A.2d 334, 341 (Md. Ct. Spec. App. 1976) (holding in a criminal case, where the cause of death cannot be determined without an autopsy, the interest of the state outweighs an individual's religious interest in preserving the bodily integrity of decedent)).

<sup>&</sup>lt;sup>130</sup> Weberman v. Zugibe, 394 N.Y.S.2d 371, 372 (N.Y. Sup. Ct. 1977). In that case, the decedent had been struck by a car and her family sued to enjoin performance of an autopsy for religious reasons. *See also*, Atkins v. Med. Exam'r of Westchester County, 418 N.Y.S.2d 839, 841 (N.Y. Sup. Ct. 1979) (holding "where there is no criminal activity or suspicion of foul play, there is no sound reason to permit an invasion of deep seated religious beliefs merely to satisfy curiosity as to the cause of death").

<sup>&</sup>lt;sup>131</sup> Hassard v. Lehane, 143 A.D. 424, 425 (N.Y. App. Div. 1911).

<sup>&</sup>lt;sup>132</sup> *Id*.

<sup>&</sup>lt;sup>133</sup> *Id.* at 427-28.

<sup>134</sup> N.J. STAT. ANN. § 52:17B-88.2 (West 2007); accord N.Y. PUB. HEALTH LAW § 4210-c(1) (McKinney 2007) (using "compelling public necessity" language); OHIO REV. CODE ANN. § 313.131(C)(1) (West 2007) (providing a 48 hour injunction on the performance of an autopsy the coroner determines is a "compelling public necessity" during which a relative or friend may seek to enjoin the autopsy as contrary to decedent's religious beliefs); R.I. GEN. LAWS ANN. § 23-4-4.1(d) (2006) (providing a 48 hour period in which an autopsy, deemed to be a "compelling public necessity," may be challenged when on the grounds being contrary to the religious beliefs of the decedent); see also CAL. GOV'T. CODE § 27491.43(c) (West 2007) (declaring that regardless of religious beliefs a coroner may "perform an autopsy or any other procedure if he or she has a reasonable suspicion that the death was caused by the criminal act"); MD. CODE ANN., HEALTH-GEN. § 5-310(b)(2) (West 2007) (requiring authorization by the Chief Medical Examiner or her designee for an autopsy to proceed in the face of religious objections raised by decedent's family).

<sup>&</sup>lt;sup>135</sup> Begay v. State, 723 P.2d 252, 255 (N.M. Ct. App. 1985), rev'd sub nom. Smialek v. Begay, 721 P.2d 1306, 1306 (N.M. 1986) (allowing siblings of a decedent to bring a claim against the state medical

Mexico Supreme Court held that only the "nearest relative," the mother, had standing to bring suit under 42 U.S.C. § 1983 claiming a violation of the decedent's religious rights when the State of New Mexico had performed an autopsy on the decedent because his body was found with bruises and scratches on his face and his wallet missing. <sup>136</sup>

In a 1979 case, a New York judge permanently enjoined the court medical examiner from conducting an autopsy on the plaintiff's mother and directed that the remains be returned to him for burial. The mother had been struck by a motor vehicle while crossing a street; she was an Orthodox Jew, a religion that prohibits dissection of the body. The court stated: "An autopsy cannot restore her mortal being. It should not be countenanced to destroy her eternal life. The grief which follows the shadow of death must not be compounded by the indignity of transgression against sacred belief." Because there was no criminal activity or suspicion of foul play connected to the death of the woman, and in light of her religious beliefs, the court determined that there was no sound reason to permit an invasion of deep-seated religious beliefs to merely satisfy curiosity as to the cause of death. The same struck by a motor vehicle that the plaintiff is mother and directed that the court determined that there was no sound reason to permit an invasion of deep-seated religious beliefs to merely satisfy curiosity as to the cause of death.

In *Kohn v. United States*, the United States District Court for the Eastern District of New York held that the parents of a deceased serviceman were entitled to damages for emotional distress because the government had violated the Jewish plaintiffs' religious beliefs when handling the body. The mishandling occurred when the Army performed an autopsy on the serviceman without giving notice to the family or getting their consent. Additionally, certain body parts were removed, intended to be retained "indefinitely," and then the rest of the body was cremated. 142

Issues with access may also arise in the context of court-imposed restitution arising under federal statutory law. <sup>143</sup> The most prevalent example of this type of restitution results from NAGPRA. <sup>144</sup> NAGPRA requires a federally-funded museum to prepare inventories of their human remains and grave artifacts and to return said artifacts upon request by a lineal descendant, Indian tribe, or Native Hawaiian

<sup>136</sup> Smialek, 721 P.2d at 1308, cert. denied 479 U.S. 1020 (1986).

examiner).

<sup>&</sup>lt;sup>137</sup> Atkins, 418 N.Y.S.2d at 841. In a similar case six years earlier, Wilensky v. Greco, 344 N.Y.S.2d 77 (N.Y. Sup. Ct. 1973), the Supreme Court of Orange County, New York, also enjoined the county coroner from performing an autopsy of an Orthodox Jewish man. As in Atkins, the court ruled that the purpose of the autopsy, to determine the manner of death, was so obvious in the case of a man killed in a car accident that the state could not justify overriding the religious beliefs of the decedent or his family. Thus, the autopsy was not performed and the coroner was directed to return the body to the plaintiff. *Id.* <sup>138</sup> See Atkins, 418 N.Y.S.2d at 840 (stating that decedent's "faith prohibits dissection of the human body after death").

<sup>139</sup> Id. at 841.

<sup>&</sup>lt;sup>140</sup> *Id.*; see also Weberman v. Zugibe, 394 N.Y.S.2d at 372 (holding "that an autopsy may not be performed over the religious, ethical or philosophical objections of a decedent's family, absent a showing of genuine necessity therefore").

<sup>&</sup>lt;sup>141</sup> 591 F. Supp. 568, 575 (E.D.N.Y. 1984).

<sup>&</sup>lt;sup>142</sup> *Id.* at 573. This case pointed out, "[p]hysical mutilation of remains may be expected to distress the next of kin. But where they believe that the treatment will affect the afterlife of the deceased, the impact inevitably is greater." *Id.* at 568.

Patty Gerstenblith, Acquisition and Deacquisition of Museum Collections and the Fiduciary Obligations of Museums to the Public, 11 CARDOZO J. INT'L & COMP. L. 409, 425-51 (2003).
 U.S.C. §§ 3001-3013 (2003).

organization.145

There are a few cases dealing specifically with biohistorical analysis of identified human remains or remains attributed to a historical figure. In each of these situations, an individual scientist, family member, or organization sought to disinter the remains of a deceased historical figure and were confronted with opposition. 146 For example, the National Park Service (NPS) has continuously denied requests from Dr. James Starrs, a forensic scientist, to exhume the remains of explorer Meriwether Lewis located on NPS-protected federal land in Tennessee. Starrs hypothesizes that Lewis was not murdered but instead committed suicide following repeated bouts with alcoholism, malaria, drug abuse, depression, <sup>148</sup> and syphilis. <sup>149</sup> The State of Tennessee and Starrs unsuccessfully petitioned in federal court, citing as the chief argument for exhumation and testing a state statute allowing exhumation where the process would aid in enforcing a criminal law or serve a penal purpose. 150 The court found that because the body was located on federal land under the control of the NPS, the issue fell squarely under ARPA, <sup>151</sup> meaning that the state lacked jurisdiction over the matter and any investigation would be at the sole discretion of the NPS under relevant ARPA provisions. 152

Starrs continues his efforts to gain the right to exhume Meriwether Lewis. Salthough the NPS has repeatedly denied Starrs' request, he managed to collect the signatures of 170 Lewis relatives and letters from three state governors supporting his research. A NPS spokesman has commented on the problematic nature of exhuming human remains merely to satisfy a forensic scientist's hunch based on questionable evidence. A Lewis biographer has also publicly questioned the circumstantial historical evidence in support of Starrs' hypotheses, as well as the scientist's right to invade Lewis' sexual privacy.

Only a few professional codes specifically address access to the object studied and are typically written in terms of acquiring informed consent from the owner, custodian, or agent. 157 Issues of informed consent are more prevalent in the context

<sup>146</sup> Constance Holden, Scientists Hope Ruling Will Lead Them to Bones, 303 SCI. 943, 943 (2004).

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<sup>&</sup>lt;sup>145</sup> § 3005(a)(1).

<sup>&</sup>lt;sup>147</sup> Another Lewis and Clark Expedition?, NATIONAL JOURNAL'S CONGRESS DAILY, Jan. 14, 2000.

<sup>&</sup>lt;sup>148</sup> *In re* Exhumation of Lewis, 999 F. Supp. 1066, 1068 (M.D. Tenn. 1998).

<sup>&</sup>lt;sup>149</sup> Senator Asks Body of Lewis Be Exhumed To Settle Explorer's Fate, COM. APPEAL (Memphis, Tenn.), Feb. 19, 2002, at B2.

<sup>&</sup>lt;sup>150</sup> Lewis, 999 F. Supp. at 1073.

<sup>&</sup>lt;sup>151</sup> *Id.* at 1071-72.

<sup>&</sup>lt;sup>152</sup> *Id.* at 1073.

 $<sup>^{153}</sup>$  Carlos Santos, Starrs Still Intent on Studying Remains of Meriwether Lewis, TIMES-DISPATCH, Nov. 13, 2005, at G-7.

<sup>&</sup>lt;sup>154</sup> Chuck McCutcheon, Solving Old Mysteries: Exhumations on the Rise, NEWHOUSE NEWS SERVICE, June 8, 2005.

<sup>&</sup>lt;sup>155</sup> Senator Asks Body of Lewis Be Exhumed To Settle Explorer's Fate, supra note 149.

<sup>&</sup>lt;sup>156</sup> Philip Weiss, *Tabloid History*, N.Y. TIMES, Nov. 29, 1998 (Magazine), at 111-12.

<sup>&</sup>lt;sup>157</sup> ICOM requires the adherence to "restrictive terms of the acquisition." International Council of Museums, *Code of Ethics for Museums* § 4.2 (2006), http://icom.museum/ethics.html. AAA states that "researchers should obtain in advance the informed consent of [concerned parties]." American Anthropological Association, *Code of Ethics of the American Anthropological Association* at 3 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf. The ASA requires that the agreement explain the nature of the research, uses understandable language, provides the opportunity for questions, informs about factors expected to influence participation, and explains refusal or withdrawal. American

of human genetics research, where federally-funded researchers must abide by federally-mandated requirements of informed consent and IRB review. <sup>158</sup> In addition, appropriate access to the artifact or object studied may be assumed as a foundational requirement for ethical codes of museums and curator groups and thus not directly discussed in their professional codes of ethics and guidelines.

### 3. Scientific Integrity and Dissemination of Results

The advent of DNA testing created the potential to reveal results that are conclusive to an extent not previously attainable. However, this type of research creates a variety of questions regarding the intrusive nature of the procedure, the adequacy of the testing methodology used, and ultimately the accurate dissemination of research findings. A biohistorical study of an object or cultural property can be controversial where analytical testing compromises the preservation of the object. Often, DNA analysis will cause irreversible damage to the artifact because a portion of the artifact must be isolated from the rest. Intrusive scientific testing with human remains is particularly contentious because of ambiguity as to the classification of the remains.

Of critical importance are the design and execution of the scientific analyses, including (1) the investigational question and study protocol, (2) study methodology, and (3) dissemination of the results. One significant consideration with respect to methodology is whether the analysis method will use the entire sample. The ability to replicate research results has always been a critical feature of scientific inquiry and using the entire sample would prevent others from repeating the analysis in order to verify or dispute findings.

It is also important to consider whether a historic artifact will be destroyed because a section needs to be cut out for analysis, whether less invasive methods are currently available to answer the research question, and whether bioanalysis should be delayed until less destructive techniques are available. The measure of the level of destructiveness should be taken into account examining a number of factors, such

Sociological Association, Code of Ethics at 12-13 (1997), http://www.asanet.org/galleries/defaultfile/Code% 20of% 20Ethics.pdf. AIA addresses the issue of group consent, instructing archaeologists to consult with representatives of the local community during planning, to invite local participation in the project, and to inform the local community about research results. Archeological Institute of America, Code of Professional Standards at 2 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_ Professional\_StandardsA5S.pdf. BIO and ISE vaguely require adherence to informed consent Biotechnology Industry Organization, Statement of Principles, http://www.bio.org/ procedures. bioethics/background/principles.asp (last visited Oct. 1, 2007); International Society for Ethnobiology, Code of Ethics at 4 (2006), http://ise.arts.ubc.ca/documents/ISECodeofEthics TEXT2006\_000.pdf. ACMG states that subjects should determine the scope of permission to use samples or results. American College of Medical Genetics, Statement on Storage and Use of Genetic Materials at § 1.A.3.a (1995), http://www.acmg.net/resources/policies/pol-028.asp. HUGO's informed consent requirements include privacy concerns and consent of relevant family members and community members. Human Genome Organization, Ethics Committee Statement on Human Genomic Databases (2002), http://www.hugo-international.org/PDFs/Statement%20on%20Human%20Genomic%20

Databases%202002.pdf. AIC requires, "[p]rior consent must be obtained from the owner, custodian, or agent before any material is removed from a cultural property. Only the minimum required should be removed, and a record of removal must be made. When appropriate, the material removed should be retained." American Institute for the Conservation of Historic and Artistic Works, *Code of Ethics and Guidelines for Practice* § 17 (1994), http://aic.stanford.edu/pubs/ethics.html.

<sup>&</sup>lt;sup>158</sup> See U.S. Dept. Health and Human Services, Office for Human Research Protections IRB Guidebook, http://www.hhs.gov/ohrp/ (follow "Chapter II: Regulation and Policies") (promulgating regulations for participants in federally-funded research).

as the age of the artifact, the rarity of the artifact and its historical significance, and the type of analysis to be used. The intrusiveness or destructiveness of certain types of bioanalysis may caution in favor of forgoing testing until less destructive techniques are available. For example, at this point in time, DNA testing of Mary Todd Lincoln's cloak housed at the CHS would require cutting out a piece of the cloak. <sup>159</sup>

There are some levels of professional guidance already in place regarding broad issues of scientific integrity. Museums especially practice extensive processes for preservation and stewardship, detailed in professional codes for curators and collections officers, as well as individual museum codes. However, existing codes tend to focus on reporting and results of research rather than issues that come at the front end of research, such as methodology and feasibility issues.

### Investigational question and study protocol

The study protocol should be appropriate and the analysis necessary to answer the specific research question. Under the legal principle and professional guidelines about stewardship, such analysis should not be done if it is unnecessary. Care must also be taken to assure that the investigational question has been generated in a disciplinarily-appropriate manner, including the critical examination of existing credible resources, whether oral, written, textual, physical, etc. For example, if the purpose of the analysis is authentication, perhaps traditional written or oral histories will provide evidence in a particular instance that renders the bioanalysis unnecessary.

The provenance, or the origin or history of an artifact or specimen, is another relevant concern. Investigators frequently assume that the historical tissue samples they are testing are authentic, although the provenance of many historical artifacts is poorly documented. This was an issue raised in response to reports from the Romanov excavation. Regarding proposals to investigate whether Abraham Lincoln suffered from Marfan's syndrome, a connective tissue disorder, researchers would need an authenticated Lincoln DNA reference sample to carry out genetic testing. Because Lincoln assassination relics became a commercial commodity

<sup>&</sup>lt;sup>159</sup> Chicago Historical Society, *supra* note 25.

<sup>&</sup>lt;sup>160</sup> It should be clear that the proposed facilities are appropriate for the investigation. The utility of the research should also be determined, looking to whether there are appropriate reference samples available and whether the information that will be obtained justifies the sampling and analysis. Adequate safeguards are also necessary, including the proper level of scientific integrity (competence, objectivity, and lack of bias), complete record-keeping, control studies, quality assurance mechanisms, proper procedures for control of contamination within the laboratory, disclosure of methodology for peer review, return of all unused portions of any specimens to the original source, and explicit documentation of the fate of any laboratory-generated specimens or sub-samples. Again, this may implicate sampling policies already in place at the proposed laboratory facility. It is also important that the proponent indicate whether the proposed specimens are homogenous because nonhomogeneity could yield different results in subsequent analyses.

<sup>&</sup>lt;sup>161</sup> Peter Gill et al., *Identification of the Remains of the Romanov Family by DNA Analysis*, 6 NATURE GENETICS 130, 134 (1994) (highlighting the existence of evidence that, to a sufficient degree of certainty, identified skeletal remains as those of the Romanov family: Tsar, Tsarina, and three of their five children).

<sup>&</sup>lt;sup>162</sup> See id. at 132 (describing the comparison of direct descendants of decedents as means of ensuring authenticity of the forensic sample); Kline v. Green Mount Cemetery, 677 A.2d 623, 633 (Md. Ct. Spec. App. 1996) (highlighting the uselessness of DNA testing in identifying remains without a living descendant with which to compare samples).

soon after the president's death, there are many tissue specimens and bloodstained garments attributed to the president in both private and museum collections nationwide, but there are no known Lincoln tissue specimens that have been definitively authenticated. <sup>163</sup>

When addressing this issue of reliable identification and provenance, a court recently determined that there was no adequate method of testing to discover whether a buried body was that of John Wilkes Booth. DNA testing was out of the question due to the fact that there were no known matrilineal descendants of Booth and more traditional methods such as examining dental records or searching for idiosyncratic features would be futile because no records of such things existed. Also, experts offered that while a type of testing known as photographic superimposition (involving the superimposition of a photograph of the deceased's head over the recovered skull) was technologically possible, it could not result in a truly positive identification and was still very experimental in nature. It follows that a research project is not methodologically appropriate in the context of biohistorical investigation if it does not have the potential to lead to scientifically definitive results.

It should also be possible to utilize the analysis results to critically evaluate the hypothesis. Where an investigator poses a question that is incapable of resolution by the proposed analysis (as where ambiguities will remain because the results will be intrinsically incapable of resolving them) the research should not be undertaken. For example, where a researcher proposes DNA analysis on a human artifact where identification can be based only on non-mitochondrial DNA analysis and there is no available reference specimen, it is not appropriate to answer the scientific question posed.

Along with being able to answer the research question posed, the researcher(s) conducting the study should also be competent to perform the research. Aside from issues of informed consent, the Harvey study on Einstein's brain was also problematic in terms of the lack of credentials of the researcher. Harvey published no scientific studies prior to, or in the forty years after, Einstein's death. By 1988, Harvey lost his medical license. In an effort to study Einstein's genius, he reportedly sliced off snippets of the brain on his kitchen breadboard for investigation. He compared Einstein's brain slices to five controls and concluded that Einstein's brain was within the average range in weight, but below the mean for men his age. Two codes specifically address the issue of scientific competence

<sup>&</sup>lt;sup>163</sup> See Chicago Historical Society, supra note 25 (noting that "[t]here is currently no authoritative reference sample of Lincoln's DNA available for a comparative analysis"); see also Davidson, supra note 31, at 15 (noting a lack of certainty over the authenticity of DNA samples and concluding that a reference sample obtained from Lincoln's mother's lineage would be required to authenticate any sample currently being investigated).

<sup>164</sup> Kline, 677 A.2d at 633.

<sup>&</sup>lt;sup>165</sup> Id.

<sup>166</sup> *Id*.

<sup>&</sup>lt;sup>167</sup> Jonathan Freedland, *In the Name of Science*, THE GUARDIAN WEEKEND PAGE, Dec. 17, 1994, at T010.

<sup>&</sup>lt;sup>168</sup> Nancy Banks-Smith, *The Man with No Brain*, THE GUARDIAN, Apr. 2, 1994, at O26.

<sup>&</sup>lt;sup>169</sup> Anderson & Harvey, *supra* note 50, at 161.

with respect to study protocol. 170

In addition to fundamental questions of scientific competence of researchers, it is also important to consider when researchers are attempting to utilize new technology or to reveal new types of information on biohistorical subjects. This reflects issues of whether a technology is viewed by scientists as sound science, much like the Frye and Daubert standards adopted by courts to introduce scientific evidence into the court record.<sup>171</sup>

### Study methodology

Another scientific concern is the actual study methodology spanning the length of the research. Specifically, this includes preservation of the sample throughout the study, documentation methods, and research environment. Eight of the twenty-six codes address the long-term scientific and preservation methodology. <sup>172</sup> Important

<sup>170</sup> The ASA Ethical Standards are unique in that they contain extensive requirements on the issue of competence. American Sociological Association, *Code of Ethics* at 2 (1997), http://www.asanet.org/galleries/default-file/Code%20of%20Ethics.pdf. Sociologists are to "conduct research, teach, practice, and provide service only within the boundaries of their competence[.]" *Id.* When venturing into new areas of work, sociologists must first "take reasonable steps to ensure the competence of their work in these areas." *Id.* at 5, HUGO also recommends that "scientific competence is the essential prerequisite for ethical research." Human Genome Organization, *Statement on the Principled Conduct of Genetic Research* (1996), http://www.eubios.info/HUGO.htm.

<sup>171</sup> These two standards refer to the admissibility of scientific evidence. In *Frye v. United States*, the Court of Appeals for the District of Columbia determined that at the trial court level, courts must determine whether the expert testifying utilized generally accepted methods in the relevant scientific community and if so, the evidence was admitted and deficiencies in testimony based on either qualification or the underlying science were matters for the jury. 293 F. 1013, 1014 (D.C. Cir. 1923). In 1993, the Supreme Court held that Frye did not withstand subsequent Federal Rules of Evidence. Daubert v. Merrell Dow Pharmaceuticals, 509 U.S. 579, 587 (1993). The Court concluded that a number of factors were to be considered by a judge in admitting scientific evidence and testimony, including (1) whether the theory or technique can be tested, (2) whether the profered work has been subjected to peer review, (3) whether the rate of error is acceptable, and (4) whether the method at issue enjoys widespread acceptance. *Id.* at 593-94. *Daubert* is only binding on federal courts, so states differ on whether they adhere to the *Frye* Standard or the more recent *Daubert* Standard.

International Council of Museums, Code of Ethics for Museums (2001), http://icom.museum/ethics.html; The Archaeological Institute of America, Code of Professional Standards at 2 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_Standards A5S.pdf; Human Genome Organization, Statement on the Principled Conduct of Genetic Research (1996), http://www.eubios.info/HUGO.htm and Human Genome Organization, Ethics Committee Statement on Human Genomic Databases at 2 (2002), http://www.hugo-international.org/PDFs/Statement%20on%20Human%20Genomic%20Databases%202002.pdf; American Association of Museums, Code of Ethics for Museums (2000), http://www.aam-us.org/museumresources/ethics/coe.cfm; American Historical Association, Statement on Standards of Professional Conduct (2005), http://www.historians.org/pubs/free/professionalstandards.cfm; Society of American Archivists, Code of Ethics for Archivists (2005), http://www.archivists.org/governance/handbook/app\_ethics.asp; American Institute for the Conservation of Historic and Artistic Works, Code of Ethics and Guidelines for Practice (1994), http://aic.stanford.edu/pubs/ethics.html; American College of Medical Genetics, Statement on Storage and Use of Genetic Materials (1995), http://www.acmg.net/resources/policies/pol-028.asp.

The ICOM Code charges museums with practicing preventive conservation; performing only reversible conservation procedures; documenting conservation procedures, maintaining a protective environment, and stabilizing museum objects. International Council of Museums, *Code of Ethics for Museums* (2001), http://icom.museum/ethics.html.

The AIA Code instructs archaeologists that "[a]pproaches and methods should be chosen that require a minimum of damage to the archaeological record." The Archaeological Institute of America, *Code of Professional Standards* at 1 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_StandardsA5S.pdf.

HUGO instructs researchers to put policies in place for the transfer and conservation of samples.

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considerations enumerated include conservation and transport of samples and documents; performing only reversible conservation procedures; documenting conservation procedures; maintaining a protective environment; stabilizing museum objects; minimization of damage; appropriate selection of research methods and materials; and determination of the necessity of procedures contemplated.

The Romanov study highlights numerous methodological concerns. The scientific methodology of the original study has been discredited by a group of scientists because of "extreme irregularities at every level" of the investigation. Overall, the study has generally been discredited for using inappropriate scientific methodology and flawed statistical analysis, 174 for introducing contaminants into the skeletal samples, 175 for failing to correctly assign bones, 176 and for "rude violations of archeological and forensic norms." Authors of an article refuting the original study cite evidence that the grave was of unknown age and had been opened numerous times before the official "discovery" in 1991. Pevidence shows that the site was originally opened in 1979 and several skulls and bones were removed and

Human Genome Organization, *Statement on the Principled Conduct of Genetic Research* (1996), http://www.eubios.info/HUGO.htm. HUGO also encourages the use of repositories to ensure the continuation of publicly available databases. *Id.* 

The AAM, AHA, SAA Codes similarly provide for protecting objects and documents. American Association of Museums, *Code of Ethics for Museums* (2000), http://www.aam-us.org/museumresources/ethics/coe.cfm; American Historical Association, *Statement on Standards of Professional Conduct* (2005), http://www.historians.org/pubs/free/professionalstandards.cfm; Society of American Archivists, *Code of Ethics for Archivists* (2005), http://www.archivists.org/governance/handbook/app\_ethics.asp.

Concerning analyses that have the potential to irreversibly damage an object, the ICOM Code provides "destructive analytical techniques undertaken for the advancement of knowledge may result in the loss of part of a specimen or object. There is a clear ethical obligation to ensure that such activities are not detrimental to the long-term survival of examples of the material studied, displayed or used and that a detailed report of all such activities becomes a permanent part of the collections record." International Council of Museums, *Code of Ethics for Museums* (2006), http://icom.museum/ethics.html.

Similarly, the AIC Code provides, "[t]he conservation professional must strive to select methods and materials that, to the best of current knowledge, do not adversely affect cultural property or its future examination, scientific investigation, treatment, or function." American Institute for the Conservation of Historic and Artistic Works, Code of Ethics and Guidelines for Practice (1994), http://aic.stanford.edu/pubs/ethics.html. The AIC Code also requires, "[b]efore undertaking any examination or tests that may cause change to the cultural property, the conservation professional should establish the necessity for such procedures." American Institute for the Conservation of Historic and Artistic Works, Code of Ethics and Guidelines for Practice (1994), http://aic.stanford. edu/pubs/ethics.html. The AIC requires, "[p]rior consent must be obtained from the owner, custodian, or agent before any material is removed from a cultural property. Only the minimum required should be removed, and a record of removal must be made. When appropriate, the material removed should be retained." Id. In contrast to ensuring preservation, the ACMG Code requires informing patients about the fate of their clinical samples—namely, will they be destroyed—implying that patients may prefer that result. American College of Medical Genetics, Statement on Storage and Use of Genetic Materials (1995), http://www.acmg.net/resources/policies/pol-028.asp.

<sup>&</sup>lt;sup>173</sup> A. Knight, et al., *supra* note 40, at 129.

 <sup>&</sup>lt;sup>174</sup> Id. (citing L.A. Zhivotovsky, Recognition of the Remains of Tsar Nicholas II and His Family: A Case of Premature Identification?, 26 ANNALS OF HUMAN BIOLOGY 569-577 (1999)).
 <sup>175</sup> Id

<sup>&</sup>lt;sup>176</sup> *Id.* at 130.

<sup>&</sup>lt;sup>177</sup> *Id.* (citing V.N. Krokov, *The Characteristics of Mechanical Damage to the Bones and Skeletons*, in EKATERINBURGSKAYA TRAGEDIYA: TAINA TSARSKIH OSTANKOV [THE EKATERINBURG TRAGEDY: A MYSTERY OF TSAR'S REMAINS] (N.E. Chuprjakova ed., The Association of Ural Publishers, Sredneural'skoe Knizhnoe Izdatel'stvo, Ekaterinburg 1994) 92-94).

replaced a year later.<sup>179</sup> Other sources indicate the grave site had been opened in 1946 by the State Security services.<sup>180</sup> In addition, the original research team has not provided, either in the published report or in any other material, proof of the chain of custody of the samples and the raw data they generated in their research.<sup>181</sup> The authors of the article attacking the original study have performed the first analysis on remains of the Tsarina's sister, the Grand Duchess Elisabeth, (who was not killed with the rest of the family, but died later) and found that the result does not support the claim that the remains found at Ekaterinburg are those of the Romanov family.<sup>182</sup> They conclude that because of the "gross violations of forensic investigative norms and factual inconsistencies" the results of the original study are scientifically unsound.<sup>183</sup>

Similarly, in the case of Billy the Kid, scientific challenges remain regarding the suggested methodology of testing his purported remains with those of his mother, Mary Antrim.<sup>184</sup> Billy the Kid is supposedly buried near the house in Fort Sumner where he was gunned down, yet is in close proximity to a number of other bodies buried at the same site.<sup>185</sup> The state would have to acquire permission to exhume additional bodies near the site due to uncertainty over where the Kid's actual grave is located.<sup>186</sup> Furthermore, in 1882, the city relocated a number of bodies, including his mother's, from the original cemetery to the cemetery in Silver City, raising the question of whether she is really buried below her headstone in Silver City.<sup>187</sup> In order to assess the forensic issues of the proposed exhumation of Antrim, leading forensic scientists have been employed to conduct forensic research on the site and report their conclusions.<sup>188</sup>

Likewise, with the Medici project, locating and exhuming the bodies has proven much more difficult than initially anticipated due to the lack of architectural plans or drawings available to the researchers. An earlier exhumation attempt in 1947 had contaminated many of the corpses. The excavators had taken numerous bodies

 $^{180}$  Id. (citing P.N. Koltypin-Wallovskoy, et al., Memorandum No. 3 (open letter to the President of Russia)).

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<sup>179</sup> Ld

<sup>&</sup>lt;sup>181</sup> Id. (citing SHAY MCNEAL, THE SECRET PLOT TO SAVE THE TSAR (2001)).

<sup>182</sup> Id. at 135

<sup>&</sup>lt;sup>183</sup> *Id.* at 134-35. Regarding the specific scientific technology employed, the Gill study is being questioned for numerous reasons. The molecular behaviors that the team reported were cited as "wholly inconsistent with the behaviours of degraded DNA and such behaviours have not been reported elsewhere for similar cases." *Id.* at 131. Specifically, the data they report indicates that rather than being from a chemically degraded sample (resulting from positioning in a shallow, damp grave for over 70 years), the samples associated with the Romanovs were actually contaminated with non-degraded DNA and thus the results were highly inconclusive. *Id.* at 134-35.

<sup>&</sup>lt;sup>184</sup> See Alan Boyle, *Billy the Kid: Case Closed*, MSNBC, Sept. 27, 2004, http://www.msnbc.msn.com/id/6092904/ (noting that flooding may have moved the gravesites); Alan Boyle, *Billy the Kid's DNA Sparks Legal Showdown*, MSNBC, Nov. 18, 2003, http://www.msnbc.msn.com/id/3475969/ (observing that multiple graves would have to be excavated in order to obtain multiple samples to obtain a true baseline sample with which to compare other samples).

<sup>&</sup>lt;sup>185</sup> Billy the Kid Investigation Resurrected, supra note 44.

<sup>186</sup> Id

<sup>&</sup>lt;sup>187</sup> First Fight in Kid Showdown Set for Monday, ALBUQUERQUE J., Dec. 7, 2003, at B1.

<sup>&</sup>lt;sup>188</sup> Billy the Kid Investigation Resurrected, supra note 44.

<sup>&</sup>lt;sup>189</sup> Maugh, *supra* note 5, at A5.

<sup>&</sup>lt;sup>190</sup> *Id*.

out of the coffins, removed clothing and other objects, taken plaster casts of the skulls, and dismantled the bones, leaving them scattered in the crypt. <sup>191</sup> A flood of the crypt in 1966 has further complicated the current efforts, as it left exposed coffins, bones of infants, and various artifacts strewn across the floor. <sup>192</sup> There are concerns that the flood may have caused extensive damage to the remains, potentially eliminating the possibility of useful samples. <sup>193</sup> There are also numerous individual tombs determined to be too fragile for exhumation, including that of Cosimo the Elder, who helped usher in the Florentine Renaissance, and Lorenzo the Magnificent, who ruled Florence during the height of the Renaissance. <sup>194</sup>

The study protocol of the Hemings and Jefferson study<sup>195</sup> has also been attacked as inappropriate for determining the paternity of Hemings' children. The only possible conclusion to draw from the research was that some Jefferson family males and Hemings male-line descendants had common relatives. Yet because the genetic testing involved Y-chromosomal analysis, it is also a possible conclusion that a Jefferson relative fathered Eston. Moreover, the original publication purported to exclude Thomas Jefferson as the father of Thomas Woodson. The lack of a Y chromosome match between Jefferson's uncle and Hemings' descendants could be due to a woman in the intervening generations having an affair (and thus not passing on her husband's Y chromosome.) In fact, the inconclusive study results have effectively caused more of a controversy among living Jefferson and Hemings descendants; a resolution to the 200-year dispute is nowhere in sight.<sup>196</sup>

One proposal for biohistorical analysis on the buried remains of John Wilkes Booth was ultimately rejected by a court of law on methodology grounds, as well as the wishes of the next of kin. In 1996, a number of interested parties along with the purported relatives<sup>197</sup> of Booth brought an action against the cemetery housing his remains seeking exhumation in an effort to authenticate them.<sup>198</sup> Ultimately, in *Kline v. Green Mount Cemetery*, the Appellate Court denied permission to the relatives based on a number of factors.<sup>199</sup> First, the court found that appellant relatives were not direct lineal descendants of Booth (they were neither spouses nor children) and as distant relatives, their wishes to exhume could not override the wishes of the true next of kin that had chosen his burial site over one hundred and twenty-five years ago.<sup>200</sup> Second, the court found that because Booth's death and subsequent identification of his body by numerous family members and

<sup>&</sup>lt;sup>191</sup> *Id*.

<sup>&</sup>lt;sup>192</sup> *Id*.

<sup>&</sup>lt;sup>193</sup> Winfield, *supra* note 1.

<sup>&</sup>lt;sup>194</sup> See, e.g., CHRISTOPHER HIBBERT, THE HOUSE OF MEDICI: ITS RISE AND FALL, 68, 164-168 (1980) (outlining the cultural contributions and political actions of Cosmo and Lorenzo respectively); Lorenzi, supra note 6 (noting the fragility of Lorenzo's grave).

<sup>&</sup>lt;sup>195</sup> Foster et al., Jefferson Fathered Slave's Last Child, supra note 51, at 27-28.

<sup>&</sup>lt;sup>196</sup> Erika Check, Jefferson's Descendants Continue to Deny Slave Link, 407 NATURE 213, 213 (2002).

<sup>&</sup>lt;sup>197</sup> These interested parties and relatives consisted of Nathaniel Orlowek, a religious educator with a background in history, Arthur Ben Chitty, a historiographer active in researching John Wilkes Booth, Virginia Kline, a self-proclaimed third cousin of Booth, and Lois Rathbun, the purported great-great-niece of Booth. *Kline*, 677 A.2d at 627.

<sup>&</sup>lt;sup>198</sup> *Id.* at 624

<sup>&</sup>lt;sup>199</sup> See id. (summarizing the lower court's reasoning in rejecting petitioner's request for exhumation and agreeing).

<sup>&</sup>lt;sup>200</sup> Id. at 630.

acquaintances was well-documented and unequivocal, the skepticism of the appellants was not sufficient reason to doubt the official documented history. <sup>201</sup> The court rejected the disinterment request because of technical factors such the location of the grave, the condition of the remains, the low likelihood of reliable identification, and the extensive time needed for examination. 202 With respect to the location of the gravesite, records indicated that Booth's actual gravesite was unmarked and the cemetery had only a "speculation" of where the body was located.<sup>203</sup> The court found that even if the body was buried where the appellants believed, a casket containing three infants was reportedly buried on top of it in 1869. leading an expert witness forensic scientist to remark that the action would be more like an "archeological dig" than an exhumation because it would disturb various other graves.<sup>204</sup> In addition, evidence was introduced that the Booth family burial plot was placed at the bottom of a hill containing acidic soil and water damaged graves. 205 The court decided that even if Booth was originally buried in the family plot back in 1869, his remains were likely extensively water damaged and unusable for analysis.<sup>206</sup>

In addition to issues of scientific competence, the research on Einstein's brain has been questioned due to a lack of sufficient controls or measures to answer the question of whether Einstein's particular brain morphology was related to his intellectual capability. In fact, other researchers have directly questioned the appropriateness of trying to learn about genius through a physical study of the brain. Dr. Janice Stevens of the neuropsychiatry branch of the National Institute of Mental Health pointed out, "Many idiots have big brains loaded with glial cells."

### Dissemination of Results

Mechanisms should be in place to assure accuracy in reporting, complete presentation of interpretations and judgments, sharing of results with affected

<sup>&</sup>lt;sup>201</sup> *Id.* at 632. To instill this point, the court drew upon evidence showing: (1) Union soldiers pursuing Booth had been given pictures by which to identify him; (2) the Lieutenant in charge of the pursuit personally knew Booth and positively identified his body following his shooting; (3) a clerk at the hotel where Booth had often stayed while in Washington was a witness at the autopsy and "distinctly recognize[d]" Booth by his general appearance, specifically India-ink lettering on his arm reading "J.W.B" and a noticeable scar on his neck; and (4) a physician autopsy witness stated that he had "no doubt" that the body was that of Booth based on the fact that he had known him for eighteen months, having removed a tumor from his neck. *Id.* at 631. In addition, a number of years after the disinterment of Booth's body from the Washington penitentiary for placement in the Green Mount Cemetery, an actress who had personally known Booth wrote to a biographer that she had been present with Booth's mother, brother, and sister prior to reburial and all four definitely identified his body. *Id.* at 631-632.

<sup>&</sup>lt;sup>202</sup> Kline, 677 A.2d 632-34.

<sup>&</sup>lt;sup>203</sup> *Id.* at 632-33.

<sup>&</sup>lt;sup>204</sup> *Id.* at 633.

<sup>&</sup>lt;sup>205</sup> *Id*.

<sup>&</sup>lt;sup>206</sup> Id.

<sup>&</sup>lt;sup>207</sup> See Witelson, et al., supra note 50, at 2152 (noting that early investigations of the brain morphology of geniuses had no control groups); Anderson & Harvey, supra note 50, at 163 (discussing multiple explanations for differences found between the control group and Einstein's brain, thus suggesting doubt as to the link between brain size and intelligence).

<sup>&</sup>lt;sup>208</sup> See Dan Colburn, Studying the Twentieth Century's Most Esteemed Brain, THE RECORD (Northern N.J.), Mar. 11, 1985, at B3 (noting that the role of certain brain cells is not understood and that natural aging may be responsible for increases in cells claimed to be linked to Einstein's intelligence).

<sup>209</sup> Id.

groups, publication in open peer-reviewed literature, societal discussions and explanation of results, full disclosure of findings without intentional withholding or omission of findings or opinions that may lead to misrepresentation or distortion, and disclosure of underlying theories, methods, measures, and research designs.

Nine of the twenty-six codes guide researchers to share source data and research results. Five of the twenty-six codes address the issue of public access to research results or materials. Eight of the organizations stress the importance of

<sup>210</sup> Two codes contain only general provisions. The ASCLS Code calls for members to "improv[e] the body of knowledge." American Society for Clinical Laboratory Science, *Code of Ethics* § II, http://ethics.iit.edu/codes/coe/amer.soc.clinical.lab.science.coe.html. Similarly, the ASIS Code calls on documentalists to "endeavor to promote the greatest exchange of scientific information." American Society for Information Science and Technology, *Code of Ethics* § 14 (1969), http://ethics.iit.edu/codes/coe/amer.soc.info.sci.html.

The AAA Code instructs anthropologists to "seriously consider all reasonable requests for access to their data and other research materials for research purposes" and to disseminate their findings to the scientific and scholarly community. American Anthropological Association, *Code of Ethics of the American Anthropological Association* at 3 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf.

The AHA Code instructs historians to make their sources, evidence, and data available to others. American Historical Association, *Statement on Standards of Professional Conduct* (2005), http://www.historians.org/pubs/free/professionalstandards.cfm.

The ASA Code, while instructing sociologists to disseminate results, recognizes that exceptions arise due to proprietary agreements with employers, contractors, or clients. American Sociological Association, *Code of Ethics* at 15 (1997), http://www.asanet.org/galleries/default-file/Code%20of%20 Ethics.pdf. However, the ASA offers no concrete guidance to members on how to balance such a conflict of interest. HUGO advocates accomplishing such availability by utilizing repositories and states in general that "[i]nsofar as it benefits humanity, the free flow, access, and exchange of data are essential." Human Genome Organization, *Ethics Committee Statement on Human Genomic Databases* at 2 (2002), http://www.hugo-international.org/PDFsStatement%20on%20Human%20Genomic%20Databases%202002.pdf.

The AIC and the American Institute of Chemists Codes specifically refer to publishing results, with the American Institute of Chemists Code expressing a preference for technical journals as opposed to reporting results via the public press. American Institute for the Conservation of Historic and Artistic Works, *Code of Ethics and Guidelines for Practice* (1994), http://aic.stanford.edu/pubs/ethics.html; American Institute of Chemists, *Code of Ethics* (1983), http://www.theaic.org/DesktopDefault.aspx?tabid=46.

Finally, ASHG addresses the issue of disseminating results after a subject's death: "Decisions related to the disposition of results or samples after the subject's death should be specified by the subject." American Society of Human Genetics, *Report, Statement on Informed Consent for Genetics Research* (1996), http://genetics.faseb.org/genetics/ashg/policy/pol-25.htm.

211 The ICOM Code provides, "[m]useum have a particular responsibility for making collections and all relevant information available as freely as possible . . . [and m]embers of the museum profession have an obligation to share their knowledge and experience with colleagues, scholars and students in relevant fields." International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.html. The AAM Code provides, "[t]he museum ensures that access to the collections and related information is permitted and regulated." American Association of Museums, Code of Ethics for Museums (2006), http://www.aam-us.org/museumresources/ethics/coe.cfm. The AAA code provides, "[a]nthropological researchers should make the results of their research appropriately available to sponsors, students, ... and other nonanthropologists." American Anthropological Association, Code of Ethics of the American Anthropological Association at 4 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf. The SAA Code "strives to promote open and equitable access to their services and the records" of documentary materials. Society of American Archivists, Code of Ethics for Archivists (2005), http://www.archivists.org/governance/handbook/app\_ethics.asp. The HUGO Code provides, "Human genomic databases are global public goods" and "[k]nowledge useful to human health belongs to humanity." Human Genome Organization, Ethics Committee Statement on Human Genomic Databases at 2 (2002), http://www.hugo-international.org/PDFs/Statement% 200n% 20Human% 20Genomic% 20Databases% 202002.pdf.

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accuracy and peer review.<sup>212</sup>

### 4. Informed Consent and Rights of Participants

Law and ethical codes protect a wide variety of people associated with research, including society in general, research subjects, and groups and/or subpopulations. <sup>213</sup> Depending on the research question, biohistory may implicate a wide range of individuals, groups, or entities, including analysis subjects, the living spouse, descendants, close relatives, distant relatives, indigenous groups, ethnic or cultural groups, religious groups, and disease groups.

Unfortunately, existing federal regulations and ethics codes do not provide much guidance on these issues. A researcher, historian, museum, or affected party would find little within the codes in the way of concrete rules or standards for informed consent and rights of participants in undertaking biohistorical analysis.<sup>214</sup> However, some of the principles of consultation and informed consent contained in the professional codes could be extended or reworked to apply to biohistorical analysis, at least regarding informing and obtaining consent from descendants.<sup>215</sup>

<sup>212</sup> The AHA instructs "[e]xhibits should be . . . subjected to rigorous peer review." American Historical Association, Standards for Museum Exhibits Dealing with Historical Subjects (2001), http://www.historians.org/info/museumstandards.htm. The AIC advocates that "[c]onservation professional[s] should recognize the importance of published information that has undergone formal peer review." American Institute for the Conservation of Historic and Artistic Works, Code of Ethics and Guidelines for Practice (1994), http://aic.stanford.edu/pubs/ethics.html. The AMA Code provides "[m]edical society ethics committees, hospital credentials and utilization committees, and other forms of peer review have been long established by organized medicine to scrutinize physicians' professional conduct. At least to some extent, each of these types of peer review can be said to impinge upon the absolute professional freedom of physicians. They are, nonetheless, recognized and accepted." AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-9.10 (2002). The ACFE Code instructs forensic scientists "[n]ot to intentionally withhold or omit any findings or opinions . . . that would cause the facts of a case to be misinterpreted or distorted. American College of Forensic Examiners, Code of Ethics, http://ethics.iit.edu/codes/coe/amer.college.forensic.examiners.coe.html (last visited Oct. 1, 2007). The ASA instructs sociologists "to ensure the accuracy of all public communications" and to "disclose underlying assumptions, theories, methods, measures, and research designs that might bear upon findings and interpretations of their work." American Sociological Association, Code of Ethics at 8, 15 (1997), http://www.asanet.org/galleries/defaultfile/Code%20of%20Ethics.pdf. The ASBMB Code instructs that investigators must fulfill an obligation to other investigators to "accurately describe methods used in experiments." American Society for Biochemistry and Molecular Biology, *Code of Ethics* (1998), http://www.asbmb.org/asbmb/site.nsf/Sub/CodeofEthics?. The NCPH Code provides that "[h]istorians owe to their sources accurate reportage of all information relevant to the subject at hand," an interesting distinction from the other codes which sither characterize the duty for accurate practice as a good to a characterize the duty for accurate practice as a good to a characterize the duty for accurate practice as a good to a characterize the duty for accurate practice as a good to a characterize the duty for accurate practice as a good to a characterize the duty for accurate practice as a good to a characterize the duty for accurate practice as a good to a characterize the duty for accurate practice as a good to a characterize the duty for accurate practice as a good to a characterize the duty for accurate practice as a good to a characterize the duty for accurate practice as a good to a characterize the duty for accurate practice as a good to a characterize the duty for accurate practice as a good to a characterize the duty for accurate practice as a good to a characterize the duty for accurate practice as a good to a characterize the duty for accurate practice and the characterize the duty for accurate practice and the characterize the good to a characterize the duty for accurate practice and the characterize the good to a c codes, which either characterize the duty for accurate reporting as owed to other researchers or do not specify to whom that duty is owed. National Council on Public History, Code of Ethics and Professional http://www.ncph.org/AbouttheCouncil/BylawsandEthics/tabid/291/Default.aspx# Conduct (2007),Ethics. HUGO states "that communication not only be scientifically accurate, but understandable to the populations, families, and individuals concerned." Human Genome Organization, *Statement on the* Principled Conduct of Genetic Research (1996), http://www.eubios.info/HUGO.htm.

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<sup>&</sup>lt;sup>213</sup> See, e.g., American Anthropological Association, Code of Ethics of the American Anthropological Association at 2 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf (requiring archeologists to respect the human populations they work with).

<sup>214</sup> See, e.g., The Archaeological Institute of America, Code of Professional Standards at 2 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_StandardsA5S.pdf (advising archeologists that "legitimate concerns of people who claim descent from, or some other connection with, cultures of the past must be balanced against the scholarly integrity of the discipline").

<sup>&</sup>lt;sup>215</sup> See, e.g., International Society for Ethnobiology, Code of Ethics at 3-6 (2006), http://ise.arts.ubc.ca/documents/ISECodeofEthicsTEXT2006\_000.pdf (detailing the duties of ethnobiologists to indigenous communities).

The effect of research on the interests of a variety of parties is articulated among seventeen of the twenty-six codes. Ten codes mention a general obligation to research subjects or participants. Several codes espouse a variety of general

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<sup>216</sup> International Society for Ethnobiology, Code of Ethics at 7 (2006), http://ise.arts.ubc.ca/documents/ ISECodeofEthicsTEXT2006\_000.pdf; The Archaeological Institute of America, Code of Professional Standards at 1-2 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_Standards A5S.pdf; American Anthropological Association, Code of Ethics of the American Anthropological Association (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf; American Historical Association, Statement on Standards of Professional Conduct (2005), http://www.historians.org /pubs/free/professionalstandards; American Historical Association, Standards for Museum Exhibits Dealing with Historical Subjects (2001), http://www.historians.org/info/museumstandards.htm; American Sociological Association, Code of Ethics at 6-7 (1997), http://www.asanet.org/galleries/ default-file/Code% 20of% 20 Ethics.pdf; Oral History Association, Oral History Evaluation Guidelines, (2000), http://omega.dickinson.edu/organizations/oha/pub\_eg.html; Council of American Survey Research Organizations, Code of Standards and Ethics for Survey Research ) at 4-9 (2004), http://www.casro.org/pdfs/CASRO%20Code%20of%20Standards%20and%20Ethics%202004.pdf; American Society for Clinical Laboratory Scientists, Code of Ethics, http://www.ascls.org/about/index.asp (last visited Sept. 29, 2007); American Society of Human Genetics, Professional Disclosure of Familial Genetic Information (1998), http://genetics.faseb.org/genetics/ashg/policy/pol-29.htm; Human Genome Organization, Statement on the Principled Conduct of Genetic Research (1996), http://www.eubios.info/HUGO.htm; AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-2.079(1) & (2) (2002); American Association of Museums, Code of Ethics for Museums (2000), http://www.aam-us.org/museumresources/ethics/coe.cfm; Code of Ethics of the American Anthropological Association at 1, 4 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf; American Cultural Resources Association, Code of Ethics and Professional Conduct, http://www.acracrm.org/Ethics.html; Biotechnology Industry Organization, Statement of Principles, http://www.bio.org/bioethics/background/principles.asp (last visited Oct. 1, 2007); College Art Biotechnology Association, Code of Ethics for Art Historians and Guidelines for the Practice of Art History (1995), http://www.collegeart.org/guidelines/histethics.html; International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.html.

<sup>217</sup> American Anthropological Association, *Code of Ethics of the American Anthropological Association* at 2 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf; American Sociological Association, *Code of Ethics* at 6-7 (1997), http://www.asanet.org/galleries/default-file/Code%20of%20 Ethics.pdf; Oral History Association, *Oral History Evaluation Guidelines* (2000), http://omega.dickinson.edu/organizations/oha/pub\_eg.html; Council of American Survey Research Organizations, Code of Standards and Ethics for Survey at 4-9 (2004), http://www.casro.org/pdfs/CASRO%20Code%20of%20Standards%20and%20Ethics%202004.pdf; Biotechnology Industry Organization, *Statement of Principles*, http://www.bio.org/biotethics/background/principles.asp; American Society for Clinical Laboratory Scientists, *Code of Ethics*, http://www.ascls.org/about/ethics.asp (last visited Sept. 29, 2007); American Historical Association, *Standards for Museum Exhibits Dealing with Historical Subjects* (2001), http://www.historians.org/info/museumstandards.htm; American Society of Human Genetics, *Professional Disclosure of Familial Genetic Information* (1998), http://genetics.faseb.org/genetics/ashg/policy/pol-29.htm; Human Genome Organization, *Statement on the Principled Conduct of Genetic Research* (1996), http://www.eubios.info/HUGO.htm; AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-2.079(1) & (2) (2002).

The AAA Code provides, "[a]nthropological researchers have primary ethical obligations to the people, species, and materials they study[.]"American Anthropological Association, *Code of Ethics of the American Anthropological Association* at 2 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf. The AAA Code also adds a rare example of ranking, albeit not definitively, the obligations owed to research subjects over other obligations: "[t]hese obligations [to the people anthropologists study] can supersede the goal of seeking new knowledge" (emphasis added). *Id*.

The ASA Code instructs against exploitation or harassment of "research participants." American Sociological Association, *Code of Ethics* at 6 (1997), http://www.asanet.org/galleries/default-file/Code% 20of% 20 Ethics.pdf.

The Oral History Association (OHA) requires that interviewers endeavor to prevent any exploitation of or harm to "interviewees." Oral History Association, *Oral History Evaluation Guidelines* (2000), http://omega.dickinson.edu/organizations/oha/pub\_eg.html.

The CASRO Code outlines broad responsibilities owed to survey respondents. Council of American Survey Research Organizations, *Code of Standards and Ethics for Survey Research* at 4-9 (2004), http://www.casro.org/pdfs/CASRO%20Code%20of%20Standards%20and%20Ethics%202004.pdf.

considerations regarding subjects and participants, including privacy, confidentiality, and appropriate informed consent. A few codes offer a relatively nebulous principle, which is essentially trusting in universal values and morals when conducting research on measurable populations. Some codes defer completely to existing laws and regulations on questions of confidentiality. Confidentiality intersects with the issue of informed consent in several codes, requiring permission for use of information gleaned from research.

BIO and American Society for Clinical Laboratory Scientists (ASCLS) also include "patients," as types of participants or research subjects unique to these organizations' area of focus. Biotechnology Industry Organization, Statement of Principles, http://www.bio.org/bioethics/background/principles.asp (last visited Oct. 1, 2007); American Society for Clinical Laboratory Scientists, *Code of Ethics*, http://www.ascls.org/about/ethics.asp (last visited Sept. 29, 2007).

AHA instructs museums to "identify stakeholders in any exhibit." American Historical Association, Standards for Museum Exhibits Dealing with Historical Subjects (2001), http://www.historians.org/info/museumstandards.htm.

Although it ultimately takes no definitive position, the American Society of Human Genetics (ASHG) engages in a lengthy analysis of various approaches to the issue of revealing to a patient's relatives, against the patient's will, genetic information about the patient that could be used to prevent or treat disease in the patient's relatives. American Society of Human Genetics, *Professional Disclosure of Familial Genetic Information* (1998), http://genetics.faseb.org/genetics/ashg/policy/pol-29.htm.

The Human Genome Organization (HUGO) warns that the Human Genome Project and other genetic research have given rise to a number of concerns, including a "lack of respect for the values, traditions, and integrity of populations, families, and individuals." Human Genome Organization, *Statement on the Principled Conduct of Genetic Research* (1996), http://www.eubios.info/HUGO.htm.

The AMA Code instructs that "[p]hysicians who participate as investigators in genomic research should have adequate training in genomic research and related ethical issues so as to be able to discuss these issues with patients and/or potential research subjects." AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-2.079(1) (2002). The AMA Code also provides that researchers should design a study so as to minimize harm for individual subjects. *Id.* E-2.079(2).

<sup>218</sup> See, International Society for Ethnobiology, Code of Ethics at 3-6 (2006), http://ise.arts.ubc.ca/documents/ISECodeofEthicsTEXT2006\_000.pdf (establishing the ethical duties of ethnobiologists in treating indigenous communities).

<sup>219</sup> The ICOM Code states that where sensitive material is used, it must be done "with respect for the feelings of human dignity held by all peoples." International Council of Museums, *Code of Ethics for Museums* § 6.6 (2006), http://icom.museum/ethics.html. Similarly, the ASA Code states that "[s]ociologists respect the rights, dignity, and worth of all people." American Sociological Association, *Code of Ethics* at 4 (1997), http://www.asanet.org/galleries/default-file/Code%20of%20Ethics.pdf. The ISE code instructs researchers to avoid the "imposition of external or foreign conceptions and standards." International Society for Ethnobiology, *Code of Ethics* at 5 (2006), http://ise.arts.ubc.ca/documents/ISECodeofEthicsTEXT2006\_000.pdf.

<sup>220</sup> The Association of Professional Genealogists (APG) Code provides generally, "[t]he professional genealogist promote[s] the trust and security of genealogical consumers." Association of Professional Genealogists, *Code of Ethics*, http://www.apgen.org/ethics/CodeofEthicsBrochure.pdf (last visited Sept. 27, 2007). No definition of "security" is offered. Beyond that protection, the code merely states, "[t]he professional . . . does not knowingly violate . . . laws and regulations concerning . . . right to privacy[.]" *Id.* While the APG Code seemed to defer to the law as the only protection of privacy, the ASA Code by contrast approaches laws as a minimum protection to be exceeded by sociologists. The ASA code instructs, "[c]onfidential information provided by . . . research participants . . . is treated as such by sociologists even if there is no legal protection or privilege to do so." American Sociological Association, *Code of Ethics* at 9 (1997), http://www.asanet.org/galleries/default-file/Code%20of% 20Ethics.pdf. The AMA Code instructs that "[t]he physician should not reveal confidential communications or information without the express consent of the patient, subject to certain exceptions which are ethically justified because of overriding considerations." AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-5.05 (2002).

<sup>221</sup> The AIC code provides, "[i]nformation derived from examination, scientific investigation, or treatment of cultural property should not be published or otherwise made public without written permission." American Institute for the Conservation of Historic and Artistic Works, *Code of Ethics and Guidelines for Practice* § 7 (1994), http://aic.stanford.edu/pubs/ethics.html. Both the OHA Code and the

measures regarding confidentiality, such as permanent confidentiality measures, including confidentiality after death, specific mechanisms for confidential information stored in databases or electronically transmitted, and removal of all identifiers. These provisions all beg the question of whether deceased should even be considered "research subjects" or "participants" in the context of biohistorical research. We argue that they should, because the information acquired from this type of research will inevitably create additional information about that person or his or her family that was not collected while that person was alive, but would have triggered human subjects protections.

Where the biohistorical research will involve living individuals, such as where the investigator plans to involve a descendant of the deceased historical figure, safeguards should be in place to assure safety to those individuals, both physical and psychological even if the research is not covered by federal human subject research protections. Where genetic analysis is involved, the specific risks should be identified to all parties and adequate privacy mechanisms should be established to protect living individuals. For example, if a living relative agrees to give a DNA sample, he or she should be warned that genetic information may lead to discrimination in terms of employment and health insurance.

A further consideration is whether the genetic results have the potential to cause emotional distress to living individuals, as in cases of genetic disorders or paternity. In all cases, if a form of genetic analysis that will not reveal health-related information or that utilizes other traces on an artifact such as soil or pollen would suffice to answer the investigational question, that technology should be utilized rather than potentially privacy-invading genetic analysis.

AHA Statement on Interviewing for Historical Documentation provide for a legal release for interviews, with the OHA Code also indicating that, "[i]nterviewees have given permission for their use." Oral History Association, *Oral History Evaluation Guidelines* (2000), http://omega.dickinson.edu/organizations/oha/pub\_eg.html. The CASRO Code instructs, "Survey Research firms confronted with a subpoena or other legal process requesting the disclosure of Respondent-identifiable information should take all reasonable steps to oppose such requests, including informing the court . . . of the factors justifying confidentiality . . . ." Council of American Survey Research Organizations, *Code of Standards and Ethics for Survey Research* § A.3.f (2004), http://www.casro.org/pdfs/CASRO%20Code% 200f%20Standards%20and%20Ethics%202004.pdf. It also provides, "[f]or research findings obtained by the agency that are the property of the Client, the Research Organization may make no public release or revelation of findings without expressed, prior approval from the Client." *Id.* 

The ASA code is particularly strong in requiring sociologists to ensure that confidentiality is maintained permanently. See American Sociological Association, Code of Ethics at 9-10 (1997), http://www.asanet.org/galleries/default-file/Code%20of%20Ethics.pdf (providing comprehensive guidelines for confidentiality). Confidentiality is to be maintained even after the death of the person who is the source of study as well as in the event of the death of the sociologist. Id. at 9, 11. The obligation to maintain confidentiality also extends to members of research or training teams and collaborating organizations. Id. at 10. Sociologists must likewise protect the anonymity of information entered into databases or electronically transmitted. Id. at 10-11. Where records are transferred to other organizations, sociologists must "obtain assurances that the recipients of the records...employ measures...at least equal to those originally pledged." Id. at 12. Similarly, CASRO imposes upon survey researchers the "responsibility for insuring that [s]ubcontractors and [c]onsultants are aware of and agree to maintain and respect [r]espondent confidentiality[.]" Council of American Survey Research Organizations, Code of Standards and Ethics for Survey Research at 5 (2004), http://www.casro.org/pdfs/CASRO%20Code%20of%20Standards%20and%20Ethics%202004.pdf. Also toward ensuring permanent confidentiality, the AMA Code provides: "Disclosure of medical information postmortem for research and educational purposes is appropriate as long as confidentiality is maintained to the greatest possible degree by removing any individual identifiers." AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-5.051 (2002).

Family members may also have direct personal interests in the research conducted on their deceased relatives. It is possible that "Genetic analysis of the tissue from [corpses] can reveal information about the health status and predispositions of family members." Clyde Snow, a forensic anthropologist who has done many DNA tests on dead bodies, once remarked, "Bones may be my business, but they're other people's families." One researcher attempted to test Einstein's brain tissue for a genetic mutation that would predispose him to an aneurysm. A positive finding may have exposed Einstein's surviving relatives to discrimination based on genetics. Provisions may be necessary to ensure the confidentiality of genetic information obtained through biohistorical analysis to protect readily identifiable living descendants who may share inherited traits.

Eight codes include considerations for the general public or society as affected by research.<sup>227</sup> A few codes refer to a narrower segment of society or the public. Four codes identify duties or considerations owed to the local community where the research happens.<sup>228</sup> Four codes consider religious groups, ethnic groups, or

<sup>&</sup>lt;sup>223</sup> Dorothy Nelkin and Lori Andrews, *Do the Dead Have Interests? Policy Issues for Research After Life*, 24 AM. J.L. & MED. 261, 281 (1998).

<sup>&</sup>lt;sup>224</sup> For example, the body thought to be Butch Cassidy was disinterred to establish its authenticity. *NOVA: Wanted: Butch and Sundance* (PBS television broadcast, Oct. 12, 1993).

<sup>&</sup>lt;sup>225</sup> Scott McCartney, *Believing Einstein's Brain Matters, Doctors Keep the Remains*, The Asian Wall Street Journal, May 6, 1994, at 1. The DNA in the particular sample was too degraded to provide a definitive answer. *Id.* 

<sup>&</sup>lt;sup>226</sup> "Genetic testing on deceased individuals can also disrupt family relationships. Einstein's adopted granddaughter, Evelyn, asked a New Jersey physician, Dr. Charles Boyd, to use genetic testing to determine if she was actually Einstein's illegitimate daughter. To undertake the genetic comparison, Boyd obtained a piece of Einstein's brain from Harvey." Nelkin & Andrews, *supra* note 223, at 281.

The ICOM Code provides, a museum is "in the service of society." International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.html. The AAM Code states that a museum represents the interests of "society" and contributes to the "public." American Association of Museums, *Code of Ethics for Museums* (2000), http://www.aam-us.org/museumresources/ethics/coe.cfm. The AAA Code refers to anthropologists' moral obligations to the "community," "society," "culture," and the "public." American Anthropological Association, Code of Ethics of the American Anthropological Association at 1, 4 (1998), http://www.aaanet.org/committees/ ethics/ethicscode.pdf. The American Cultural Resources Association (ACRA) outlines a number of responsibilities merely to the "public." American Cultural Resources Association, Code of Ethics and Professional Conduct, http://www.acra-crm.org/Ethics.html. The BIO Statement of Principles acknowledges a responsibility to consider the interests of "all segments of society." Biotechnology Industry Organization, http://www.bio.org/bioethics/background/principles.asp (last visited Oct. 1, 2007). The AHA Code instructs researchers to be aware of the diverse community and constituency the researchers serve. American Historical Association, Standards for Museum Exhibits Dealing with Historical Subjects (2001), http://www.historians.org/info/museumstandards.htm. HUGO warns that the Human Genome Project and other genetic research have given rise to a number of concerns, including a "lack of respect for the values, traditions, and integrity of populations, families, and individuals." Human Genome Organization, Statement on the Principled Conduct of Genetic Research (1996), http://www.eubios.info/HUGO.htm. The AMA Code provides that researchers should design a study so as to minimize harm for the community studied. AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-2.079(2)(2002).

<sup>&</sup>lt;sup>228</sup> The ICOM Code directs that field exploration must abide by the laws and regulations of the "host country." International Council of Museums, *Code of Ethics for Museums* (2006), http://icom.museum/ethics.html. For handling human remains, the ICOM Code also requires honoring the interests and beliefs of "members of the community ... from which the objects originated." *Id.* The CAA Code instructs that art history field data that are unique and irreplaceable documents must remain under the control of the "host community." College Art Association, *Code of Ethics for Art Historians and Guidelines for the Practice of Art History* (1995), http://www.collegeart.org/guidelines/histethics.html. The AIA Code instructs that archeologists have responsibilities to "local communities [where research is carried out]" and should respect the cultural dignity and norms of "local inhabitants."

indigenous peoples as affected groups.<sup>229</sup> Original owners of an object or artifact are recognized as affected individuals in one code.<sup>230</sup> Two codes recognize descendants of past cultures as affected individuals.<sup>231</sup>

#### Research subjects

Federally-funded research on human subjects must comply with existing federal and state regulation pertaining to human subjects. By federal statute definition, these provisions apply only to living people. However, biohistorical research effectively involves various other living parties, whether genetically related to the deceased figure or socially or culturally-linked. These could be the person who possesses the artifact or sample; a community that is closely linked to the historic figure because of religion, culture, or disease; or a living person providing a genetic sample for comparison analysis.

Responsibilities to the deceased under study necessarily entail compliance with existing legal provisions, such as federal repatriation statutes, federal and state statutes regarding treatment of the dead and burial grounds, and any legally

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Archeological Institute of America, *Code of Professional Standards* at 2 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_StandardsA5S.pdf. The International Society for Ethnobiology Code states its commitment to working with "local communities" to avoid injustices. International Society for Ethnobiology, *Code of Ethics* at 1-2 (2006), http://ise.arts.ubc.ca/documents/ISECodeofEthicsTEXT2006\_000.pdf.

<sup>&</sup>lt;sup>229</sup> International Society for Ethnobiology, *Code of Ethics* (2006), http://ise.arts.ubc.ca/documents/ISECodeofEthicsTEXT2006\_000.pdf; International Council of Museums, *Code of Ethics for* Museums (2006), http://icom.museum/ethics.html; Biotechnology Industry Organization, Statement of Principles, http://www.bio.org/bioethics/background/principles.asp (last visited Oct. 1, 2007); American Anthropological Association, Code of Ethics of the American Anthropological Association (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf . The ISE Code is committed to a genuine partnership with "indigenous peoples" and "traditional societies." International Society for Ethnobiology (ISE) Code of Ethics (2006), http://ise.arts.ubc.ca/documents/ISECodeofEthics TEXT2006 000.pdf. Other codes mention ethnic or religious groups. The ICOM Code instructs that research on human remains must be done in a manner consistent with the interests and beliefs of "members of . . . ethnic or religious groups from which the objects originated." International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.html. The BIO Statement of Principles includes a responsibility to seek a dialogue with, among others, "religious leaders." Biotechnology Industry Organization, Statement of Principles, http://www.bio.org/bioethics/background/ principles.asp (last visited Oct. 1, 2007). In contrast, the AAA Code provides that anthropologists have a moral obligation to their own religion. American Anthropological Association, Code of Ethics of the American Anthropological Association (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf.

<sup>&</sup>lt;sup>230</sup> In the context of confidentiality, the wishes of "owners" who bring objects to a museum for identification are to be respected. International Council of Museums, *Code of Ethics for Museums* (2006), http://icom.museum/ethics.html. The Code also recognizes a duty to return stolen or illegally exported items to the "country or people of origin." *Id.* 

Archeological Institute of America, *Code of Professional Standards* at 2 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_StandardsA5S.pdf; American Cultural Resources Association, *Code of Ethics and Professional Conduct*, http://www.acra-crm.org/Ethics.html (last visited Nov. 30, 2007). The AIA Code provides "[t]he legitimate concerns of people who claim descent from, or some other connection with, cultures of the past must be balanced against the scholarly integrity of the discipline. A mutually acceptable accommodation should be sought." Archeological Institute of America, *Code of Professional Standards* at 2 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_StandardsA5S.pdf. In certain instances, this may imply some sort of veto power on the part of claimed descendants. The ACRA Code provides that members "shall strive to respect the concerns of people whose histories and/or resources are the subject of ... investigation." American Cultural Resources Association, *Code of Ethics and Professional Conduct*, http://www.acra-crm.org/Ethics.html (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>232</sup> See supra note 86.

recognized familial quasi-property rights. The deceased individual may have left an indication during life of how he or she wanted his or her remains to be treated after death, which will be considered by a court on a case by case basis if controversy arises.

#### Individual Views on Research

The underlying ethical principle governing the conduct of research is that participation in research is not a matter of conscription. Many individuals may have strong feelings about the type of research they are willing to be involved in. Recent litigation brought against researchers by research participants demonstrates that people feel harmed if research is done on their tissue without their consent, <sup>233</sup> beyond their consent, <sup>234</sup> or for purposes that they do not approve of, such as commercial gain. <sup>235</sup>

Religious, cultural, and personal beliefs color whether a person would be willing to have research done on his or her tissue or DNA after death. Orthodox Jewish individuals and Native Americans have beliefs about burial that preclude most research after death. Other groups, such as Southern Baptists, have religious objections to certain types of research, such as efforts that result in the patenting of human genes. Family members may also be troubled by the use of their deceased loved one's tissue in research and may indeed have legal claims against researchers.

#### Informed Consent

Using DNA testing in biohistorical research also raises pressing ethical and legal issues of informed consent. A researcher or commercial outfit would argue that at some point descendants become too far generationally removed to warrant having to obtain their permission. A descendant will argue that her privacy, property, and other rights as well as her religious or cultural feelings require that she be consulted before testing is done. But how does a researcher locate such descendants? How does a researcher verify who are the descendants of a historical figure? Should the descendants of historical figures be accorded absolute veto power over any bioanalysis on the historical figures' artifacts or relics?

Twelve of the twenty-six codes include at least some requirement of informed

<sup>&</sup>lt;sup>233</sup> See Moore v. Regents of Univ. of Cal., 793 P.2d 479, 486 (Cal. 1990) (holding that a physician must disclose his/her personal interests, such as using a patient's tissue for research purporses, in order to secure informed consent).

<sup>&</sup>lt;sup>234</sup> See Wash. Univ. v. Catalona, 490 F.3d 667, 674 (8th Cir. 2007) (finding that, under Missouri law, research participants must intend to make a valid *inter vivos* gift of anatomical samples).

<sup>&</sup>lt;sup>235</sup> Greenberg v. Miami Children's Hosp. Research Inst., Inc., 264 F. Supp. 2d 1064, 1066-67 (S.D. Fla. 2003) (ruling on a suit brought by donees of tissue against researchers obtained a patent based on the donated tissue).

<sup>&</sup>lt;sup>236</sup> Nelkin & Andrews, *supra* note 223, at 271, 278-79.

<sup>&</sup>lt;sup>237</sup> Southern Baptist Convention, Resolution on the Patenting of Animal and Human Genes (1995), http://www.sbc.net/resolutions/amResolution.asp?ID=570.

<sup>&</sup>lt;sup>238</sup> Harriet A. Washington, *Henrietta Lacks -- An Unsung Hero*, EMERGE 24-35, 29 (Oct. 1994).

<sup>&</sup>lt;sup>239</sup> See Kohn v. United States, 591 F. Supp. 568, 573 (E.D.N.Y. 1984), aff'd without opinion, 760 F.2d 253 (2d Cir. 1985) (recounting case where family brought suit against the Army after it performed autopsy on an Orthodox Jewish man and retained multiple organs in contravention of Jewish burial customs).

consent.<sup>240</sup> Two codes contain only a minimal treatment of the informed consent

Association, Code of Ethics at Sociological 10, 12-14 American http://www.asanet.org/galleries/default-file/Code%20of%20Ethics.pdf; Oral History Association, Oral History Evaluation Guidelines (2000), http://omega.dickinson.edu/organizations/oha/pub\_eg.html; Council of American Survey Research Organizations, Code of Standards and Ethics for Survey Research (2004), http://www.casro.org/pdfs/CASRO%20Code%20of%20Standards%20and%20Ethics%202004. pdf; International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ ethics.html; American Anthropological Association, Code of Ethics of the American Anthropological Association at 3 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf; American College of Medical Genetics (ACMG) Statement on Storage and Use of Genetic Materials (1995), http://www.acmg.net/resources/policies/pol-028.asp; Human Genome Organization, Statement on Patenting DNA Sequences (2000), http://www.hugo-international.org/PDFs/Statement%20on%20 Patenting%20of%20DNA%20Sequences%202000.pdf; AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-5.075 and E-2.079(3), (2002); American Institute for the Conservation of Historic and Artistic Works, Code of Ethics and Guidelines for Practice (1994), http://aic.stanford.edu/pubs /ethics.html; American Historical Association, Statement on Standards of Professional Conduct (2005), http://www.historians.org/pubs/free/professionalstandards.cfm; Biotechnology Industry Organization, Statement of Principles, http://www.bio.org/bioethics/background/principles.asp (last visited Oct. 1, 2007); International Society for Ethnobiology, Code of Ethics (2006), http://ise.arts.ubc.ca/ documents/ISECodeofEthicsTEXT2006\_000.pdf.

According to the ASA *Code of Ethical Standards*, sociologists can access publicly available information or conduct research in public places without obtaining consent. This also applies to the use of recording technology. Consent to film, record or videotape a participant in a study warrants consent from the participant unless their activities involve "naturalistic observations in public places" and it is not anticipated that these recordings will cause the subject any undue harm. American Sociological Association, *Code of Ethics* at 14 (1997), http://www.asanet.org/galleries/default-file/Code%20of%20Ethics.pdf. Otherwise, the ASA Code requires that an informed consent agreement explain the nature of research, use understandable language, provide an opportunity for questions, include factors expected to influence participation, explain that refusal or withdrawal involves no penalty, and explicitly discuss confidentiality as well as any limits to guarantees of confidentiality. *Id.* at 10, 12-13. The ASA Code instructs sociologists to keep records of informed consent obtained and to conform to state and federal regulations and institutional review board requirements on informed consent. *Id.* at 12-13. In addition, sociologists working with "vulnerable populations (e.g. youth, recent immigrant populations, and the mentally ill)" should "take special care to ensure that the voluntary nature of the research is understood and that consent is not coerced." *Id.* at 12.

The OHA Principles provides that proper informed consent should include an explanation of an interviewee's legal rights. Oral History Association, Oral History Evaluation Guidelines (2000), http://omega.dickinson.edu/organizations/oha/pub\_eg.html. The CASRO Code instructs, "[t]he Interviewer/Research Company representative must provide prompt and honest identification of his/her research firm affiliation." Council of American Survey Research Organizations, Code of Standards and Ethics for Survey Research at 6 (2004), http://www.casro.org/pdfs/CASRO%20Code%20of%20 Standards%20and%20Ethics%202004.pdf. The CASRO Code also requires informing research participants of electronic equipment and one-way viewing rooms. Id. at 7. The ICOM Code requires museums to adhere to any restrictive terms attached to an acquisition and to obtain informed consent for the intentional disposal of samples from all parties that contributed to the original purchase. International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.html. The AAA Code requires designing informed consent procedures for studies and continuing to ensure informed consent through dialogue and negotiation. American Anthropological Association, Code of Ethics of the American Anthropological Association at 3 (1998), http://www.aaanet.org/committees/ ethics/ethicscode.pdf. According to the AAA, informed consent is a "dynamic" and "continuous" process. *Id.* The ACMG Code instructs clinicians or researchers to inform patients that the test or research might yield information that requires difficult choices regarding the patient's current or future health, insurance coverage, career, marriage, or reproductive options. American College of Medical Genetics, Statement on Storage and Use of Genetic Materials (1995), http://www.acmg.net/ resources/policies/pol-028.asp. The ACMG Code also recommends that in the clinical testing context, if samples will be retained after initial use, patients should be informed about the scope of permission to use those samples in counseling relatives. Id. ACMG also recommends, when obtaining samples for research, that researchers obtain permission from patients to use their samples without identifiers for other types of research. Id. HUGO takes the position that where a patent application is filed for an invention based on biological material of human origin, it should be required to obtain the free and informed consent of the donor. Human Genome Organization, Statement on Patenting DNA Sequences

issue in the form of a single, general statement to the effect that research should not be conducted without obtaining informed consent from participants or subjects in advance.<sup>241</sup>

#### Confidentiality

Seventeen of the twenty-six codes address the issue of confidentiality. Most of the seventeen ethics codes require to some extent that members protect the confidentiality of information obtained in a study, particularly where there was a prior agreement or understanding.<sup>242</sup>

(2000), http://www.hugo-international.org/PDFs/Statement%20on%20Patenting%20of%20DNA%20 Sequences%202000.pdf. The AMA Code instructs that "[w]hen obtaining the informed consent of individuals to participate in genomic research ... [d]isclosure should include information about whether investigators or subjects stand to gain financially from research findings." AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-2.079(3), E-2.079(3d) (2002). The AMA also cautions that physicians' arrangement with data collection firms that sell data to marketing firms may violate principles of informed consent. *Id.* E-5.075.

One final specific informed consent provision, found in the American Institute for the Conservation of Historic and Artistic Works (AIC) Guidelines for Practice, is particularly relevant to biological testing: "Prior consent must be obtained from the owner, custodian, or agent before any material is removed from a cultural property. Only the minimum required should be removed, and a record of removal must be made. When appropriate, the material should be retained." American Institute for the Conservation of Historic and Artistic Works, *Code of Ethics and Guidelines for Practice* (1994), http://aic.stanford.edu/pubs/ethics.html.

<sup>241</sup> Biotechnology Industry Organization, *Statement of Principles*, http://www.bio.org/bioethics/background/principles.asp (last visited Oct. 1, 2007); International Society for Ethnobiology, *Code of Ethics* (2006), http://ise.arts.ubc.ca/documents/ISECodeofEthicsTEXT2006\_000.pdf.

Sociological Association, Codeofhttp://www.asanet.org/galleries/default-file/Code%20of%20Ethics.pdf; Council of American Survey Research Organizations, Code of Standards and Ethics for Survey Research (2004), http://www.casro.org/pdfs/CASRO% 20Code% 200f% 20Standards% 20and% 20Ethics% 202004.pdf; 20Code%20of%20Standards%20and%20Ethics%202004.pdf; American Anthropological Association, Code of Ethics of the American Anthropological Association at 2-3 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf; International Council of Museums, Code of Ethics for Museums § 7.3 (2006), http://icom.museum/ethics.html; American Institute for the Conservation of Historic and Artistic Works, Code of Ethics and Guidelines for Practice § 7 (1994), http://aic.stanford.edu/pubs/ethics.html; National Council on Public History, Code of Ethics and Professional Conduct (2007), http://www.ncph.org/AbouttheCouncil/BylawsandEthics/tabid/291/ Default.aspx#Ethics; American Board of Forensic Document Examiners, Code of Ethics and Competency (2006), http://www.abfde.org/Downloads/Tab3-CodeofEthics(8-8-06).pdf; Society of American Archivists, Code of Ethics for Archivists (2005), http://www.archivists.org/governance/ handbook/app\_ethics.asp; International Society for Ethnobiology, Code of Ethics (2006), http://ise.arts.ubc.ca/documents/ISECodeofEthicsTEXT2006\_000.pdf; Human Genome Organization, Ethics Committee Statement on Human Genomic Databases (2002), http://www.hugo-international.org/ PDFs/Statement%20on%20Human%20Genomic%20Databases%202002.pdf and Human Genome Organization, Statement on the Principled Conduct of Genetic Research (1996) at Recommendations, http://www.eubios.info/HUGO.htm; American Historical Association, Statement on Standards of Professional Conduct (2005), http://www.historians.org/pubs/free/professionalstandards.cfm; Oral History Association, Oral History Evaluation Guidelines (2000), http://omega.dickinson.edu/ organizations/oha/pub\_eg.html; American Society for Clinical Laboratory Scientists, Code of Ethics § I, http://ethics.iit.edu/codes/coe/amer.soc.clinical.lab.science.coe.html (last visited Nov. 12, 2007); (BIO) Biotechnology Industry Statement Principles, Organization of http://www.bio.org/bioethics/background/principles.asp (last visited Nov. 12, 2007); American Society of Human Genetics, *Professional Disclosure of Familial Genetic Information* (1998), http://genetics.faseb.org/genetics/ashg/policy/pol-29.htm; AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-5.05 and E-5.075 (AMA Press 2002); American College of Medical Genetics Use and Statement on Storage of Genetic Materials http://www.acmg.net/resources/policies/pol-028.asp.

The ASA Code provides methods to identify confidential information and outlines requirements for informed consent, including discussion with information sources. American Sociological Association,

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Several codes defer to the research subjects on whether to treat information confidentially rather than requiring that researchers take active measures to ensure confidentiality. Two codes deem confidentiality necessary only in limited circumstances. In contrast, six codes require confidentiality as an overriding value, not dependent on the research subjects' preference, the researchers' preference, or the circumstances of the research.

Code of Ethics at 12-14 (1997), http://www.asanet.org/galleries/default-file/Code%20of%20Ethics.pdf. The ASA Code provides an objective test that focuses on the research subject: "[i]nformation is private when an individual can reasonably expect that the information will not be made public with personal identifiers (e.g. medical or employment records)." Id. at 10. In contrast, the CASRO Code contains an objective test focused on the researcher to identify information that falls under the Code's rules: "information that [the survey researcher] knows or reasonably believes to be confidential[.]" Council of American Survey Research Organizations, Code of Standards and Ethics for Survey Research at 3 (2004), http://www.casro.org/pdfs/CASRO%20Code%20of%20Standards%20and%20Ethics%202004. pdf. While the AAA Code vaguely requires, "[a]nthropological researchers must do everything in their power to ensure that their research does not harm the safety, dignity, or privacy of [those studied]," it further states "[a]nthropological researchers must determine in advance whether their hosts/providers of information wish to remain anonymous or receive recognition and make every effort to comply with those wishes." American Anthropological Association, Code of Ethics of the American Anthropological Association at 6 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf. The ICOM, AIC, NCPH, American Board of Forensic Document Examiners (ABFDE), and SAA codes contain only general statements supporting a goal of confidentiality, anonymity, or privacy. International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.html; American Institute for the Conservation of Historic and Artistic Works, Code of Ethics and Guidelines for Practice (1994), http://aic.stanford.edu/pubs/ethics.html (last visited Nov. 30, 2007); National Council on Public History, Code of Ethics and Professional Conduct (2007), http://www.ncph.org/AbouttheCouncil/ BylawsandEthics/tabid/291/Default.aspx#Ethics; American Board of Forensic Document Examiners, Code of Ethics and Competency (2006), http://www.abfde.org/Downloads/Tab3-CodeofEthics(8-8-06).pdf (last visited Nov. 30, 2007); Society of American Archivists, Code of Ethics for Archivists (2005), http://www.archivists.org/governance/handbook/app\_ethics.asp.

<sup>243</sup> The ISE code requires that ethnobiologists recognize "indigenous peoples, traditional societies and local communities, at their sole discretion, have the right . . . to have kept confidential any information concerning their culture[.]" International Society for Ethnobiology, *Code of Ethics* at 4-5 (2006), http://ise.arts.ubc.ca/documents/ISECodeofEthicsTEXT2006\_000.pdf. Similarly, HUGO adopted the following principle: "The choices and privacy of individuals, families and communities with respect to the use of their data should be respected." Human Genome Organization, *Ethics Committee Statement on Human Genomic Databases* (2002), http://www.hugo-international.org/PDFs/Statement%20on%20 Human%20Genomic%20Databases%202002.pdf. Thus, the ISE and HUGO codes defer to the source of information and leave it unclear regarding what should be done when a source's privacy preference is not ascertained.

American Historical Association, *Statement on Standards of Professional Conduct* (2005), http://www.historians.org/pubs/free/professionalstandards.cfm; Oral History Association (OHA) Oral History Evaluation Guidelines (2000), http://omega.dickinson.edu/organizations/oha/pub\_eg.html. The AHA does not set confidentiality as the default but rather establishes that "[c]ertain kinds of research and conditions attached to ... use of records impose obligations to maintain confidentiality[.] Scholars should honor any pledges made." American Historical Association, Statement on Standards of Professional Conduct § 1 (2005), http://www.historians.org/pubs/free/professionalstandards.cfm. The AHA recognizes "the appropriateness of some national security and corporate and personal privacy claims, but [historians] must challenge unnecessary restrictions." *Id.* Thus, the AHA does not see confidentiality as a superseding ethical priority but rather as something to be weighed against "making [historical resources] under [a historian's] control available to other scholars as soon as possible." *Id.* The OHA code guides oral historians to give interviewees the option "even to choose anonymity . . . in extremely sensitive circumstances," (emphasis added) though it is apparent why anonymity may be viewed as a rare circumstance in the context of the field of oral history. Oral History Association, *Oral History Evaluation Guidelines* (2000), http://omega.dickinson.edu/organizations/oha/pub\_eg.html.

<sup>245</sup> Council of American Survey Research Organizations, *Code of Standards and Ethics for Survey Research* (2004), http://www.casro.org/pdfs/CASRO%20Code%20of%20Standards%20and%20Ethics% 202004.pdf; American Society for Clinical Laboratory Scientists, *Code of Ethics* § I (2004), http://ethics.iit.edu/codes/coe/amer.soc.clinical.lab.science.coe.html; Biotechnology Industry Organization, *Statement of Principles*, http://www.bio.org/bioethics/background/principles.asp (last

Of the medical and genetics codes, a few provisions relate both to informed consent and to confidentiality concepts. One code requires informing patients of whether sample identifiers will be removed. Another provides: "Patients divulge information to their physicians only for purposes of diagnosis and treatment." If information is sold to a data collection agency for marketing purposes, "patients must give their permission after being fully informed about the purpose of such disclosures." <sup>247</sup>

## Groups

Similar to informed consent for individuals, ethical issues arise when ownership of historical objects is linked to a group such as a religious affiliation, tribe, or family line. Group consent can be extremely complicated due to the elusive nature of cultural property and its ownership. Where a biohistorical project is undertaken, how can scientists, museums, researchers, historians, etc. identify groups who may be affected by such research? Where a group makes its presence and interests known on an issue, how should researchers assess the validity and scope of the group's claim? Do organizations hoping to benefit from the testing have an appropriate claim to the materials or results? How much influence should they be able to exert over a researcher's decisions and methods?

When identifying responsibilities to groups or subpopulations, it is hard to draw definitive lines as to who is affected by the proposed analysis and what the level of responsibility is to each person or group of people. Groups or subpopulations

visited Nov. 28, 2007); American Society of Human Genetics, *Professional Disclosure of Familial Genetic Information* § I.A.1 (1998), http://genetics.faseb.org/genetics/ashg/policy/pol-29.htm; Human Genome Organization, *Statement on the Principled Conduct of Genetic Research* (1996), http://www.eubios.info/HUGO.htm; AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-5.05 (2002).

The CASRO code, which contains an extensive section on confidentiality, requires as the default that survey researchers protect individuals' identities unless express permission is obtained. Council of American Survey Research Organizations, Code of Standards and Ethics for Survey Research at 5 (2004), http://www.casro.org/pdfs/CASRO%20Code%20of%20Standards%20and%20Ethics%202004. pdf. ASCLS and BIO, whose members' relationships with those they study probably are somewhat analogous to doctor-patient relationships, at least insofar as a physician would likely either have ordered the tests or provided some interface, treat client (patient) data confidentially. The ASCLS code provides, "[c]linical laboratory professionals maintain strict confidentiality of patient information and test results. They safeguard the dignity and privacy of patients[.]" American Society for Clinical Laboratory Scientists, Code of Ethics, http://ethics.iit.edu/codes/coe/amer.soc.clinical.lab.science.coe.html (last visited Nov. 28, 2007). The BIO Statement of Principles similarly provides, "[w]e support strong protection of the confidentiality of medical information, including genetic information." Biotechnology Industry Organization, Statement of Principles, http://www.bio.org/bioethics/background/principles.asp (last visited Nov. 28, 2007). The ASHG, HUGO, and AMA contain similar provisions setting confidentiality as the presumption. American Society of Human Genetics, Professional Disclosure of Familial Genetic Information (1998), http://genetics.faseb.org/genetics/ashg/policy/pol-29.htm; Human Genome Organization, Statement on the Principled Conduct of Genetic Research (1996), http://www.eubios.info/HUGO.htm; AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-

<sup>&</sup>lt;sup>246</sup> American College of Medical Genetics, *Statement on Storage and Use of Genetic Materials* (1995), http://www.acmg.net/resources/policies/pol-028.asp. ACMG seems to require the same for medical photographs only if the patient could be identified: "It is universally accepted that patients must give consent to publication whenever there is a possibility that the patient will be identified." American College of Medical Genetics (ACMG) Statement, *Informed Consent for Medical Photographs*, 2 GENOMICS IN MEDICINE 353-55, 353 (2000), *available at* http://www.acmg.net/resources/policies/pol-020.pdf.

<sup>&</sup>lt;sup>247</sup> AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-5.075 (2002).

affected by biohistorical research are those that belong to a subset of the overall population and are tied to the artifact, specimen or historical figure in such a way that the proposed analysis has some type of distinct effect on them not felt by the rest of society. Biohistorical analysis should be designed with the consultation of these groups or subpopulations, such as a social or cultural group, whose customs, traditions, genetic background, or other characteristics may be an indirect subject of the research. Investigators should respect the traditions, customs, and beliefs of that community and incorporate those aspects into the proposed research.

A few federal statutes recognize the importance of group interests with regard to archeological findings. The federal government passed the National Museum of the American Indian Act in 1989<sup>248</sup> and NAGPRA in 1990.<sup>249</sup> These acts enable requesting Native Americans to reclaim cultural items and familially related skeletal remains discovered on federal or tribal land from all federally-funded institutions and museums.<sup>250</sup>

Under NAGPRA, there are a number of requirements that must be met in order to satisfy cultural affiliation, which are:

(1) Existence of an identifiable present-day Indian tribe or Native Hawaiian organization with standing under these regulations of the act; and (2) Evidence of the existence of an identifiable earlier group. Support for this requirement may include, but is not necessarily limited to evidence sufficient to: (i) Establish the identity and cultural characteristics of the earlier group, (ii) Document distinct patterns of material culture manufacture and distribution methods for the earlier group, or (iii) Establish the existence of the earlier group as a biologically distinct population; and (3) Evidence of the existence of a shared group identity that can be reasonably traced between the present-day Indian tribe or Native Hawaiian organization and the earlier group. Evidence to support this requirement must establish that a present-day Indian tribe or Native Hawaiian organization has been identified from prehistoric or historic times to the present as descending from the earlier group.<sup>251</sup>

As a result of this federal legislation, whenever Native American remains are discovered on federal or tribal land or are found or stored by federally-funded museums or institutions, they must be handed over to the affiliated tribe.<sup>252</sup>

Research on artifacts and remains of unidentified individuals, such as the

<sup>&</sup>lt;sup>248</sup> See National Museum of the American Indian Act, Pub. L. No. 101-185, 103 Stat. 1226 (1989), amended by Pub. L. No. 104-278, 110 Stat 2255 (1996) (requiring the Smithsonian Institute, which has the largest collection of Native American remains, to repatriate their Native American remains and grave goods to requesting tribes who could present a preponderance of evidence showing they were familialy related to the remains).

<sup>&</sup>lt;sup>249</sup> 25 U.S.C. §§ 3001-3013 (1996).

<sup>&</sup>lt;sup>250</sup> See Sarah Harding, Justifying Repatriation of Native American Cultural Property, 72 INDIANA L.J. 723, 723 (1997) (describing the Native American Graves Protection and Repatriation Act).

<sup>&</sup>lt;sup>251</sup> 43 C.F.R. §10.14 (c) (2006). The statute defines cultural affiliation as "a relationship of shared group identity that may be reasonably traced historically or prehistorically between a present-day Indian tribe or Native Hawaiian organization and an identifiable earlier group." Harding, *supra* note 250, at 728-29 (quotations omitted).

<sup>&</sup>lt;sup>252</sup> Harding, *supra* note 250, at 725.

"Kennewick Man," is generally informative as to how these federal laws apply to the disturbance of artifacts. NAGPRA has recently been triggered regarding unidentified human skeletal remains discovered in Washington State on the banks of the Columbia River in 1996.<sup>253</sup> The remains were found near Kennewick, Washington on federal land controlled by the United States Army Corps of Engineers (COE).<sup>254</sup> In accordance with federal provisions, <sup>255</sup> the COE immediately seized the skeletal remains and refused access to scientists wishing to study them. Radio-carbon dating preformed by the Department of the Interior placed these remains at approximately 8,500 to 9,500 years old.<sup>256</sup> The COE subsequently concluded that the remains were to be considered Native American under regulations set forth in the NAGPRA<sup>257</sup> and the remains were to be returned to the Umatilla tribe, a culturally affiliated tribe, for repatriation without further scientific study.<sup>258</sup>

In response to the COE decision, a group of eight scientists seeking access to the remains then challenged the constitutionality of NAGPRA.<sup>259</sup> The scientists asserted that the initial radiocarbon dating indicated that the approximately 9,000 year-old skeleton<sup>260</sup> was in fact Caucasoid, not Native American.<sup>261</sup> If true, they argued, this would validate the belief held by many archaeologists that "some early Native American inhabitants came from European stock, migrating over a land bridge across the Bering Sea."<sup>262</sup> The scientists filed suit to halt the repatriation and "demanded a detailed scientific study to determine the origins of the man,"<sup>263</sup> which they viewed as "a rare discovery of national and international significance."<sup>264</sup> They

that represents Asatru, one of the major indigenous, pre-Christian, European religions," also filed suit asking the court to compel the Corps of Engineers to allow further scientific testing of the remains in order to determine whether the remains are Native or non-Native. The Asatru contend that if in fact Kennewick Man is non-Native, they request custody of the remains 'for study and for eventual reburial in accordance with native European belief.'

*Id.* at 618.

<sup>264</sup> *Id.* (quotations omitted). These scientists include Robson Bonnischen, an archaeologist at Oregon State University, who in 1994 discovered through DNA analysis that hairs found at burial sites in Oregon, Montana, Nebraska and Nevada were at least 10,000 years-old. Afrasiabi, *supra* note 258, at 818-19. A tribe has since claimed these hairs pursuant to NAGPRA and a review panel initially decided to repatriate these hairs. *Id.* Two other scientist plaintiffs, Douglas Owsley, a forensic anthropologist at the Smithsonian, and Richard Jantz, a professor of anthropology at the University of Tennessee in

<sup>&</sup>lt;sup>253</sup> CNN, *Court: Scientists Can Study Kennewick Man*, Feb. 5, 2004, http://www.cnn.com/2004/TECH/science/02/05/kennewick.man.ap/index.html.

<sup>&</sup>lt;sup>254</sup> *Id*.

<sup>&</sup>lt;sup>255</sup> 16 U.S.C. §§ 470aa-470mm (2006).

<sup>&</sup>lt;sup>256</sup> BRUCE BABBITT, UNITED STATES DEPARTMENT OF THE INTERIOR, SECRETARY OF THE INTERIOR REPORT (2000), http://www.cr.nps.gov/aad/Kennewick/babb\_letter.htm.

<sup>&</sup>lt;sup>258</sup> See Bonnichsen v. U.S. Dep't of the Army, 969 F. Supp. 614, 618 (D. Or. 1997) (noting Umatilla Indian tribe's claim to the remains based on ancestry and the intent of the Army Corps to repatriate the remains); Peter R. Afrasiabi, Note, *Property Rights in Ancient Human Skeletal Remains*, 70 S. CAL. L. REV. 805, 805 (1997) (commenting on Umatilla Indian tribe remains claim) [hereinafter Afrasiabi].

<sup>&</sup>lt;sup>259</sup> Constance Holden, Scientists Hope Ruling Will Lead Them to Bones, 303 Sci. 943, 943 (2004).

<sup>&</sup>lt;sup>260</sup> See Bonnichsen, 969 F. Supp. at 617 (referring to these remains as the "Richland Man").

Bill Dietrich, Skeleton Leads to Bones of Contention: Science Collides with Tribal Beliefs, THE ARIZONA REPUBLIC, Sept. 1, 1996, at A28.

<sup>&</sup>lt;sup>262</sup> Afrasiabi, *supra* note 258, at 805.

<sup>&</sup>lt;sup>263</sup> See Bonnichsen, 969 F. Supp. at 618 (describing potential study). The Asatru Folk Assembly, described by their Complaint as a church:

claimed that NAGPRA violated their right to scientific inquiry.

In February 2004, after the initial radiocarbon dating found that the remains dated farther back than NAGPRA's scope, the Ninth Circuit ruled that the remains were not Native American human remains within the meaning of NAGPRA.<sup>265</sup> The court's decision effectively rules that studies of the remains may proceed pursuant to the Archeological Resources Protection Act of 1979. Subsequently, in September 2004, the United States Court of Appeals for the Ninth Circuit denied the petition for rehearing with an eleven judge en banc panel to reconsider the February decision.<sup>267</sup> Each of the 380 individual Kennewick bones resided in custom-designed, temperature and humidity-controlled containers at the Burke Museum of Natural History and Culture in Seattle, Washington and studies have begun.

At least five codes require consultation with affected populations before research is undertaken. 268 While not explicitly requiring consent, these codes highlight commitments to outside interests and obligations to cultural property, owners and custodians, the conservation profession and to overall society<sup>269</sup> and particularly indigenous peoples, traditional societies and local communities.<sup>270</sup>

Knoxville, have developed a computerized, "specialized protocol for measuring and documenting human skeletal remains" which "permits various comparisons to be made between modern and ancient populations which would not otherwise be possible." Complaint at 2, Bonnichsen, 969 F. Supp. 614 (D. Or. 1997) (No. 96-1481-JE).

<sup>&</sup>lt;sup>265</sup> Bonnichsen v. United States, 357 F.3d 962, 979 (9th Cir. 2004).

<sup>&</sup>lt;sup>266</sup> *Id*.

Bonnichsen v. United States, 367 F.3d 864, 868 (9th Cir. 2004) (denying Petition for Rehearing En Banc).

<sup>&</sup>lt;sup>268</sup> The ICOM Code acknowledges that cultural concerns should be considered in the planning process of a research venture or exhibit creation "[t]he governing body should have regard to the professional opinion available to them, the interests of the object or specimen under consideration, the national or other cultural or natural heritage and the special interests of other museums." International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.html. The AHA Code provides, "(a)t the outset of the exhibit process, museums should identify stakeholders in any exhibit and may wish to involve their representatives in the planning process." American Historical Association, Standards for Museum Exhibits Dealing with Historical Subjects (2001), http://www.historians.org/ info/museumstandards.htm. Concerning field study ICOM notes, "where fieldwork involves a living community or its heritage, acquisitions should only be made on the basis of informed and mutual consent without exploitation of the owner or informants. Great care is necessary to respect the wishes of the community involved, which should be paramount." International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.html. The AIA similarly notes that in conducting field study "archaeologists should consult with appropriate representatives of the local community during the planning stage, invite local participation in the project, and regularly inform the local community about the results of the research." Archeological Institute of America, Code of Professional Standards at 2 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_StandardsA5S.pdf. In an effort to balance interests that are particularly relevant to the current problem, the AIA Code provides, "[t]he legitimate concerns of people who claim descent from, or some other connection with, cultures of the past must be balanced against the scholarly integrity of the discipline. A mutually acceptable accommodation should be sought." *Id.* The AAA Code recommends that anthropologists balance mutual interests by "consult[ing] actively with the affected individuals or group(s), with the goal of establishing a working relationship that can be beneficial to all parties involved." American Anthropological Association, Code of Ethics of the American Anthropological Association at 2 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf. HUGO provides that "consultation should precede recruitment of possible participants and should continue throughout the research." Human Genome Organization, Statement On The Principled Conduct of Research (1996), http://www.eubios.info/HUGO.htm.

See, e.g., American Institute for the Conservation of Historic and Artistic Works, Code of Ethics and Guidelines for Practice (1994), http://aic.stanford.edu/pubs/ethics (establishing ethical guidelines for Conservation of historical objects).

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See, e.g., International Society for Ethnobiology, Code of Ethics (2006), http://ise.arts.ubc.ca/

Five of the twenty-six codes guide members on acquiring group consent.<sup>271</sup> One contains the most unequivocal adoption of group consent as a prerequisite to research:

Educated prior informed consent must be established before any research is undertaken, at individual and collective levels, as determined by community governance structures. Prior informed consent is recognised as an ongoing process that is based on relationship and maintained throughout all phases of research. This principle recognises that prior informed consent requires an educative process that employs bilingual and intercultural education methods and tools, as appropriate, to ensure understanding by all parties involved. Establishing prior informed consent also presumes that all directly affected communities will be provided complete information in an understandable form regarding the purpose and nature of the proposed programme, project, study or activities, the probable results and implications, including all reasonably foreseeable benefits and risks of harm (be they tangible or intangible) to the affected communities. Indigenous peoples, traditional societies and local communities have the right to make decisions on any programme, project, study or activities that directly affect them. In cases where the intentions of proposed research or related activities are not consistent with the interests of these peoples, societies or communities, they have a right to say no.<sup>272</sup>

 $documents/ISECode of Ethics TEXT 2006\_000.pdf \quad (encouraging \quad ethnobiologists \quad to \quad respect \quad local \\ indigenous populations).$ 

The ISE Code contains the most unequivocal adoption of group consent as a prerequisite to research: "Educated prior informed consent must be established before any research is undertaken, at individual and collective levels, . . . In cases where the intentions of proposed research or related activities are not consistent with the interests of these peoples, societies or communities, they have a right to say no. International Society for Ethnobiology, Code of Ethics at 4 (2006), http://ise.arts.ubc.ca/documents/ ISECodeofEthicsTEXT2006\_000.pdf. The ICOM Code acknowledges that cultural concerns should be considered in the planning process of a research venture or exhibit creation stating "[t]he governing body should consider the professional opinions available to them, and the views of all interested parties. Consideration will include the significance of the object or specimen including its context in the cultural or natural heritage, and the special interests of other museums collecting such material." International Council of Museums, *Code of Ethics for Museums* (2006), http://icom.museum/ethics.html. ICOM notes "where fieldwork involves a living community or its heritage, acquisitions should only be made on the basis of informed and mutual consent without exploitation of the owner or informants. Great care is necessary to respect the wishes of the community involved, which should be paramount." *Id.* The AHA Code provides, "[a]t the outset of the exhibit process, museums should identify stakeholders in any exhibit and may wish to involve their representatives in the planning process." American Historical Association, Standards for Museum Exhibits Dealing with Historical Subjects (2001), http://www.historians.org/info/museumstandards.htm. The AIA provides "archaeologists should consult with appropriate representatives of the local community during the planning stage, invite local participation in the project, and regularly inform the local community about the results of the research.' Archeological Institute of America, Code of Professional Standards at 2 (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_StandardsA5S.pdf. The AAA Code also recommends anthropologists balance mutual interests by "consult[ing] actively with the affected individuals or group(s), with the goal of establishing a working relationship that can be beneficial to all parties involved." American Anthropological Association, *Code of Ethics of the American Anthropological Association* at 3-5 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf.

<sup>&</sup>lt;sup>272</sup> International Society for Ethnobiology, *Code of Ethics* at 5 (2006), http://ise.arts.ubc.ca/documents/

Where there is such an affected group, there should be special responsibilities owed to this group and sufficient mechanisms created to include the group in the proposed research. These responsibilities should (1) foster a partnership between the investigating body and the affected group and (2) prevent exploitation of the group. Mechanisms should also be established to deal with the potential impact of the research on the group when appropriate, including counseling, follow-up, and group discussions. Ideally, the investigator should meet with the group face-to-face and thoroughly describe the proposed analysis in detail, providing key details including the investigative question posed, types of analysis, level of destructiveness to the artifact or specimen, and funding sources.

At least fourteen of the twenty-six ethics codes address protecting the interests of the culture from which a studied object derives. The codes attempt to balance the quest for scientific knowledge against a respect for privacy, preservation, and cultural beliefs. The codes vary significantly, but do share six principles. The first such principle, found in eight codes, requires researchers to discover and consider the interests of another culture and then use their own best judgment in making decisions.<sup>273</sup>

A second principle, found in three codes, is that there should be a dialogue between the researcher and the group studied.<sup>274</sup> A step beyond merely objectively determining, as the researcher sees it, the interests of the culture studied, these codes guide the researcher to engage those subjects who may be impacted by a study and learn of their concerns firsthand.

A third principle, found in three codes, is for researchers, beyond merely

International Council of Museums, Code of Ethics for Museums §§ 6.5-6.8 (2006), http://icom.museum/ethics.html; American Anthropological Association, Code of Ethics of the American Anthropological at 2 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf; Archeological Institute of America, Code of Professional Standards (1997), http://www.archaeological.org/ pdfs/AIA\_Code\_of\_Professional\_StandardsA5S.pdf. The ICOM Code calls for research to be "accomplished in a manner consistent with . . . professional standards and the interests and beliefs of members of the community, ethnic or religious groups from which the objects originated, where these are known." International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.html. It is important to note that the ICOM code accepts that in some cases the value of an object may be of such international significance that its contribution to the public knowledge overrides factors that would prohibit its acquisition. Id. The AAA Code instructs researchers to ensure their research does not harm the safety, dignity, or privacy of those studied. American Anthropological Association, Code of Ethics of the American Anthropological Association at 2 (1998), http://www.aaanet.org/committees/ethics/ ethicscode.pdf. The AAA Code also offers, "the development of knowledge can lead to change which may be positive or negative for people . . . studied," which cautions that not only the impact of the manner of research but also the impact of the result of research should be considered. Id. The CAA, OHA, AIA, ACRA, BIO, and ISE codes all contain statements comparable to ICOM's, with the AIA adding a concern for the ecological impact that research has on a studied culture. Archeological Institute of America, Code of Professional Standards (1997), http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_StandardsA5S.pdf.

E.g., American Anthropological Association, Code of Ethics of the American Anthropological Association at 2 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf (instructing researchers to "consult actively with the affected groups" and establish a working relationship). The AHA Code guides researchers, at the outset, to identify stakeholders and involve them in the planning process. American Historical Association, Standards for Museum Exhibits Dealing with Historical Subjects (2001), http://www.historians.org/info/museumstandards.htm. HUGO also provides, "consultation should precede recruitment of possible participants and should continue throughout the research. Cultural norms vary, as do perceptions of health, disease, and disability; of family; and of the place and importance of the individual." Human Genome Organization, Statement on the Principled Conduct of Genetic Research (1996), http://www.eubios.info/HUGO.htm.

ISECodeofEthicsTEXT2006 000.pdf.

objectively safeguarding the interests of a studied culture or engaging in dialogue with them, to actually give the studied culture the final say in whether or how the research is carried out. <sup>275</sup>

Once researchers decide to proceed with research, a fourth principle, found in three codes, is to keep the host community in the loop by sharing research results with them and, in some cases, leaving the research data exclusively in the host community's control.<sup>276</sup>

Five codes advocate a fifth principle—benefiting the host (studied) community in some way.<sup>277</sup> Furthermore, a sixth principle, found in seven codes, is to avoid actively harming individuals or groups via research methods. 278

<sup>&</sup>lt;sup>275</sup> E.g., International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ ethics.html (advising researchers that "respect for the wishes of the community involved should be paramount"). The CASRO Code directs survey researchers to "respect the right of individuals to refuse to be interviewed" albeit with some qualifications. Council of American Survey Research Organizations, Code of Standards and Ethics for Survey Research (2004), http://www.casro.org/pdfs /CASRO%20Code%20of%20Standards%20and%20Ethics%202004.pdf. The AMA Code provides: "When substantial opposition to the research is expressed within the community, investigators should not conduct the study." AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-2.079(2) (2002). <sup>276</sup> E.g., College Art Association, Code of Ethics for Art Historians and Guidelines for the Practice of Art History (1995), http://www.collegeart.org/guidelines/histethics.html (providing that field data ultimately should remain under the host community's control and the results of research should be filed with the host community). The OHA Code instructs interviewers to make interviews accessible to the community from which they are derived. Oral History Association, Oral History Evaluation Guidelines (2000), http://omega.dickinson.edu/organizations/oha/pub\_eg.html. The AIA code guides archaeologists to inform the local community about research results. Archeological Institute of America, Code of Professional Standards at 2 (1997), http://www.archaeological.org/pdfs/AIA Code of Professional StandardsA5S.pdf.

<sup>277</sup> E.g., American Anthropological Association, Code of Ethics of the American Anthropological Association at 3 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf (guiding researchers to recognize a debt to those studied and reciprocate). The OHA code guides oral historians to consider how to share rewards and recognition with the communities from which they have collected oral histories. Oral History Association, Oral History Evaluation Guidelines (2000), ttp://omega.dickinson.edu/ organizations/oha/pub\_eg.html. ACMG, recognizing the sharing of benefits as a possibility, provides that subjects should be informed of "the extent to which they can expect to receive any profits." American College of Medical Genetics, Statement on Storage and Use of Genetic Materials (1995) § I.B.2, http://www.acmg.net/resources/policies/pol-028. The AMA Code allows that "profits from the commercial use of human tissue and its products may be shared with patients, in accordance with lawful contractual agreements." AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-2.08 (2002). Absent undue inducement through compensation, HUGO similarly approves of agreements with research participants that foresee, inter alia, technology transfer, joint ventures, or reimbursement. Human Genome Organization, Statement on the Principled Conduct of Genetic Research (1996), http://www.eubios.info/HUGO.htm.

The ICOM, AAA and OHA codes each contain a general statement prohibiting exploitation of studied communities; individuals or groups; or interviewees, respectively. International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.html; American Anthropological Association, Code of Ethics of the American Anthropological Association at 3 (1998), http://www.aaanet.org/committees/ethics/cethicscode.pdf; Oral History Association, Oral History Evaluation Guidelines (2000), http://omega.dickinson.edu/organizations/oha/pub\_eg.html. In addition to the general statement, the AAA Code, however, goes a small step further and provides that anthropologists should ensure that information they release is well understood, properly contextualized, and responsibly utilized, recognizing possible harm their information may cause to the subjects of their work. American Anthropological Association, Code of Ethics of the American Anthropological Association at 4 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf. Beyond merely requiring its members to meet publication standards that should prevent research findings from being misapplied, the above requirement of the AAA Code may be viewed as extending researchers responsibilities to participating, if possible, in any subsequent discourse that could prove detrimental to the studied community. The CASRO code instructs survey researchers to avoid deceptive practices and misrepresentations and to protect respondents from intrusions and harassment. Council of American

These principles could have helped guide numerous actual biohistorical investigations by encouraging researchers to give thought to the range of people and communities affected by biohistorical research. With respect to Billy the Kid, the goal was to exhume three bodies – that of his mother and that of a corpse buried in Fort Sumner, New Mexico and another corpse buried in Texas. Obviously, the relatives of the three deceased individuals were affected. But since bodies had been moved and there was uncertainty about who was buried where, strangers to the controversy might be exhumed in the process, which would affect their descendants. In addition, the local communities (and the states) where the graves were situated would be affected.

Originally, New Mexico governor Bill Richardson supported the exhumation of the purported remains of Billy the Kid in Fort Sumner, New Mexico. He believed that solidifying the Billy the Kid story would boost New Mexico tourism. He asked scientists at Los Alamos and Sandia National Labs and an historian at the University of New Mexico to aid in the biohistorical investigation. The only reputed heir of Billy the Kid, self-proclaimed great-grandson Elbert Garcia, also supported the request to exhume Antrim's and Kid's remains.

But the project met with significant controversy in the communities. The mayor of Silver City, the city housing Catherine Antrim's remains (the mother of Billy the Kid), filed a motion to stop the exhumation of Antrim.<sup>281</sup> The mayor argued that the city had a right to intervene because the cemetery is public property and Antrim's gravesite is a publicly protected historical landmark.<sup>282</sup> The Mayor of Fort Sumner, Raymond Lopez, and many citizens of that community opposed the exhumation as well.<sup>283</sup> Lopez argued that Billy the Kid's grave and his museum are popular tourist destinations in Fort Sumner and key revenue would be lost if an exhumation proved that the Kid's remains did not reside in the grave.<sup>284</sup> Due to those pressures of the community, the legal action to exhume Billy the Kid was dropped.<sup>285</sup>

Similarly, with the ongoing Medici exhumations, Italian authorities and numerous

Survey Research Organization, Code of Standards and Ethics for Survey Research at 6-7 (2004), http://www.casro.org/pdfs/CASRO%20Code%20of%20Standards%20and%20Ethics%202004.pdf. The ASA code contains wording similar to that in the CASRO code. American Sociological Association, Code of Ethics at 6, 14 (1997), http://www.asanet.org/galleries/default-file/Code%20of%20Ethics.pdf. ASHG requires its members to disclose "the possibility [that research subjects may experience effects] of adverse psychological sequelae, disruption of family dynamics, and social stigmatization and discrimination." American Society of Human Genetics, Report, Statement on Informed Consent for Genetics Research (1996), http://genetics.faseb.org/genetics/ashg/policy/pol-25.htm. ACMG specifically warns of how gene patents may harm patients: "They . . . limit the number of knowledgeable individuals who can assist physicians, geneticists and counselors in the diagnosis, management, and care of at-risk patients." American College of Medical Genetics, Position Statement on Gene Patents and Accessibility of Gene Testing (1999), http://www.acmg.net/resources/policies/pol-015.asp.

<sup>&</sup>lt;sup>279</sup> *Id. See also* State of New Mexico Office of the Governor, *Governor Richardson Announces State Support of Billy the Kid Investigation*, June 10, 2003, http://www.governor.state.nm.us/press/2003/june/061003\_1.pdf.

<sup>&</sup>lt;sup>280</sup> Billy the Kid Investigation Resurrected, supra note 44.

<sup>&</sup>lt;sup>281</sup> First Fight in Kid Showdown Set for Monday, supra note 187.

<sup>&</sup>lt;sup>282</sup> *Id*.

<sup>&</sup>lt;sup>283</sup> Id.

 $<sup>^{284}</sup>$  Jean Marbella, The Ultimate Cold-Case File, Baltimore Sun, Feb. 8, 2004, at 2A.

<sup>&</sup>lt;sup>285</sup> Thomas Korosec, *Trail of a Desperado. Is the Real Billy the Kid Buried in Cental Texas?*, HOUSTON CHRON., May 10, 2007 at A1; Alan Boyle, *Billy the Kid: Case Closed*, MSNBC, Sept. 27, 2004, http://www.msnbc.msn.com/id/6092904/ (last visited Nov. 26, 2007).

Medici descendants have approved the exhumations, <sup>286</sup> yet the research has met with some opposition from other descendants. <sup>287</sup>

A 1981 legal case involving both the widow and brother of Lee Harvey Oswald illustrates the recognition from state courts that the closest surviving family member has control over requests for exhumation. It also illustrates commercial motivations to conduct bioanalysis resulting from mere sensationalism and conspiracy theory. In Eddowes v. Oswald, Lee Harvey Oswald's surviving brother Robert sought to prevent a foreign author from exhuming the remains. 288 Michael Eddowes, British author of *The Oswald File*, was the leading proponent of a theory that the Oswald burial was a conspiracy and that the body in Oswald's coffin was that of a Soviet agent who had assumed Oswald's identity when Oswald had been in the U.S.S.R. in 1959.<sup>289</sup> After Robert Oswald filed suit against Eddowes in order to prevent him from removing the body from Rose Hill Cemetery in Fort Worth, Texas, the lower court awarded Oswald a temporary injunction. However, on appeal, the court found that the brother did not have the right to control the remains as long as there was a surviving spouse, children, or parents who ordered the exhumation.<sup>291</sup> Since both Maria Porter (formerly Maria Oswald) and her eighteen year-old daughter had agreed to the exhumation and reautopsy to be carried out at the expense of Eddowes, Robert had no control in the matter.<sup>29</sup>

Subsequently, the examining team concluded beyond any doubt that the remains removed from Oswald's grave were correctly attributed, mainly due to the match-up of dental records and a childhood scar mentioned in military records that was received during a childhood mastoid operation. The most interesting aspect of this litigation and ensuing exhumation was that during the litigation Maria Porter withdrew her permission for Eddowes to exhume the body and took over the plans for exhumation herself, citing the fact that Eddowes had reneged on an earlier agreement to pay for exhumation by withholding financial backing, likely because he knew his conspiracy theory was going to be dispelled.

## 5. Conflicts of Interest

Another ethical concern is the avoidance of a conflict of interest. A conflict of

<sup>293</sup> Oswald's Body Is Exhumed: An Autopsy Affirms Identity, N.Y. TIMES, Oct. 5, 1981, at A1.

<sup>&</sup>lt;sup>286</sup> Winfield, *supra* note 1.

<sup>&</sup>lt;sup>287</sup> Alan Feuer, Where the Bodies Are Buried, Modern-Day Medici Feud, N.Y. TIMES, May 4, 2004, at A4; Be Careful With My Family's Bones, Says Medici Descendant, ANSA ENGLISH MEDIC SERVICE, March 17, 2005.

<sup>&</sup>lt;sup>288</sup> Eddowes v. Oswald, 621 S.W.2d 843, 845 (Tex. App. 1981).

<sup>&</sup>lt;sup>289</sup> Alex Heard, *Exhumed Innocent*, NEW REPUBLIC, Aug. 5, 1991, 12, 13.

<sup>&</sup>lt;sup>290</sup> Eddowes v. Curry, 599 S.W.2d 367, 370 (Tex. Civ. App. 1980).

<sup>&</sup>lt;sup>291</sup> Oswald, 621 S.W.2d at 846.

<sup>&</sup>lt;sup>292</sup> Id.

<sup>&</sup>lt;sup>295</sup> Dan Carmichael, UNITED PRESS INTERNATIONAL, Aug. 25, 1981. Apparently, Mrs. Porter cut all ties with Eddowes because she felt that his motivations were more in promoting his books and in the end he was more interested in blocking the exhumation so as not to disprove his theory. *Id.* Five years later, as a means to thwart the attempts of Eddowes to gain access to products of the investigation, Porter reportedly entered into an out-of-court settlement with two men paid by Eddowes to record the autopsy, giving her exclusive possession of videotapes and photographs taken during the exhumation and autopsy in 1981. *Id.* 

interest exists when the initiator, investigator, or funding source of the proposed analysis has competing interests in conducting the proposed study, whether they be personal, professional, or financial in nature. Conflicts of interest are important to avoid not merely because such appearances may tarnish the reputation of, or public faith in, an organization (although that is a legitimate concern). The real goal should be to avoid biased, non-objective, or unnecessary research and to require the reporting of research. These conflicts, both actual and potential, should be identified and disclosed to all interested parties.

Bribes or extensive gift-giving on the part of the researchers in return for the participation of the research subjects are another concern. Efforts to induce individuals or groups into assisting or allowing research raise conflicts of interest, in that the individuals or groups are going along with the research project in return for financial or proprietary gain.

Fourteen of the twenty-six codes provide guidance to members on avoiding or handling potential personal, professional, or financial conflicts of interest. Six codes instruct members to avoid either actual conflicts of interest, apparent conflicts of interest, or both. Six codes explicitly instruct members to avoid bias. Five

<sup>&</sup>lt;sup>296</sup> See International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.html (defining a conflict of interest).

<sup>&</sup>lt;sup>298</sup> American Society for Information Science & Technology, Code of Professional Practice §§ 12, 15 and 17 (1961), http://ethics.iit.edu/codes/coe/amer.soc.info.sci.html; American Sociological Association, Code of Ethics (1997), http://www.asanet.org/galleries/default-file/Code%20of%20Ethics; American Society for Biochemistry and Molecular Biology, Code of Ethics (1998), http://www.asbmb.org/asbmb/ site.nsf/Sub/CodeofEthics?; American Institute for the Conservation of Historic and Artistic Works, Code of Ethics and Guidelines for Practice §§ 4c, 7, 14, and 15 (1994), http://aic.stanford.edu/ pubs/ethics.html; International Council of Museums, Code of Ethics for Museums §§ 8.12-.18 (2001), http://icom.museum/ethics.html; American Cultural Resources Association, Code of Ethics and Professional Conduct, http://www.acra-crm.org/Ethics.html (last visited Nov. 28, 2007); American College of Medical Genetics, Informed Consent for Medical Photographs, 2 GENETICS IN MED., 353-55, 355 (2000), http://www.acmg.net/resources/policies/pol-020.pdf; American Board of Forensic Document Examiners, Code of Ethics and Competency at 5 (2006), http://www.abfde.org/Downloads/Tab3-CodeofEthics(8-8-06).pdf; Society of American Archivists, Code of Ethics for Archivists (2005) § VII, http://www.archivists.org/governance/handbook/app\_ethics.asp; AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-2.079(3)(d) and E-8.031 (2002); College Art Association, Code of Ethics for Art Historians and Guidelines for the Practice of Art History §§ IV.A., V.B and V.C (1995), available at http://www.collegeart.org/guidelines/histethics.html; Council of American Survey Research Organizations, Code of Standards and Ethics for Survey Research at 10 (2004), http://www.casro.org/ pdfs/CASRO% 20Code% 20of% 20Standards% 20and% 20Ethics% 202004.pdf; American Anthropological Association, Code of Ethics of the American Anthropological Association (1998), http://www.aaanet.org/ committees/ethics/ethicscode.pdf; Human Genome Organization, Statement on the Principled Conduct of Genetic Research (1996), http://www.eubios.info/HUGO.htm.

<sup>&</sup>lt;sup>299</sup> The ASIS Code provides the broadest coverage of this issue directing documentalists to "never allow [a personal interest] to affect adversely the documentation work for which he is employed." American Society for Information Science & Technology, *Code of Professional Practice* (1961), http://ethics.iit.edu/codes/coe/amer.soc.info.sci.html. *See also* American Sociological Association, *Code of Ethics* at 9 (1999), http://www.asanet.org/galleries/default-file/Code%20of%20Ethics.pdf (containing a similar statement concerning personal, financial, or other conflicts of interest); American Society for Biochemistry and Molecular Biology, *Code of Ethics* (1998), http://www.asbmb.org/asbmb/site.nsf/Sub/CodeofEthics?Opendocument (prohibiting similar conflicts of interest). The AIC Code adds a concern for how members actions are perceived, providing, "[t]he conservation professional should avoid situations in which there is a potential conflict of interest that may affect the quality of work, lead to the dissemination of false information, or give the appearance of impropriety." American Institute for the Conservation of Historic and Artistic Works, *Code of Ethics and Guidelines for Practice* (1994) § 14, http://aic.stanford.edu/pubs/ethics.html. The ICOM and ACRA contain similar statements concerning both actual and apparent conflicts of interest. International Council of Museums, *Code of Ethics and Council of Museums*, *Code of Ethics and Council* 

codes address conflicts of interest arising from wearing two hats.<sup>301</sup> One of these codes specifically instructs members not to compete with their own institution, museum, or repository for acquisitions of objects for members' private collections.<sup>302</sup> Another advises that clinical investigators not buy or sell stock in a company with which they are involved in a research project, receive excessive compensation for their role in the research, and that investigators should disclose material ties to any companies whose products they are investigating.<sup>303</sup> Three codes address matters of compensation and accepting gifts.<sup>304</sup>

Ethics for Museums (2006), http://icom.museum/ethics.html; American Cultural Resources Association, Code of Ethics and Professional Conduct, http://www.acra-crm.org/Ethics.html (last visited Nov. 28, 2007). The ICOM Code, which has similar principles discouraging a conflict of interest, defines conflict of interest as "[t]he existence of a personal or private interest which gives rise to a clash of principle in a work situation, thus restricting, or having the appearance of restricting, the objectivity of decision-making." International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.html.

<sup>300</sup> The ASA Code, the only code to actually use the term "bias," provides, "[c]onflicts of interest arise when sociologists' personal or financial interests prevent them from performing their professional work in an unbiased manner." American Sociological Association, *Code of Ethics* (1997) at 9, http://www.asanet.org/galleries/default-file/Code%20of%20Ethics.pdf. The ICOM, AIC, ASBMB, and ASIS codes instruct members to recognize and either avoid or flag work that is non-objective, of compromised quality, influenced, or adversely affected by a conflict of interest. International Council of Museums, *Code of Ethics for Museums* (2006), http://icom.museum/ethics.html; American Institute for the Conservation of Historic and Artistic Works, *Code of Ethics and Guidelines for Practice* § 14 (1994), http://aic.stanford.edu/pubs/ethics.html; American Society for Biochemistry and Molecular Biology, *Code of Ethics* (1998), http://www.asbmb.org/asbmb/site.nsf/Sub/CodeofEthics?Opendocument; American Sociological Association, *Code of Ethics* at 9 (1997), http://www.asanet.org/galleries/default-file/Code%20of%20Ethics.pdf. In its statement on the use of medical photographs, ACMG stresses that consent forms must "explicitly state that the patient's medical care will not be affected in any way by their refusal to consent to photography nor by their request to remove an image from any of its uses." American College of Medical Genetics, *Informed Consent for Medical Photographs*, 2 GENETICS IN MED., 353, 355 (2000), http://www.acmg.net/resources/policies/pol-020.pdf.

American Board of Forensic Document Examiners, *Code of Ethics and Competency* (2006), http://www.abfde.org/Downloads/Tab3-CodeofEthics(8-8-06).pdf at 1; American Institute for the Conservation of Historic and Artistic Works, *Code of Ethics and Guidelines for Practice* (1994), http://aic.stanford.edu/pubs/ethics.html; International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.html; Society of American Archivists (SAA), Code of Ethics for Archivists (2005), http://www.archivists.org/governance/handbook/app\_ethics.asp; AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-8.031 (2002). The ABFDE Code provides, "[a] diplomat . . . shall not knowingly perform any service for a person whose interests are opposed to those of his/her client/agency unless directed to do so by the client/agency[.]" American Board of Forensic Document Examiners, *Code of Ethics and Competency* at 1 (2006), http://www.abfde.org/Downloads/Tab3-CodeofEthics(8-8-06).pdf. Addressing the same concern, the American Institute of Chemists instructs members not "[t]o accept commission or commission or compensation in any form from more than one interested party only with the full knowledge and consent of all parties concerned[.]" American Institute for the Conservation of Historic and Artistic Works, *Code of Ethics and Guidelines for Practice* (1994), http://aic.stanford.edu/pubs/ethics.html.

 $<sup>^{302}</sup>$  International Council of Museums, *Code of Ethics for Museums* (2006), http://icom.museum/ethics.html.

 $<sup>^{303}</sup>$  American Medical Association, Code of Medical Ethics E-8.031 (2002).

<sup>&</sup>lt;sup>304</sup>International Council of Museums, *Code of Ethics for Museums* (2006), http://icom.museum/ethics.html; College Art Association, *Code of Ethics for Art Historians and Guidelines for the Practice of Art History* (1995), http://www.collegeart.org/guidelines/histethics.html; Council of American Survey Research Organizations, *Code of Standards and Ethics for Survey Research* at 10 (2004), http://www.casro.org/pdfs/CASRO%20Code%20of%20Standards%20and%20Ethics%202004.pdf. The ICOM Code instructs museum professionals to use special care in considering gifts, and the CAA Code instructs art historians to refuse gifts altogether from donors or artists. International Council of Museums (ICOM) Code of Ethics for Museums (2001), http://icom.museum/ethics.html; College Art Association (CAA) Code of Ethics for Art Historians and Guidelines for the Practice of Art History

These fourteen codes offer various measures members can undertake to prevent conflicts of interest, appearances of impropriety, and biased research. One method of dealing with potential conflicts of interest, found in seven codes, is to simply disclose conflicts of interest, appearently leaving the task of assessing bias to others. Beyond disclosure, two of these codes also require that a researcher obtain the consent of interested or concerned parties. One code is unique in that it advises researchers that "actual or potential conflicts should . . . be reviewed by an ethical review committee before any research begins." Three codes caution members not to assume obligations incongruent with their professional responsibilities or ethics.

(1995), http://www.collegeart.org/guidelines/histethics.html. The CAA Code also recommends that art historians charge only fixed for attribution and connoisseurship, rather than a percentage of the sale price. College Art Association, *Code of Ethics for Art Historians and Guidelines for the Practice of Art History* (1995), http://www.collegeart.org/guidelines/histethics.html The CASRO Code explicitly deems accepting bribes a violation. Council of American Survey Research Organizations, *Code of Standards and Ethics for Survey Research* at 10 (2004), http://www.casro.org/pdfs/CASRO%20Code%20of%20Standards%20and%20Ethics%202004.pdf.

American Society for Biochemistry and Molecular Biology, Code of Ethics (1998), http://www.asbmb.org/asbmb/site.nsf/Sub/CodeofEthics?Opendocument; American Sociological Association, Code of Ethics (1997), http://www.asanet.org/galleries/default-file/Code%20of%20 Ethics.pdf; American Society for Information Science & Technology, Code of Professional Practice (1961), http://ethics.iit.edu/codes/coe/amer.soc.info.sci.html; AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-2.079(3)(d) (2002); American Anthropological Association, Code of Ethics of the American Anthropological Association at 3 (1998), http://www.aaanet.org/committees/ ethics/ethicscode.pdf; American Institute of Chemists, Code of Ethics (1983), http://www.theaic.org/ DesktopDefault.aspx?tabid=46; American Cultural Resources Association, Code of Ethics and Professional Conduct, http://www.acra-crm.org/Ethics.html. The ASBMB Code instructs, "investigators will disclose financial and other interests that might present a conflict-of-interest in their various activities such as reporting research results [or] serving as reviewers[.]" American Society for Biochemistry and Molecular Biology, *Code of Ethics* (1998), http://www.asbmb.org/asbmb/site.nsf/Sub/CodeofEthics?Opendocument. The ASA, ASIS, and AMA codes contain similar provisions requiring disclosure. American Sociological Association, Code of Ethics § 9.02 (1997), http://www.asanet.org/galleries/default-file/Code%20of%20Ethics.pdf; American Society Information Science & Technology, Code of Professional Practice (1961), http://ethics.iit.edu/codes/coe/ amer.soc.info.sci.html; AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-2.079(3)(d) (2002). The AAA Code is unique in requiring that a section responding to potential conflicts of interest and other ethical issues is part of every research proposal. American Anthropological Association, Code of Ethics of the American Anthropological Association at 3 (1998), http://www.aaanet.org/committees/ ethics/ethicscode.pdf.

American Institute of Chemists, *Code of Ethics* (1983), http://www.theaic.org/Desktop Default.aspx?tabid=46; American Cultural Resources Association, *Code of Ethics and Professional Conduct* (1983), http://www.acra-crm.org/Ethics.html. The American Institute of Chemists Code imposes a duty on chemists "[I]o accept commission or compensation in any form from more than one interested party only with the full knowledge and consent of all parties concerned[.]" American Institute of Chemists, *Code of Ethics* (1983), http://www.theaic.org/DesktopDefault.aspx?tabid=46. The ACRA Code similarly imposes on members a responsibility "[n]ot to provide professional services if there is a . . conflict of interest, . . . without full written disclosure and agreement by all concerned parties." American Cultural Resources Association, Code of Ethics and Professional Conduct (1983), http://www.acra-crm.org/Ethics.html.

<sup>307</sup> Human Genome Organization, *Statement on the Principled Conduct of Genetic Research* (1996), http://www.eubios.info/HUGO.htm.

<sup>308</sup> American Anthropological Association, *Code of Ethics of the American Anthropological Association* § V.2 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf; American Institute for the Conservation of Historic and Artistic Works (AIC) Code of Ethics and Guidelines for Practice (1994) § 4c, *available at* http://aic.stanford.edu/pubs/ethics.html; AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-8.03 (2002). The AAA Code instructs anthropologists "[w]orking for governmental agencies or private businesses [to] be especially careful not to promise or imply acceptance of conditions contrary to professional ethics or competing commitments." *Code of Ethics of the American* 

Motivations to secure intellectual property protections for a product or finding of the study should also be examined as they may restrict public access to information derived from a particular study. Two professional codes specifically cite patenting and licensing schemes as potentially detrimental to the promotion of research.<sup>309</sup>

#### IV. CONCLUSION

Biohistorical analysis is a complicated area, drawing from multiple scientific fields. Existing federal and state regulations, case law, and professional guidelines are woefully inadequate to address the myriad ethical, legal, and scientific concerns that this type of research raises. A mechanism for professional review and guidance needs to be established.

Ethical guidelines should provide a framework for addressing the ethical, scientific, legal, and social issues underlying biohistorical analysis, with the potential for more strict requirements to be adopted by a particular professional group, institution, or individual. Guidelines need not be exhaustive, rather they could serve to provide foundational considerations for individuals or institutionally affiliated professionals would consider before undertaking biohistorical analysis. Although not legally enforceable, these guidelines would establish a system of professional self-regulation, in which professionals from all specialties will uniformly address appropriate concerns surrounding bioanalysis. In addition, each profession and/or organization would apply its own relevant professional guidelines, including those detailed in this article.

There is a broad spectrum of individuals and institutions that support, propose, and/or conduct biohistorical analyses. These may include the proponents of the bioanalysis, the principal and/or secondary investigators that will undertake the actual bioanalysis, any other scientific personnel involved in the bioanalysis, owners of the artifact or specimen to be utilized in the bioanalysis, sponsors of the bioanalysis, human participants to the bioanalysis, and any other party with an interest. One individual, group, or institution may play multiple roles. Sometimes particular roles will be covered by existing regulations, but most often they will not. Guidelines should be intended to cover all participants in the biohistorical analysis at any level of involvement.

The academic and cultural pursuit of biohistory will generally take place in institutions, such as museums, universities, or research facilities. Such institutions

Anthropological Association § V.2 (1998), http://www.aaanet.org/committees/ethics/ethicscode.pdf. The AIC Code contains a similar provision about entering into contractual agreements. American Institute for the Conservation of Historic and Artistic Works, Code of Ethics and Guidelines for Practice §4c (1994), http://aic.stanford.edu/pubs/ethics.html. The AMA Code provides, "[u]nder no circumstances may physicians place their own financial interests above the welfare of patients. ... For a physician to unnecessarily hospitalize a patient, prescribe a drug, or conduct diagnostic tests for the physician's financial benefit is unethical." AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-8.03 (2002).

<sup>&</sup>lt;sup>309</sup> HUGO "expresses concerns that reach-through patent claims and reach-through licenses, as partly accepted in the current practice, will not only seriously affect further research and development but could, eventually, discredit the entire patent system as an invaluable incentive to invent, innovate and invest in new technologies." Human Genome Organization, *Statement on Patenting DNA Sequences* (2000), http://www.hugo-international.org/PDFs/Statement%20om%20Patenting%20of%20DNA%20 Sequences%202000.pdf. The AMA Code similarly provides: "One of the goals of genetic research is to achieve better medical treatments and technologies. Granting patent protection should not hinder this goal." AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-2.105 (2002).

should take steps to create a biohistorical review board (BRB) made up of an interdisciplinary group of professionals who are not involved in the proposed biohistorical investigation, either in a personal or financial respect. As biohistorical analysis is fundamentally an interdisciplinary exercise, the BRB should include specialists trained in a number of relevant fields as a means to facilitate comprehensive review of a proposal. We suggest the BRB consist of at least five members, such as: a historian, a biological scientist (for example, a geneticist, a chemist, or a biologist), an anthropologist or sociologist, a lawyer or ethicist, and a member of the public. In some instances, the institution may utilize an existing institutional review board. If the project affects a particular vulnerable group, that group should have representation on the BRB. No BRB should consist entirely of members of one profession and care should be taken to avoid BRB members who may have a potential or actual conflicting interest, such as an affiliation with an outside individual or entity proposing the biohistorical project at issue.

Individuals not affiliated with an institution, such as people for whom history is an avocation or people who possess a biohistorical artifact, should perform a similar level of review for their analysis proposals. This could be done by submitting an analysis proposal to interdisciplinary professionals for review or using BRB resources of an existing institution. The case of an individual researcher may also be dealt with merely by requiring that he or she examine the guidelines and reach a decision on the appropriateness of his or her own proposal based on the guidelines. Both institutions and individuals should be held accountable by their peers in the relevant professions, as well as by society as a whole.

Additionally, guidelines would be useful for entities that are considering funding a particular biohistorical project. These entities could use the fundamental concerns exemplified within the guidelines as a starting point for evaluating a proposal presented to them. The guidelines could also apply to any artifact owners that either propose biohistorical analysis or are presented with a proposal from an outside source.

Compliance with guidelines should be required before the results from a biohistorical analysis are published. Editors of journals could be encouraged to help enforce guidelines by requiring evidence of compliance for relevant items submitted for review. Journalists themselves could also be encouraged to seek evidence of compliance with these guidelines prior to reporting results.

However guidelines are eventually developed and utilized, whether through consideration by an organized BRB, independent review by an individual, or as a tool for potential funding sources, the review of any proposal for biohistorical analysis should consist of collection of relevant background information; examination of ethical, legal, scientific and social considerations. As detailed throughout this article, these considerations are contemplated by numerous professional organizations in existing guidelines and codes of ethics, but should also be specifically applied to the field of biohistorical analysis. While this article highlights some key issues with biohistorical analysis and offers suggestions for increased professional oversight, the next step is getting professional societies and biohistorical researchers involved in the conversation.

# Tales from the Crypt: Scientific, Ethical and Legal Considerations for Biohistorical Analysis of Deceased Historical Figures

Appendix: Codes of Ethics and Guidelines Summaries from Twenty-Six (26) Professional Societies and Organizations Informative to the Field of Biohistory

Jordan Paradise, J.D. and Lori Andrews, J.D.\*

## **Abbreviations:**

AAA	American Anthropological Association
AAM	American Association of Museums
ABFDE	American Board of Forensic Document Examiners
ACFE	American College of Forensic Examiners
ACMG	American College of Medical Genetics
ACRA	American Cultural Resources Association
AHA	American Historical Association
AIA	Archaeological Institute of America
none	American Institute of Chemists
AIC	American Institute for the Conservation of Historic and Artistic Works
AMA	American Medical Association
APG	Association of Professional Genealogists
ASA	American Sociological Association
ASBMB	American Society for Biochemistry and Molecular Biology
ASCLS	American Society for Clinical Laboratory Scientists
ASHG	American Society of Human Genetics
ASIS	American Society for Information Science
BIO	Biotechnology Industry Organization
CAA	College Art Association
CASRO	Council of American Survey Research Organizations
HUGO	Human Genome Organization
ICOM	International Council of Museums
ISE	International Society for Ethnobiology
NCPH	National Council on Public History
OHA	Oral History Association
SAA	Society of American Archivists

## **Codes of Ethics and Guidelines Summaries:**

# American Anthropological Association (AAA)

This organization, founded in 1902, states as its mission "to advance anthropology as the science that studies humankind in all its aspects, through archeological, biological, ethnological, and linguistic research; and to further the professional interests of American anthropologists; including the dissemination of

<sup>\*</sup> The authors thank research assistant David Gonen for research and material informing the development of this Appendix.

anthropological knowledge and its use to solve human problems."310 Because the circumstances of many research ventures are too complex and diverse to be governed by a single code of ethics, the AAA recognizes that its Code of Ethics, approved June 1998, "provides a framework, not an ironclad formula, for making decisions."311 The anthropologist's ethical obligation to people that are the objects of research can supersede the goal of seeking knew knowledge.<sup>312</sup> Interestingly, the AAA, in its Code, recognizes that "the development of knowledge can lead to change which may be positive or negative for people . . . studied."<sup>313</sup> Researchers should "consult actively with the affected groups," establish a working relationship, and ensure their research does not harm the safety, dignity, or privacy of those studied.<sup>314</sup> Researchers should not exploit those studied and should recognize a debt to those studied and reciprocate. 315 Anthropologists must obtain in advance proper informed consent as required by other codes, laws, and local ethics and should incorporate informed consent into study design and continue by way of dialogue and negotiation.<sup>316</sup> Anthropologists must preserve opportunities for future fieldworkers and disseminate their results into the scientific community, and consider reasonable requests for access to data and research materials for purposes of research.<sup>317</sup> Anthropologists should make their results available to sponsors, students, and other nonanthropologists, while ensuring that the information is well understood, properly contextualized, and responsibly utilized, recognizing possible harm their information may cause the subjects of their work. 318 Because Anthropologists often study human remains, their experience may prove valuable when drafting guidelines for biohistorical research.

#### American Association of Museums (AAM)

This organization, founded in 1906, is "dedicated to ensuring that museums remain a vital part of the American landscape, connecting people with the greatest achievements of the human experience, past, present and future" This code also intends to provide a framework for ethical guidelines rather than offering detailed provisions, which should be created by individual institutions. The AAM Code states that museums must maintain integrity to warrant public confidence. Acquisition of items must conform to the mission of public trust and must

<sup>&</sup>lt;sup>310</sup> American Anthropological Association, *Mission and Goals*, § 1, http://www.aaanet.org/mission.htm (last visited Nov. 28, 2007).

<sup>&</sup>lt;sup>311</sup> American Anthropological Association, *Code of Ethics of the American Anthropological Association* at 2 (1998), http://www.aaanet.org/committees/ethicscode.pdf.

<sup>&</sup>lt;sup>312</sup> *Id*.

<sup>&</sup>lt;sup>313</sup> *Id*.

<sup>&</sup>lt;sup>314</sup> *Id*.

 $<sup>^{315}</sup>$  *Id.* at 3

<sup>&</sup>lt;sup>316</sup> *Id*.

<sup>&</sup>lt;sup>317</sup> *Id*.

 $<sup>^{318}</sup>$  *Id.* at 4.

<sup>&</sup>lt;sup>319</sup> American Association of Museums, *About AAM*, http://www.aam-us.org/aboutaam/index.cfm (last visited Nov. 28, 2007).

<sup>&</sup>lt;sup>320</sup> American Association of Museums, *Code of Ethics for Museums* (2000), http://www.aam-us.org/museumresources/ethics/coe.cfm.

<sup>&</sup>lt;sup>321</sup> *Id*.

discourage illicit trade.<sup>322</sup> Museums must ensure that "collections in its custody are lawfully held, protected, secure, unencumbered, cared for, and preserved."323 The museum must be responsive to and represent the interests of society.<sup>324</sup> Museums must ensure that "access to the collections and related information is permitted and regulated"325 and that programs encourage participation of the widest possible audience. 326 Museums should resolve competing ownership claims openly, seriously, and responsively, with respect for the dignity of parties.<sup>327</sup> The AAM's Code does not specifically provide guidelines dealing with confidentiality, informed consent, or how to apply new technologies to existing collections.

#### American Board of Forensic Document Examiners (ABFDE)

This organization, established in 1977, which certifies forensic document examiners, states its accompanying purposes include advancing the science of forensic document examination and promoting adherence to a high standard of ethics. 328 The ABFDE Code of Ethics and Professional Conduct includes objectives of confidential treatment of documents and scientifically sound methodology and reporting.<sup>329</sup> Examiners, likely to be handling evidence in court cases, may be bound to such standards despite their inclusion here.

## American College of Forensic Examiners (ACFE)

This organization has a very short Code of Ethics. Forensic examiners are to maintain the highest standards of professional practice and are to remain objective when making a factual determination.<sup>330</sup> Forensic examiners must not "intentionally withhold or omit any findings or opinions discovered during a forensic examination that would cause the facts of a case to be misinterpreted."<sup>331</sup>

# American College of Medical Genetics (ACMG)

This organization, incorporated in 1991, 332 has a mission to provide "education. resources and a voice for the medical genetics profession. To make genetic services available to and improve the health of the public, the ACMG promotes the development and implementation of methods to diagnose, treat and prevent genetic disease."333 ACMG's Position Statement on Gene Patents and Accessibility of Gene

<sup>&</sup>lt;sup>322</sup> *Id*.

<sup>&</sup>lt;sup>323</sup> *Id*.

<sup>&</sup>lt;sup>324</sup> *Id*.

<sup>&</sup>lt;sup>325</sup> *Id*.

<sup>&</sup>lt;sup>326</sup> Id.

<sup>&</sup>lt;sup>328</sup> American Board of Forensic Document Examiners, *By-Laws*, Art. II, §§ 2a-2b, http://www.abfde.org (password required) (last visited Nov. 12, 2007).

<sup>&</sup>lt;sup>329</sup> American Board of Forensic Document Examiners, Code of Ethics and Competency at 1 (2006), http://www.abfde.org/Downloads/Tab3-CodeofEthics(8-8-06).pdf.

American College of Forensic Examiners, *Code of Ethics*, http://ethics.iit.edu/codes/coeamer.college.forensic.examiners.coe.html (last visited Nov. 1, 2007). <sup>331</sup> *Id*.

<sup>332</sup> American College of Medical Genetics, *History*, http://www.acmg.net/ (click on "About ACMG," and select "History of ACMG") (last visited Nov. 28, 2007).

<sup>333</sup> American College of Medical Genetics, Mission Statement, http://www.acmg.net/ (click on "About ACMG," and select "Mission Statement") (last visited Nov. 28, 2007).

Testing opposes gene patents and addresses the attendant scientific and social The Gene Patent statement claims monopolistic patents lead to exorbitant testing and licensing fees, which in turn both limit patients' access to testing and limit the number of knowledgeable individuals who can assist physicians and genetic counselors with the management and care of at-risk patients.<sup>335</sup> Furthermore, restricting availability via patents retards the otherwise rapid improvement of testing. 336 ACMG's Statement on the Storage and Use of Genetic Materials addresses issues of informed consent, confidentiality, sample preservation. and various social concerns.<sup>337</sup> On the issue of informed consent, the Genetic Materials statement provides that patients should be informed that the result of a genetic test may lead to difficult choices regarding their health, insurance, career, reproduction, marriage, and that patients should be informed about whether their genetic information may be shared to counsel, test, and treat their relatives.<sup>338</sup> The informed consent also should cover any anticipated use of the sample or the intention to destroy the sample. 339 If, after obtaining the patient's permission, samples are put to further use, identifiers should be removed. ACMG's paper on Informed Consent for Medical Photographs addresses issues of informed consent, dissemination, promotion of research, confidentiality, public access, and conflicts of interest. The Medical Photographs paper stresses the importance of obtaining consent for all uses that will be made of medical images, including worldwide distribution via the internet.<sup>342</sup> Additionally, informed consent should include the fact that the image will enter the public domain for good. 343 The paper acknowledges the importance of medical photographs for future phenotype recognition and longitudinal research. 344 Finally, addressing a conflict of interest, the paper directs physicians to state explicitly that a patient's medical care will not be affected by refusal to consent to photography.<sup>345</sup> ACMG's position statement Points to Consider in Preventing Unfair Discrimination Based on Genetic Disease Risk addresses social, scientific, and confidentiality concerns raised by genetic services and research.<sup>346</sup> The Discrimination statement warns that discrimination in health insurance and employment will have a negative impact on patients' willingness to seek genetic

<sup>&</sup>lt;sup>334</sup> American College of Medical Genetics, *Position Statement on Gene Patents and Accessibility of Gene Testing* (1999) at 1, available at http://www.acmg.net/StaticContent/StaticPages/Gene\_Patents.pdf.
<sup>335</sup> Id

<sup>336</sup> Ld

<sup>&</sup>lt;sup>337</sup> American College of Medical Genetics, *Statement on Storage and Use of Genetic Materials* (1995), http://www.acmg.net/StaticContent/StaticPages/Storage.pdf.

<sup>&</sup>lt;sup>338</sup> *Id.* at 2.

<sup>&</sup>lt;sup>339</sup> *Id.* at 1-2.

<sup>&</sup>lt;sup>340</sup> *Id.* at 2.

American College of Medical Genetics, *Statement, Informed Consent for Medical Photographs*, 2 GENOMICS IN MED. 353-355 (2000), http://www.acmg.net/StaticContent/StaticPages/Informed\_Consent.pdf (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>342</sup> *Id.* at 353.

<sup>&</sup>lt;sup>343</sup> *Id.* at 355.

<sup>&</sup>lt;sup>344</sup> *Id.* at 353.

<sup>345</sup> *Id.* at 355.

<sup>&</sup>lt;sup>346</sup> Michael S. Watson & Carol L. Greene, *Points to Consider in Preventing Unfair Discrimination Based on Genetic Disease Risk: A Position Statement of the American College of Medical Genetics*, 3 GENETICS IN MED. 436 (2001).

services and participate in research.<sup>347</sup> Therefore, the privacy of genetic information must be adequately protected.<sup>348</sup> Finally, the Discrimination statement charges legislators with distinguishing familial genetic conditions from other genetic conditions and not creating barriers to use of genetic technology that does *not* create novel risks of discrimination.<sup>349</sup>

#### American Cultural Resources Association (ACRA)

This organization, incorporated in 1995, states its mission as promoting the professional, ethical, and business practices of the cultural resources industry for the benefit of its members, the public, and the resources themselves. The ACRA Code of Ethics calls on members to responsibly present significant research results to the public, to actively support conservation of cultural resource base, and to respect the concerns of people whose histories and resources are the subject of investigation. 351

#### American Historical Association (AHA)

This organization of academic historians, founded in 1884, defines its mission as "the promotion of historical studies through the encouragement of research, teaching, and publication; the collection and preservation of historical documents and artifacts; the dissemination of historical records and information; the broadening of historical knowledge among the general public; and the pursuit of kindred activities in the interest of history." AHA members typically work with library archives as opposed to other artifacts. The AHA Statement on Standards of Professional Conduct guides historians to document and preserve their sources as well as to make them promptly available to other historians. In certain cases, particularly where there is an agreement in advance of an interview, historians must maintain confidentiality. Historians must present interpretations and judgments about their data in a careful manner, so as not to foreclose discussions of alternative interpretations. The AHA also adopted Standards for Museum Exhibits Dealing with Historical Subjects. Under these standards, exhibits should be subject to rigorous peer review. At the outset, museums should identify stakeholders and

<sup>347</sup> Id. at 436.

<sup>&</sup>lt;sup>348</sup> *Id*.

<sup>&</sup>lt;sup>349</sup> *Id*.

<sup>&</sup>lt;sup>350</sup> American Cultural Resources Association, *Mission*, http://www.acra-crm.org/index.html (last visited Nov. 28, 2007).

<sup>&</sup>lt;sup>351</sup> American Cultural Resources Association (ACRA), *Code of Ethics and Professional Conduct*, http://www.acra-crm.org/Ethics.html (last visited Nov. 28, 2007).

<sup>&</sup>lt;sup>352</sup> American Historical Association, *Constitution and Bylaws*, at Art. II (2007), http://www.historians.org/info/Constitution.cfm.

<sup>&</sup>lt;sup>353</sup> American Historical Association, *About Us*, http://www.historians.org/info/index.cfm (last visited Nov. 28, 2007).

<sup>354</sup> American Historical Association, Statement on Standards of Professional Conduct (2005), http://www.historians.org/pubs/free/professionalstandards.cfm.
355 Id.

<sup>&</sup>lt;sup>356</sup> *Id*.

American Historical Association, *Standards for Museum Exhibits Dealing with Historical Subjects*, (2001) http://www.historians.org/info/museumstandards.htm.

involve them in the planning process.<sup>358</sup> Museums, because they are publicly funded, "should be keenly aware of the diversity within the communities and constituencies that they serve."<sup>359</sup> Exhibits should acknowledge competing points of view when addressing a controversial subject.<sup>360</sup>

#### Archaeological Institute of America (AIA)

This organization, founded in 1879

exists to promote archaeological inquiry and public understanding of the material record of the human past worldwide. The Institute is committed to preserving the world's archaeological resources and cultural heritage for the benefit of people in the present and in the future. Believing that greater understanding of the past enhances our shared sense of humanity and enriches our existence, the AIA seeks to educate people of all ages about the significance of archaeological discovery."

The AIA's very brief Code of Ethics instructs members to refuse to participate in the trade of undocumented antiquities and to inform authorities of threats to or plunder of archaeological sites and illegal import or export. The AIA's Code of Professional Standards comprises sections on responsibilities to the archaeological record, responsibilities to the public, and responsibilities to colleagues. Concerning the archaeological record, research "methods should be chosen that require minimum damage [.]"362 Archaeologists should provide long-term storage and curatorial facilities for records and archives.<sup>363</sup> Regarding the public, archaeologists should engage in outreach, consider the ecological impact of research, and consider the overall impact of research on local communities.<sup>364</sup> "Professional archaeologists should not participate in projects whose primary goal is private gain." The Code addresses the issue of group consent, instructing archaeologists to consult with representatives of the local community during planning, to invite local participation in the project, and to inform the local community about research results.<sup>366</sup> Researchers should respect the cultural norms and dignity of the research area's local inhabitants and balance the legitimate concerns of descendants of the past culture being studied against scholarly integrity, seeking a mutually acceptable accommodation. 367 Towards colleagues, archaeologists should share information useful to others' research and should obtain permission from antiquities authorities in the country of origin before studying or publishing.<sup>368</sup>

<sup>&</sup>lt;sup>358</sup> *Id*.

<sup>&</sup>lt;sup>359</sup> *Id*.

<sup>&</sup>lt;sup>360</sup> *Id*.

<sup>&</sup>lt;sup>361</sup> Archeological Institute of America, *About the AIA*, http://www.archaeological.org/webinfo.php?page=10027.

<sup>&</sup>lt;sup>362</sup> Archeological Institute of America, *Code of Professional Standards* (1997) at 1, http://www.archaeological.org/pdfs/AIA\_Code\_of\_Professional\_StandardsA5S.pdf.

<sup>&</sup>lt;sup>363</sup> *Id.* at 2.

<sup>&</sup>lt;sup>364</sup> *Id*.

<sup>&</sup>lt;sup>365</sup> *Id*.

<sup>&</sup>lt;sup>366</sup> *Id*.

<sup>&</sup>lt;sup>367</sup> *Id*.

<sup>&</sup>lt;sup>368</sup> *Id.* at 3.

#### American Institute of Chemists (no acronym used)

This organization, established in 1923, includes in its dedication a commitment to "promote and protect the public welfare" and "to establish and maintain standards of practice." Their Code of Ethics includes duties both to treat data confidentially and to share scientific knowledge. Themselves also have a duty to uphold the law and not engage in illegal work. 371

#### American Institute for Conservation of Historic and Artistic Works (AIC)

This organization, established around 1959, describes the primary goal of conservation professionals as seeking to preserve cultural property, described as "individual objects, structures, or aggregate collections." AIC's Code of Ethics requires conservation professionals to possess an "informed respect for the cultural property."<sup>373</sup> Professionals should advocate the preservation of cultural property. <sup>374</sup> Professionals must select methods that "do not adversely affect cultural property or its future examination, scientific investigation, treatment, or function."375 Conservations professionals should document all examination and investigation, should practice preventive conservation to limit damage or deterioration of cultural property, and should provide guidelines for continuing exhibition, storage, and care. 376 Members should contribute to the evolution and growth of the profession by sharing skills and knowledge and by promoting educational opportunities in the AIC's Guidelines for Practice instructs conservation professionals to publish research to undergo peer review.<sup>378</sup> Professionals should follow laws and regulations concerning dealing with artists' and estates' rights, sacred and religious material, human remains, and stolen property.379 The professional must communicate with the owner, custodian, or agent of the cultural property to ensure agreement and should act only with consent. Relationships with an owner, custodian, or agent are to be considered confidential and information should not be published or made public without written permission.<sup>381</sup> Tests that may cause damage to cultural property must be deemed necessary after careful examination of the property.<sup>382</sup> Removing a sample of material from any cultural property for

<sup>&</sup>lt;sup>369</sup> American Institute of Chemists, *About the AIC*, http://www.theaic.org/DesktopDefault.aspx?tabid=31 (last visited Nov. 28, 2007).

American Institute of Chemists, *Code of Ethics* (1983), *available at* http://www.theaic.org/DesktopDefault.aspx?tabid=46.

<sup>&</sup>lt;sup>371</sup> *Id*.

American Institute for the Conservation of Historic and Artistic Works, *Code of Ethics and Guidelines for Practice* (1994), http://aic.stanford.edu/pubs/ethics.html.

<sup>&</sup>lt;sup>373</sup> *Id*.

<sup>&</sup>lt;sup>374</sup> *Id*.

<sup>&</sup>lt;sup>375</sup> *Id.* <sup>376</sup> *Id.* 

<sup>&</sup>lt;sup>377</sup> *Id*.

<sup>&</sup>lt;sup>378</sup> *Id*.

<sup>&</sup>lt;sup>379</sup> *Id*.

<sup>380</sup> *Id*.

<sup>&</sup>lt;sup>381</sup> *Id*.

<sup>&</sup>lt;sup>382</sup> *Id*.

testing requires prior consent from the owner.<sup>383</sup> Additionally, only a minimum amount of material should be removed, a record must be kept, and the material removed should be retained.<sup>384</sup>

#### American Medical Association (AMA)

This organization, founded in 1847, <sup>385</sup> is "the nation's largest physician group," with physicians across all states<sup>387</sup> and more than one hundred specialties.<sup>388</sup> The AMA Code of Medical Ethics is a massive, comprehensive body of ethical statements developed primarily for the benefit of the patient.<sup>389</sup> The principles in the AMA Code "are not laws, but standards of conduct which define the essentials of honorable behavior for the physician."<sup>390</sup> The AMA Code addresses issues of informed consent, group consent, affected individuals, conflicts of interest, sample preservation, confidentiality, dissemination of results, promotion of research, and other social and scientific concerns. The principles in the AMA Code are not laws, but rather standards of conduct. 391 Regarding confidentiality, information disclosed in the physician-patient relationship context is confidential to the greatest possible degree. <sup>392</sup> Physicians should then not reveal confidential communications or information without the patient's express consent, unless the physician is required to do so by law.<sup>393</sup> Even postmortem, disclosure of medical information for research and educational purposes is appropriate only if confidentiality is maintained by removing individual identifiers.<sup>394</sup> Sample identifiers, including demographic information to protect subsets of the population from stigmatization and discrimination, should be removed where conducting genomic research.<sup>395</sup> Finally, disclosure of patient records for marketing purposes may violate the principle of confidentiality. 396

Regarding affected individuals, physicians are to discuss with patients and/or potential research subjects the ethical issues related to genomic research.<sup>397</sup> Studies

<sup>&</sup>lt;sup>383</sup> *Id*.

<sup>&</sup>lt;sup>385</sup> American Medical Association, *About the AMA*, http://www.ama-assn.org/ama/pub/category/ 1922.html (last visited Nov. 28, 2007).

<sup>386</sup> American Medical Association, About the AMA, http://www.ama-assn.org/ama/pub/category/ 1810.html (last visited Nov. 28, 2007).

<sup>&</sup>lt;sup>387</sup> American Medical Association, State Medical Societies, http://www.ama-assn.org/ama/pub/category/ 7630.html (listing societies from all fifty states) (last visited Nov. 28, 2007).

<sup>&</sup>lt;sup>388</sup> American Medical Association, National Medical Specialty Society Web Sites, http://www.amaassn.org/ama/pub/category/7634.html (last visited Nov. 28, 2007) (listing over one hundred specialty associations); see also American Medical Association, Member Groups, http://www.ama-assn.org/ama/pub/category/1522.html (last visited Nov. 28, 2007) (listing the member groups of AMA).

<sup>&</sup>lt;sup>389</sup> AMERICAN MEDICAL ASSOCIATION, CODE OF MEDICAL ETHICS E-0.01 (2002).

<sup>&</sup>lt;sup>390</sup> Id.

<sup>&</sup>lt;sup>391</sup> *Id*.

<sup>&</sup>lt;sup>392</sup> *Id.* E-5.05.

<sup>&</sup>lt;sup>393</sup> Id.

<sup>&</sup>lt;sup>394</sup> *Id.* at E-5.051.

 $<sup>^{395}</sup>$  *Id.* at E-2.079, ¶ 4.

<sup>&</sup>lt;sup>396</sup> *Id.* at E-5.075.

<sup>&</sup>lt;sup>397</sup> *Id.* at E-2.079, ¶ 1.

should be designed to minimize the harm to individual subjects as well as to any subset of the population that is an identifiable community. Standard informed consent requirements apply to participants in genomic research, within that informed consent, investigators should disclose whether the investigator or the subjects stand to gain financially from the research findings. Also, in clinical research, informed consent must be obtained from patients for the use of organs or tissues. As with confidentiality, disclosing data for marketing purposes may violate the principle of informed consent. Finally, researchers must consult any group or subset of the population that is an identifiable community to design a study that will minimize any harm to that community.

In terms of promoting research, physicians have an ethical responsibility to contribute to the total store of scientific knowledge and should strive to advance medical science. It is unethical to patent medical procedures, and patent holders should license their patents in order to encourage development of better medical technology. Regarding the dissemination of results patenting should be condemned where it limits the availability of new procedures to patients. Regarding scientific concerns, physicians should have adequate training in genomic research and related ethical issues to be able to discuss these issues with patients. Although it impinges upon absolute professional freedom, peer review is necessary, recognized, and accepted. Regarding social concerns, where a community substantially opposes a research project, investigators should not conduct the study. Additionally, "profits from the commercial use of human tissue and its products may be shared with patients, in accordance with lawful contractual agreements."

Regarding conflicts of interest, physicians should never place their own financial interests above a patient's welfare. Conducting a diagnostic test for the physician's financial benefit is unethical. Investigators also should disclose whether they stand to gain financially from research findings. Investigators should not disclose confidential information after the death of a patient for the purpose of the physician's personal gain. Finally, clinical investigators should disclose

 $^{399}$  *Id.* at E-2.079, ¶ 3.

 $<sup>^{398}</sup>$  *Id.* at E-2.079, ¶ 2.

<sup>&</sup>lt;sup>400</sup> *Id.* at E-2.079, ¶ 3(d).

<sup>&</sup>lt;sup>401</sup> *Id.* at E-2.08, ¶ 1.

<sup>&</sup>lt;sup>402</sup> *Id.* at E-5.075.

 $<sup>^{403}</sup>$  *Id.* at E-2.079, ¶ 2.

<sup>404</sup> Id. at E-9.095.

<sup>&</sup>lt;sup>405</sup> *Id*.

<sup>&</sup>lt;sup>406</sup> *Id.* at E-2.105.

<sup>&</sup>lt;sup>407</sup> *Id.* at E-9.095.

 $<sup>^{408}</sup>$  *Id.* at E-2.079, ¶ 1.

 $<sup>^{409}</sup>$  *Id.* at E-9.10.

<sup>&</sup>lt;sup>410</sup> *Id.* at E-2.079,  $\P$  2.

<sup>&</sup>lt;sup>411</sup> *Id.* at E-2.08.

<sup>&</sup>lt;sup>412</sup> *Id.* at E-8.03.

<sup>&</sup>lt;sup>413</sup> *Id.* at E-8.03.

<sup>&</sup>lt;sup>414</sup> *Id.* at E-2.079,  $\P$  3(d).

<sup>&</sup>lt;sup>415</sup> *Id.* at E-5.051.

material ties to companies whose products they are investigating, and should not buy or sell stock in a private company participating in the physician's research, until the involvement ends. 416

#### Association of Professional Genealogists (APG)

This organization, registered in 1979, states as its objectives to promote awareness of genealogical services; to promote professional standards in genealogical research; to improve access to, facilitate research on, and preserve genealogical records; to promote awareness of pertinent laws; to educate the public; and to support genealogists in business. The APG Code of Ethics calls for "promot[ing] the trust and security of genealogical consumers" and "support[ing] records access and preservation."

## American Sociological Association (ASA)

This organization, founded in 1905, is "dedicated to advancing sociology as a scientific discipline and profession serving the public good." The ASA Code of Ethics is comprehensive, including guidelines for professional and scientific standards, harassment, conflicts of interest, public communication, confidentiality, and informed consent. The ASA Code begins with general concerns. "Sociologists respect the rights, dignity, and worth of all people[,]" "make public their knowledge," and "strive to advance the science of sociology." Additional social concerns include that sociologists do not engage in harassment of research participants or in deceptive practices. The ASA Code sets forth a number of scientific guidelines. Sociologists practice only "within the boundaries of their competence." Sociologists take reasonable steps to correct or minimize the misuse or misrepresentation of their work and ensure the accuracy of all public communications. Sociologists avoid conflicts of interest and disclose sources of financial support and professional relationships.

The Code includes detailed sections on confidentiality and informed consent.<sup>426</sup> Sociologists are obligated to ensure that confidential information is protected (even if there is no legal protection or privilege), protect sensitive information obtained in research, and take into account long-term uses of information in public archives or

<sup>417</sup> Association of Professional Genealogists, *Objectives*, http://www.apgen.org/about\_us/objectives.html (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>416</sup> *Id.* at E-8.031.

<sup>&</sup>lt;sup>418</sup> Association of Professional Genealogists, *Code of Ethics*, http://www.apgen.org/ethics/CodeofEthicsBrochure.pdf (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>419</sup> American Sociological Association, http://www.asanet.org/page.ww?section=About+ASA& name=About+ASA (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>420</sup> American Sociological Association, *Code of Ethics* (1997), http://www.asanet.org/galleries/default-file/Code%20of%20Ethics.pdf.

<sup>&</sup>lt;sup>421</sup> *Id.* at 3-4.

<sup>422</sup> *Id.* at 14.

<sup>&</sup>lt;sup>423</sup> *Id.* at 5.

<sup>&</sup>lt;sup>424</sup> *Id.* at 5, 8.

<sup>&</sup>lt;sup>425</sup> *Id.* at 7.

<sup>&</sup>lt;sup>426</sup> See id. at 9-14 (detailing duty of confidentiality and informed consent).

by other researchers. 427 Information is confidential if an individual can reasonable expect it will not be made public with personal identifiers. 428 Sociologists must inform research participants of any limitations to a guarantee of confidentiality at the outset of research. 429 If confidential information is entered into databases without the prior consent of participants, sociologists must protect anonymity by not including personal identifiers. 430 Sociologists plan for the maintenance of confidentiality in the event of their death or withdrawal from practice and where records are transferred to other persons or organizations. 431 intrusiveness, sociologists minimize intrusions on privacy by including only relevant information in reports and discussing confidential information only for appropriate scientific purposes. 432 As a general matter, sociologists do not involve a human being as a research subject without prior informed consent. 433 Sociologists "conform to applicable state and federal regulations and, where applicable, institutional review board requirements."434 Sociologists take special care when dealing with vulnerable populations to ensure the "voluntary nature of the research is understood." There are exceptions to the requirement of informed consent: research in public places, 436 research that would be undermined by prior informed consent (in which case misconceptions are to be corrected no later than at the conclusion of the research), 437 research that poses no more than a minimal risk to participants. 438 The use of recording technology requires informed consent. 439 The requirements of informed consent are that the agreement clarifies the nature of the research; uses understandable language; provides an opportunity to ask questions; informs potential participants of significant factors that are expected to influence willingness to participate; explains refusal or withdrawal involves no penalty; and explicitly discusses confidentiality. 440 Sociologists must keep records of informed consent. 441 The Code addresses several scientific concerns. In reporting on research, sociologists state all relevant qualifications and disclose methods, measures, research designs, 442 and sources of financial support. 443 Sociologists disseminate results and permit their open assessment and verification. 444 Towards the promotion of

<sup>427</sup> *Id.* at 9.

<sup>&</sup>lt;sup>428</sup> *Id.* at 10.

<sup>&</sup>lt;sup>429</sup> *Id*..

<sup>&</sup>lt;sup>430</sup> *Id.* at 11.

<sup>&</sup>lt;sup>431</sup> *Id.* at 11-12.

<sup>&</sup>lt;sup>432</sup> *Id.* at 11.

<sup>&</sup>lt;sup>433</sup> *Id.* at 12. <sup>434</sup> *Id.* at 12.

<sup>&</sup>lt;sup>435</sup> *Id*.

<sup>&</sup>lt;sup>436</sup> *Id*.

<sup>&</sup>lt;sup>437</sup> *Id.* at 14.

<sup>&</sup>lt;sup>438</sup> *Id.* at 12.

<sup>&</sup>lt;sup>439</sup> *Id.* at 14.

<sup>&</sup>lt;sup>440</sup> *Id.* at 12-13.

<sup>&</sup>lt;sup>441</sup> *Id.* at 13.

<sup>&</sup>lt;sup>442</sup> *Id.* at 15.

<sup>&</sup>lt;sup>443</sup> *Id.* at 16.

<sup>&</sup>lt;sup>444</sup> *Id.* at 15.

research, sociologists share pertinent data as a regular practice. 445

## American Society for Biochemistry and Molecular Biology (ASBMB)

This organization, founded in 1906, states its purposes as being to advance the science through publication of journals, to organize meetings, to advocate funding of basic research, to support education, and to promote diversity in the field. The ASBMB Code of Ethics raises primarily scientific concerns of proper reporting of research findings.

## American Society for Clinical Laboratory Science (ASCLS)

This organization (known prior to 1993 as the *American Society for Medical Technology*), established in 1933, "vigorously promotes all aspects of clinical laboratory science practice, education and management to ensure excellent, accessible cost-effective laboratory services for the consumers of health care."

The ASCLS Code of Ethics outlines the duties assumed by clinical laboratory professionals as owed towards three groups: to the patient, to colleagues and the profession, and to society. Within these categories, the code addresses goals to protect patient confidentiality and privacy, improve the body of scientific knowledge, contribute to the general well being of the community, comply with relevant laws and regulations, and actively seek to change those that don't meet high standards of care.

## American Society of Human Genetics (ASHG)

This organization, "founded in 1948, is the primary professional membership organization for human geneticists in the Americas. The nearly 8,000 members include researchers, academicians, clinicians, laboratory practice professionals, genetic counselors, nurses and others involved in or with special interest in human genetics." ASHG's principal objectives include providing venues for investigators to share their findings; educating health professionals, legislators, policy makers, and the public about human genetics; and facilitating communication between geneticists and other groups such as patients, educators, and advocacy groups. ASHG's Professional Disclosure of Familial Genetic Information 455

<sup>445</sup> *Id.* at 16.

<sup>&</sup>lt;sup>446</sup> American Society for Biochemistry and Molecular Biology, *About ASBMB*, http://www.asbmb.org/asbmb/site.nsf/main/aboutasbmb?opendocument (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>447</sup> American Society for Biochemistry and Molecular Biology, *Code of Ethics* (1998), http://www.asbmb.org/asbmb/site.nsf/Sub/CodeofEthics?Opendocument.

<sup>&</sup>lt;sup>448</sup> American Society for Clinical Laboratory Science, *About ASCLS*, http://www.ascls.org/about/index.asp (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>449</sup> American Society for Clinical Laboratory Scientists, *Code of Ethics*, http://www.ascls.org/about/ethics.asp (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>450</sup> *Id*.

<sup>&</sup>lt;sup>451</sup> *Id*.

<sup>&</sup>lt;sup>452</sup> *Id*.

<sup>&</sup>lt;sup>453</sup> American Society of Human Genetics, *About ASHG*, http://www.ashg.org/genetics/ashg/menu-about.shtml (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>454</sup> *Id*.

<sup>&</sup>lt;sup>455</sup> American Society of Human Genetics, *Professional Disclosure of Familial Genetic Information*, 62 AM J. HUM. GENET. 474 (1998), *available at* http://genetics.faseb.org/genetics/ashg/policy/pol-29.htm.

policy paper addresses, in the context of the professional-patient relationship, the conflict between patient confidentiality and an ethical duty to inform a patient's relatives who are genetically at-risk for preventable diseases. Although ASHG officially adopts no position on this issue, the Disclosure paper explains various approaches to resolving the question and notes the effects of domestic law and the policies of foreign nations on this discourse. The Disclosure paper also notes that disclosure of confidential genetic test results could be warranted for public health reasons (no example given). Finally, the Disclosure paper notes ASHG's scientific concern that physicians understand "[t]he inherent limitations of test results to predict the onset, severity, or complexity of a disorder."

ASHG's Statement on Informed Consent for Genetic Research<sup>461</sup> addresses issues of informed consent, affected individuals, disseminating results, and promoting research. The Informed Consent statement requires that studies maintaining identifiable samples must maintain the subjects' confidentiality and not share research results with the subjects' family members, insurance companies, employers, or other parties. The Informed Consent statement addresses the social concern that research subjects be educated on the potential risk of adverse psychological affects, disruption of family dynamics, social stigmatization, and discrimination. ASHG's Background Statement on Genetic Testing and Insurance advocates protecting patient confidentiality and preventing the use of genetic information to exclude genetically at-risk people from insurance policy eligibility. Additionally, the Insurance statement raises the scientific concern of the lack of a clear boundary between genetic and nongenetic conditions and tests.

## American Society for Information Science and Technology (ASIS)

This organization, started in 1937, states that its mission is "to advance the information sciences and related applications of information technology[.]" The ASIS Code of Ethics calls for promoting exchange of scientific information without violating confidential affairs of client or employer. 468

<sup>456</sup> Id. at 474.

<sup>&</sup>lt;sup>457</sup> *Id.* at 475

<sup>&</sup>lt;sup>458</sup> *Id.* at 475-76.

<sup>459</sup> *Id.* at 481.

<sup>460</sup> Id. at 476.

<sup>&</sup>lt;sup>461</sup> American Society of Human Genetics, *Statement on Informed Consent for Genetic Research*, 59 AM. J. HUM. GENET. 471 (1996), *available at* http://genetics.faseb.org/genetics/ashg/policy/pol-25.htm.

<sup>&</sup>lt;sup>462</sup> *Id.* at 471-72.

<sup>&</sup>lt;sup>463</sup> *Id.* at 472.

<sup>&</sup>lt;sup>464</sup> American Society of Human Genetics, *Background Statement: Genetic Testing and Insurance*, 56 AM. J. HUM. GENET. 327 (1995), *available at* http://www.ashg.org/genetics/ashg/pubs/policy/pol-12.htm.

<sup>465</sup> Id. at 327.

<sup>&</sup>lt;sup>466</sup> *Id*.

<sup>&</sup>lt;sup>467</sup> American Society for Information Science & Technology, *About ASIS&T*, http://www.asis.org/about.html (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>468</sup> American Society for Information Science & Technology, *Code of Professional Practice* (1961), http://ethics.iit.edu/codes/coe/amer.soc.info.sci.html.

## Biotechnology Industry Organization (BIO)

This group, formed in 1993 through the merger of rival organizations the *Biotechnology Association* (represented large companies) and the *Association of Biotechnology Companies* (represented emerging companies and universities), advances the interests of the biotechnology industry on Capitol Hill. BIO encourages public discussion of ethical and social implications of scientific developments in biotechnology and, at the behest of Justice Breyer, initiated the BIO Judiciary Project to develop objective educational materials for judges, law clerks, and attorneys. BIO also established a standing committee for bioethics. BIO's Statement of Principles includes a social concern "to consider the interests and ideas of all segments of society and to be sensitive to cultural and religious differences;" a goal of confidentiality "to support strong protection of medical [and genetic] information;" a policy of strict adherence to informed consent procedures; and a desire to promote research to develop efficient, environmentally beneficial biotechnology, while opposing germ-line alteration, human reproductive cloning, and bioweapons.

## College Art Association (CAA)

This organization "is committed to the highest professional and ethical standards of scholarship, creativity, connoisseurship, criticism, and teaching." CAA's Code of Ethics for Art Historians and Guidelines for the Professional Practice of Art History "provides a broad framework of rules of professional conduct." The Code supports "full, free, equal, and nondiscriminatory access to research materials for all qualified art historians." Art historians should be obligated to share primary source material with colleagues and students but are not obligated to share interpretations of source material, though they should publish as soon as possible. Excavators should make materials available to other researchers within three to five years. Field data (often unique and irreplaceable documents, recordings, etc.) ultimately should remain under the host community's control and art historians should file the results of research (dissertations, articles, books, etc.) with the host community. The Code has a lengthy section charging museums, dealers, and historians not to support destructive illegal traffic in cultural treasures.

<sup>&</sup>lt;sup>469</sup> Biotechnology Industry Organization, *History of BIO*, http://bio.org/aboutbio/history.asp (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>470</sup> Biotechnology Industry Organization, *Ethics / BIO Activities*, http://www.bio.org/speeches/pubs/er/ethics.asp (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>471</sup> *Id*.

Biotechnology Industry Organization, *BIO Statement of Principles*, http://www.bio.org/bioethics/background/principles.asp (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>473</sup> College Art Association, *Strategic Plan, Mission Statement and Core Values*, http://www.collegeart.org/aboutus/mission.html (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>474</sup> College Art Association, *Code of Ethics for Art Historians and Guidelines for the Practice of Art History* (1995), http://www.collegeart.org/guidelines/histethics.html.

<sup>&</sup>lt;sup>475</sup> *Id*.

<sup>&</sup>lt;sup>476</sup> *Id*.

<sup>&</sup>lt;sup>477</sup> *Id*.

<sup>&</sup>lt;sup>478</sup> *Id*.

<sup>&</sup>lt;sup>479</sup> *Id*.

historians should acknowledge all scholarly and financial assistance. 480

## Council of American Survey Research Organizations (CASRO)

This organization, a trade association founded in 1975, represents over three hundred Survey Research firms in the United States and "promote[s] a rigorous code of conduct that enhances the image of survey research and protects the public's rights and privacy." CASRO's Code of Standards and Ethics for Survey Research is organized into responsibilities to respondents, responsibilities to clients, responsibilities in reporting, and responsibilities to outside contractors and interviewers. 482 Survey research organizations are to protect a respondent's identity from disclosure to third parties without the respondent's permission; this includes opposing disclosures mandated by subpoena. Survey research organizations must protect respondents from unnecessary and unwanted intrusions and from personal harassment. 484 Where it may not be clear, respondents must be informed that participation is voluntary and researchers must identify his research firm affiliation. 485 "Deceptive practices and misrepresentations . . . are expressly prohibited."486 Survey research organizations "must respect the right of individuals to refuse to be interviewed[,]" but may attempt to gain interviews via explaining the "purpose of the project[,]" "providing a gift or monetary incentive[,]" or recontacting an individual at a later time. 487 "Electronic equipment (taping, recording, photographing) and one-way viewing rooms may be used only with the full knowledge of respondents." Survey research organizations will hold clients' information confidential and will not publicly release research findings that are the property of the client without express, prior approval. 489 Survey research organizations have a responsibility to clients and to the public to include at the following information with any reports: sponsorship of the study (client), purpose, sample description, dates of data collection, name or research company, exact wording of questions, any other information a lay person would need to reasonably assess the findings. 490

#### Human Genome Organization (HUGO)

This organization's mission includes sponsoring dialogue on "the social, legal, and ethical issues related to genetic and genomic information and championing the regionally-appropriate, ethical utilization of this information for the good of the

<sup>&</sup>lt;sup>481</sup> Council of American Survey Research Organizations, CASRO - Who We Are - What We Do (2006), http://www.casro.org/whatis.cfm.

<sup>&</sup>lt;sup>482</sup> Council of American Survey Research Organizations, Code of Standards and Ethics for Survey Research at 2 (2004), http://www.casro.org/pdfs/CASRO%20Code%20of%20Standards%20and%20 Ethics% 202004.pdf.

<sup>&</sup>lt;sup>483</sup> *Id.* at 4-6

<sup>&</sup>lt;sup>484</sup> *Id.* at 6.

<sup>&</sup>lt;sup>485</sup> *Id*.

<sup>&</sup>lt;sup>486</sup> *Id.* at 7.

<sup>&</sup>lt;sup>487</sup> *Id*.

<sup>&</sup>lt;sup>488</sup> *Id*.

<sup>&</sup>lt;sup>489</sup> *Id.* at 10.

<sup>&</sup>lt;sup>490</sup> *Id.* at 12.

individual and the society." The HUGO-ELSI Committee's Statement on the Principled Conduct of Genetics Research addresses social, scientific, education, and promotion of research concerns raised by genetics research. 492 The committee comprised "experts from a number of countries and disciplines, to provide guidance and procedures which would address these concerns and ensure that ethical standards are met as the Human Genome Project and the Human Genome Diversity Project Specifically, the Conduct statement recommends that scientific competence is a prerequisite for ethical research and that communications with the public be accurate. 494 Such communications must be understandable to populations, families, and individuals concerned. Although technology transfer or joint venture agreements with individuals, families, groups, communities, or populations may be acceptable, undue inducement to participate through compensation should be prohibited.49

Potential conflicts of interest should be reviewed by an ethics committee prior to research. 497 Genetic information should remain confidential, 498 and procedures for controlled access and policies for the transfer and conservation of samples and information should be put into place before sampling. 499 Because cultural norms vary, consultation should precede recruitment of possible participants and should continue throughout the research.<sup>500</sup> Informed consent can be individual, familial, or at the level of communities and populations.<sup>501</sup> In the HUGO Statement on Patenting of DNA sequences, <sup>502</sup> the organization "agrees, in principle, with the requirement of a free and informed consent of the donor, where a patent application is filed for an invention based on biological material of human origin," yet expresses concerns about the development of health care improvements should laws "require researchers and physicians to ask, over and above the required informed consent to the research planned, for specific consent for the filing of patent applications and the exploitation of research results based on such material." However, in its Patenting statement, HUGO also expresses concerns that reach through patent claims and licenses will seriously affect further research and development and could discredit the entire patent system as an invaluable incentive to innovate. 504

In the HUGO Ethics Committee Statement on Human Genomic Databases, the

Human Genome Organization, Mission Statement, http://www.hugo-international.org/mission.htm (last visited Nov. 30, 2007).

<sup>&</sup>lt;sup>492</sup> Human Genome Organization, Statement on the Principled Conduct of Genetic Research (1996), http://www.eubios.info/HUGO.htm.

<sup>&</sup>lt;sup>493</sup> *Id*.

<sup>&</sup>lt;sup>494</sup> *Id*.

<sup>&</sup>lt;sup>495</sup> *Id*.

<sup>&</sup>lt;sup>496</sup> Id. 497 *Id*.

<sup>&</sup>lt;sup>498</sup> *Id*.

<sup>&</sup>lt;sup>499</sup> Id.

<sup>&</sup>lt;sup>500</sup> *Id*.

<sup>&</sup>lt;sup>502</sup> Human Genome Organization, Statement on Patenting DNA Sequences (2000), http://www.hugointernational.org/PDFs/Statement%20on%20Patenting%20of%20DNA%20Sequences%202000.pdf.

<sup>&</sup>lt;sup>504</sup> *Id*.

organization proposes principles and recommendations to apply to genomic databases, addressing concerns of public access, preservation, disseminating results, and confidentiality, as well as social and scientific concerns. Regarding public access, "[h]uman genomic databases are global public goods," "[k]nowledge useful to human health belongs to humanity," "[h]uman genomic databases are a public resource," and "[a]ll humans should share in and have access to the benefits of databases." Regarding disseminating results, "[i]nsofar as it benefits humanity, the free flow, access, and exchange of data are essential." Story

Regarding preservation, "[r]epositories should be established and funded to ensure the continuation of publicly available databases." Regarding confidentiality, the "choices and privacy of individuals, families, and communities should be respected" with regard to donation, storage, and uses of samples and the information derived therefrom. Regarding scientific concerns, "[t]here is a scientific responsibility to ensure the professional competence of researchers working with data, as well as the quality and accuracy of the data." Finally, regarding social concerns, "[I]ndividuals, families and communities should be protected from discrimination and stigmatization." [C]onsideration should be given to the possible negative socio-economic effects, if any, of the collection, sharing, and publishing of the data."

#### International Council of Museums (ICOM)

This organization, created in 1946, is a "an international organisation of museums and museum professionals which is committed to the conservation, continuation and communication to society of the world's natural and cultural heritage, present and future, tangible and intangible." ICOM's Code of Professional Ethics (revision planned for 2004) provides "a global minimum standard on which...groups can build to meet their particular requirements." The ICOM Code's extensive provisions further a number of objectives. A museum should "develop its educational role and attract wider audiences." Collections and even subjects of personal research or a special field of interest should be accessible to the public and to scholars. Museum professionals have an obligation to share their knowledge, techniques, and experience with scholars and students, placing benefit to others above personal

<sup>&</sup>lt;sup>505</sup> Human Genome Organization, *Ethics Committee Statement on Human Genomic Databases* at 1-2 (2002), http://www.hugo-international.org/PDFs/Statement%20on%20Human%20Genomic%20Databases%202002.pdf.

<sup>&</sup>lt;sup>506</sup> *Id.* at 2.

<sup>&</sup>lt;sup>507</sup> *Id*.

<sup>&</sup>lt;sup>508</sup> *Id*.

<sup>&</sup>lt;sup>509</sup> *Id*. <sup>510</sup> *Id*.

<sup>511</sup> *Id*.

<sup>1</sup>a.

<sup>&</sup>lt;sup>513</sup> International Council of Museums, *What is ICOM*, http://icom.museum/organization.html (last visited Nov. 30, 2007).

<sup>514</sup> International Council of Museums, Code of Ethics for Museums (2006), http://icom.museum/ethics.

<sup>&</sup>lt;sup>515</sup> *Id*.

<sup>&</sup>lt;sup>516</sup> *Id*.

gain. 517 Objects should be loaned only to other museums and scholars, not to private individuals. 518 Exhibitions "should not compromise either the quality or proper care of collections" and museums should realize that displaying materials without provenance "may be seen to condone illicit trade in cultural property." Research to establish provenance should be encouraged and should conform to ethical and academic practices and copyright law. 520 Museum professionals must practice preventive conservation, creating and maintaining a protective environment for collections, the principle goal being to stabilize the object. S21 "All conservation procedures should be documented and reversible[.]",522 A museum should consider the interests of the object studied, including "national or other cultural or natural heritage." 523 No objects should be obtained where the museum has reason to believe their recovery involved unscientific destruction or damage of monuments, sites, habitats, or without the consent of the owner or occupier of the land or governmental authorities, although in some cases the value of an object may be of such international significance that its contribution to the public knowledge overrides factors that would prohibit its acquisition. 524 Acquisitions from fieldwork involving a living community or its heritage should only be made on the basis of informed consent (group consent) and without exploitation, treating the community's wishes as paramount. 525 Where a community seeks the return of an object that was exported in violation of the principle of group consent, a museum should cooperate in its return.526

Regarding destructive analytical techniques, "there is a clear ethical obligation to ensure such activities are not detrimental to the long-term survival of examples of the material studied... and that a detailed report of all such activities becomes a permanent part of the collections record." The intentional disposal of samples requires the consent of parties involved in the original acquisition and restrictions that the original acquisition was subject to must be adhered to.<sup>528</sup> The ICOM Code addresses social concerns in general by calling for research, particularly when dealing with sacred works, to be "accomplished in a manner consistent with...the interests and beliefs of...the community, ethnic, or religious groups from which the objects originated."<sup>529</sup> Where such sensitive material is used, it must be done "with respect for the feelings of human dignity held by all peoples."530 The ICOM Code directs that members must protect confidential information obtained during the

<sup>&</sup>lt;sup>517</sup> *Id*. <sup>518</sup> *Id*.

<sup>&</sup>lt;sup>519</sup> *Id*.

<sup>&</sup>lt;sup>520</sup> *Id*.

<sup>&</sup>lt;sup>521</sup> *Id*. <sup>522</sup> *Id*.

<sup>&</sup>lt;sup>523</sup> *Id*.

<sup>&</sup>lt;sup>524</sup> *Id*.

<sup>&</sup>lt;sup>525</sup> *Id*.

<sup>&</sup>lt;sup>526</sup> *Id*. <sup>527</sup> *Id*.

<sup>&</sup>lt;sup>528</sup> *Id*.

<sup>&</sup>lt;sup>529</sup> *Id*.

<sup>&</sup>lt;sup>530</sup> *Id*.

course of their work.<sup>531</sup>

### International Society of Ethnobiology (ISE)

This organization, founded around 1990, defines, in its constitution, its vision and objectives to include understanding the relationships between human societies and their environments and establishing, maintaining, and enforcing an ethics code to direct researchers' dealings with local communities and indigenous peoples.<sup>532</sup> The ISE Code of Ethics is a conscientious and comprehensive set of principles that supports public access by holding that research results should be disseminated and returned to the local communities studied, resulting in a continuous dialogue; acknowledges that "prior informed consent of all peoples and their communities must be obtained before any research is undertaken;" recognizes the rights of indigenous peoples, traditional societies, and local communities to keep confidential or anonymous any information concerning their culture; advocates preventing intrusive harms resulting from research activities "even if cause-and-effect relationships have not yet been scientifically proven" and providing for restitution for adverse consequences; prioritizes promoting indigenous peoples' own research; and recognizes the social concern that researchers "respect the integrity, morality, and spirituality" of the cultures being studied, while avoiding the "imposition of external [(i.e. Western)] or foreign conceptions and standards."55

## National Council on Public History (NCPH)

This organization, established in 1980, has a mission to "[a]dvise historians about their public responsibilities [,] [prepare students] for careers in public history [,] and [p]rovide a forum for historians [.]"<sup>534</sup> The NCPH Code of Ethics guides historians to preserve records, report accurate results, provide public access to records, respect the confidentiality of information gained, assist in professional growth of other historians, and protect the community's historical resources.<sup>535</sup>

#### Oral History Association (OHA)

This organization, established in 1967, seeks to bring together all persons interested in oral history (gathering and preserving historical information through recorded interviews with participants in past events and ways of life). OHA's Principles and Standards outline responsibilities to interviewees, responsibilities to the public and the profession, and responsibilities to sponsoring and archival institutions. Interviewees should be informed of the purposes and procedures of

<sup>531</sup> Id

<sup>&</sup>lt;sup>532</sup> International Society of Ethnobiology, *Constitution for the ISE* at 3 (2006), http://ise.arts.ubc.ca/documents/ISEConstitution2006.pdf.

<sup>&</sup>lt;sup>533</sup> International Society for Ethnobiology, *Code of Ethics* at 4-5 (2006), http://ise.arts.ubc.ca/documents/ISECodeofEthicsTEXT2006\_000.pdf.

<sup>534</sup> National Council on Public History, NCPH Code of Bylaws (2005), http://www.ncph.org/AbouttheCouncil/BylawsandEthics/tabid/291/Default.aspx#Bylaws.

<sup>535</sup> National Council on Public History, *Code of Ethics and Professional Conduct* (2007), http://www.ncph.org/AbouttheCouncil/BylawsandEthics/tabid/291/Default.aspx#Ethics.

<sup>&</sup>lt;sup>536</sup> Oral History Association, Oral History Evaluation Guidelines (2000), http://omega.dickinson.edu/organizations/oha/pub\_eg.html.
<sup>537</sup> Id.

the specific project and of the wide range of potential uses of their interviews.<sup>538</sup> Interviewees should be informed that they will be asked to sign a legal release, and interviews should remain confidential until interviewees have given permission for Interviewers should "guard against possible exploitation of interviewees" and explain the option to remain anonymous. 540 Interviewers should strive to record "candid information of lasting value" and make it accessible to the public.<sup>541</sup> Interviewers should attempt to extend the inquiry to create as complete a record as possible for the benefit of others and should, with the prior consent of interviewees, arrange to deposit interviews in a repository. 542 "Interviewers should be sensitive to the communities from which they have collected oral histories [,]" should make the interviews accessible to them, and should consider how to share rewards and recognition with them. 543 Institutions sponsoring interviewers have a responsibility to preserve records and make them known and available for other research, subject to conditions the interviewees set. 544 OHA's Oral History Evaluation Guidelines offers a lengthy list of questions to evaluate how a project will comply with proper standards, including fully informing interviewees about the potential uses of the material, including in a repository; informing about potential disposition of royalties; and providing a "full and easily comprehensible explanation of their legal rights before being asked to sign a contract."545

## Society of American Archivists (SAA)

This organization, founded in 1936, has a mission to lead in identifying, preserving, and using historical records. 546 SAA's lengthy Code of Ethics instructs archivists to not "endanger integrity or safety of documentary materials [,]" "to respect the privacy of individuals who... are the subject of records," to "discourage... restrictions on access or use," and to work with other researchers to be more effective. 547

<sup>&</sup>lt;sup>538</sup> *Id*.

<sup>&</sup>lt;sup>539</sup> *Id*.

<sup>&</sup>lt;sup>540</sup> *Id*.

<sup>&</sup>lt;sup>541</sup> *Id*. <sup>542</sup> *Id*.

<sup>&</sup>lt;sup>543</sup> *Id*.

<sup>&</sup>lt;sup>544</sup> *Id*.

<sup>&</sup>lt;sup>546</sup> Society of American Archivists, http://www.archivists.org/ (last visited Nov. 30, 2007).

<sup>547</sup> Society of American Archivists, Code of Ethics for Archivists (2005), http://www.archivists.org/ governance/handbook/app\_ethics.asp.