

American Society of Law, Medicine & Ethics
DNA Fingerprinting and Civil Liberties

Report of Workshop 3

I. Background

A. Overview of Project:

The American Society of Law, Medicine & Ethics held the third of a series of four workshops as part of the project *DNA Fingerprinting and Civil Liberties* on May 13 and 14, 2005. The project is funded by an ELSI grant from the National Institutes of Health, grant no. 1R01 HG002836 -01. The workshops are the centerpiece of the project and are designed to bring together a multi-disciplinary group of experts and stakeholders to explore various positions on new and controversial privacy and civil liberties issues involved in the application of DNA technology to the criminal justice system.

Each workshop consists of a half-day Public Forum, followed by a full day invitation-only meeting devoted to more in-depth exploration of the workshop theme. Through discussion sessions, participant viewpoints are sought on key issues consistent with the workshop theme. The grant goals are to record these viewpoints, to document consensus where it exists and to otherwise clarify positions on issues, noting advantages and disadvantages of each. These positions will be disseminated at a national symposium for law and policy makers so that this two-year, four-workshop process may inform their work in this area.

B. Overview of Workshop 3:

Workshop 3 explored the theme of research on and ownership of DNA samples. On the first day of the Workshop a public forum was held featuring talks including an overview of human tissue and DNA uses in medical research; the status of behavioral genetics research; ethical and regulatory issues in DNA databases and repositories; and expansions of ethical analysis for biobanks. On the second day of Workshop 3, background talks, a small group discussion session and a plenary session explored technical and policy issues surrounding (1) DNA databank debate expansion to include mass disasters and other DNA collections; and (2) sample ownership questions.

The discussions were conducted in three groups of eight or fewer participants, including the group discussion leader. Project consultants Frederick R. Bieber, David Lazer, and Mark Rothstein served as discussion leaders. Rapporteurs recorded and summarized these discussions. The following is a summary of the breakout group and plenary sessions.

II. Summary of Workshop 3 Breakout and Plenary Discussions

A. Breakout Session: Widening the Net— Mass Disasters and DNA Collections

- 1. Question considered:** Where DNA samples collected from mass disaster sites could be considered crime scene samples, should they be retained indefinitely after laboratory testing is completed?

The type of disaster matters. The World Trade Center case was central to each discussion, but airline crashes, tsunamis, genocide, biological disasters, and fires were also mentioned. Indeed, even though the ‘science’ might be the same for each case (and even that it likely to be different), the political and ethical questions will vary widely. Confounding the issue further are questions about classification: it may not always be clear whether a disaster was criminally motivated, naturally occurring, an accident, or even some combination of these. One participant suggested that it might be impossible to know whether remains found at a scene were actually from that particular case or from another situation in the past. Participants also noted that jurisdictions matter. Another argued that the WTC disaster created the public expectation that unidentified remains would be kept by the state for future identification purposes instead of buried, as has been the practice in previous situations (like a Swiss aircraft accident). Finally, beliefs about the identity of a sample are important: samples thought to be from a victim are treated differently from those thought to be from perpetrators (the latter given more expansive utilization and stored indefinitely).

Family interests are critical to sample retention policies on several levels. First, participants considered that families likely want samples kept until identifications are made. Related to this, once identified, families have a right to be notified and to make the decision as to whether a sample is returned to the family, stored, or destroyed. One participant noted that the WTC policy is to keep remains until identified and then to return them to family members (if they wish) or inter them at the WTC site (if the family does not want the sample). Each group also discussed storage post-identification for related familial interests such as paternity or disease-related questions. There was some tension over this last point, with participants uncomfortable about the state retaining samples for purposes not directly related to the immediate case (particularly when the sample was not from a perpetrator).

Retention also depends upon a variety of other ‘stakeholders’—among these ‘the public’ or citizens writ large, researchers, and religious, ethnic or other ‘cultural’ groups. The first set of interests revolves around a question raised related to family interests: why would the state hold onto disaster samples for so long? What are the risks and benefits? For example, should the samples be held only until all perpetrators have been identified? Should the state retain samples for research purposes?

New technologies shape the potential for identification (both the nominal identity of the sample as well as other kinds of identification, such as paternity and genetic linkage studies) and thus must be taken into account. One participant suggested that mass disaster samples constituted ‘windfall databases’ that could be used to validate expert systems or software search

engines—in the interest of protecting against future disasters of a similar nature. Further discussion opened the possibility that mass disaster databases could be used as tools to improve DNA identification technologies (but not to solve crimes).

Consensus: Unidentified remains may be kept indefinitely, but identified remains should be returned to families or destroyed.

- 2. Question considered:** What about the DNA profiles? Should these DNA profiles be searched in the future against those obtained from unsolved crimes or against those in missing persons databases?

The type of database matters. Groups discussed missing persons, mass disaster, crime scene/unsolved crimes, and convicted offender databases. Acceptable DNA searches depend on the database searched. Generally, there was less concern with cross-searching samples from a mass disaster against those in missing persons database, and even against convicted offenders, than against the crime scene/unsolved crimes database. One group made a distinction between the CODIS rules that disallow such searches and local rules that are more open. A participant in another group noted that there are different CODIS databases with the express intent of keeping their uses separate. Unidentified human remains, missing persons, and relatives are in one category while unsolved crimes and convicted offenders are in another. There was some consensus in this group that victims and families should not be searched against unsolved crimes or the offender database. Conflict arose, however, on whether samples from the deceased should be run against unsolved crimes; one participant argued that the public interest in solving crimes suggests such searches. Another set of discussions revolved around whether there was a difference between searches in the convicted offender versus the crime scene database. Finally, a participant noted that the proliferation of databases suggested a public relations question and a policy dilemma regarding how to inform the public about the various databases, their functions, and potential uses.

Individual rights and family interests should be considered. Many participants felt that privacy, both of the deceased and the families, would be compromised through database cross-searches. Some debate arose regarding the profiles of the deceased versus those from the living. One participant suggested that searches could be made for all deceased people, not just those from mass disasters. Another took it one step further to ask “why wait until deceased?”; such selective searches suggest that a national forensic database, based on a collective decision, puts everyone in the same, equal position. Everyone is at risk and everyone is a beneficiary. A different group noted that if the crime scene and convicted offender databases are used for identification purposes only, then the question becomes an ethical one: “the dead may not have rights, but they have interests,” and while the families want to know that their missing relative has been identified, they do not necessarily wish to know that the deceased committed a crime. The amount of information conveyed is also a policy question: there should be a balance of interests.

- 3. Question considered:** What consent/disclaimers, if any, should be offered to those who volunteer samples to help identify their missing relatives lost in mass disasters?

Consent rests on clear rules/boundaries. Two groups agreed that samples should only be retained until identifications are made, at which point the family could choose to have them destroyed or returned. A caveat was suggested, related to the World Trade Center case, that in cases where samples might be kept in perpetuity, this fact should be included in the consent form. One participant added that volunteers should have the option to ask that if other databases are searched for identification purposes and the deceased relative is, for example, identified through the convicted offender database, the family would not be informed. These same groups raised the question as to whether consent forms should allow for searches beyond the immediate case, but they varied in their conclusions. In one group, a consensus formed suggesting that volunteer samples should not be used for any purposes other than identification. Disagreement on this point occurred in the other group, with argument over whether families should be able to consent to the use of samples for other uses (such as validating databases and search engines, or future genetic research). For example, one participant stated that samples might provide a useful dataset for linkage studies while another participant responded that the samples should not be used as a control population.

Standardized forms might be useful tools. One group discussed the usefulness of a national consent form and questioned its feasibility. Based on a personal experience, one participant argued that a dual-level consent form (federal and state) for missing persons might be necessary (though the specifics were not outlined). Another group briefly discussed the World Trade Center case, noting that the consent forms were very hastily constructed with no mention of how the samples might be used in connection with other databases (implying the question raised by the first group as to whether a universal form would be an effective tool). It was suggested that the WTC form be posted on the workshop website as a model and to serve as a basis for future discussion.

Timing is important. While the groups reached consensus on the need for volunteer sample consent, two groups debated the timing of these requests. A participant in one group, with experience in these situations, noted that the best time to get samples (and thus, consent) occurs immediately after an incident. Both samples and consent may be procured at the family assistance center and if samples are not taken at that time, contact information for relevant family members may be requested. In response to a similar discussion in another group, a different participant argued that following an incident people are upset and will not want to read through the consent forms, much less sign them, and that, moreover, such requests are “cold and impersonal.” “The notification stage (when families are contacted about sample destruction/retention) seems a more reasonable time to try to gain consent.”

Consensus: Consent should accompany volunteer sample procurement.

Consensus: Clear boundaries/guidelines need to be articulated in these consent forms (though these boundaries are contentious).

Consensus: Standardized (universal) forms for consent should be considered.

- 4. Question considered:** Should other DNA or tissue collections (e.g. military, medical, newborn screening, insurance physicals, etc.) be protected in any way from future seizure or searching for a. forensic purposes or b. for identification following mass disasters?

In one group, a participant asked whether there should be legislation prohibiting sample disclosure for any law enforcement purposes (citing military records and newborn screening spots as examples). Others suggested that in forensics, the type of record or database could be distinguished on a case-by-case basis until the point at which there is a national database. Another participant pointed out that in the UK, volunteer samples are given for rape and murder, but the permissions granted are for these cases alone. This helps put limits on how the information can be used. One participant suggested that there should always be limitations on subpoenas for both criminal investigations and mass disasters. Another participant questioned why there is even the need to identify everyone in mass disaster situations; it is unclear as to what other costs accrue. Moreover, the cultural and social context is very important. Different systems could be set up, so as to make citizens understand the different goals that may be at hand with respect to DNA profiling, and furthermore, to create a society in which such goals are not only understood to be different, but are appreciated for their differences. Visibility and accountability are key issues. Finally, one participant worried that mass disaster cases are the most virtuous ones and that there should be more pushing at the borders of what is and is not acceptable. Once searches become acceptable for one case, they become acceptable for others.

Consent is important, but may be hard to acquire. A distinction was made in one group between family members requesting a test on a sample versus simply trying to identify remains without any consent; family consent is essential. However, participants noted that in the WTC case, the fire department requested bone marrow samples to identify firefighters and there was no family consent; in other mass disaster cases like airline crashes where entire families are wiped out, identification becomes very difficult if consent is required. Moreover, criminals and undocumented aliens might not be willing to submit samples.

A distributed database already exists. Two groups worried that a large-scale sample database was already in place. One group noted that this raises concerns for people going to the doctor, because samples essentially create a distributed database for most people. Another group agreed that if all the different forms of collection are considered, nearly the entire population (in the US) already has a sample that could be typed. Both groups recalled the recent case in which a serial killer was caught after the police obtained a biopsy sample from the daughter's doctor, using a subpoena, without her permission. This illustrated current status quo possibilities for criminal justice cases. A related question is whether there is any right to biological privacy at all; the sheer number of databases erodes such privacy significantly.

Consensus: Two groups reached the conclusion that DNA and tissue collection searches are acceptable for identification alone (especially in cases for which there is no way to get the information otherwise), but not for forensic purposes (while the third group found the question overly broad and thus not answerable in the time allotted).

B. Plenary Discussion: Ownership of Samples

Plenary discussion centered on the ownership of DNA samples; specifically two models for thinking about this issue were raised. First, ownership could be viewed from the ‘bundle of rights’ perspective of a sample as ‘real’—tangible—property. It was noted that inmates are not allowed to keep their DNA profile (e.g. to use in a paternity test) and that criminality might imply the loss of one’s rights to their genetic information. Alternately, why make the distinction between types of people? It is unclear as to why a person’s ownership rights to use their DNA profile should vary (e.g. among inmates, accident victims, and sample donors). Following this point, a participant suggested that the ‘bundle of rights’ idea meant a relationship between all people, not just a person and some ‘thing’. One may have some rights, but not full rights (citing the example that a person may own land, but not have the right to build a Wal-Mart there). The paradigm recognizes a number of different interests. Ownership provides a starting point for thinking about where those interests lay, but there has been a general unwillingness to decide who owns DNA. One solution may be the British idea of ‘moral interest points’. The moral interest is a right to withdrawal—a person may not own the sample, but can withdraw it and the information that goes along with it from further use.

The second model for considering ownership is the intellectual property framework. In the case of music, for example, rights lay in the information (i.e. the recording), not the physical thing that holds the music (e.g. a CD). Though the technology to multiply record a person’s DNA profile is not yet available, it raises the question of whether there is a real difference between the physical sample and the data extracted from it. There are two types of property in play: a physical sample and an informational one. Both of these ownership models raised the more deeply theoretical need to think about the connection between the person, the sample, and the information: in a technological era, identity can be separated spatially, temporally, and in terms of phenotypic continuity. Such issues should not be addressed ad hoc, but in a more holistic, future-looking manner.

IV. Conclusion

The success of this third Workshop was due in large part to the efforts and expertise of the project consultants, Drs. Frederick R. Bieber, David M. Lazer, Philip R. Reilly, and Mark Rothstein, and to the distinguished participants who attended and contributed so generously of their insights and perspectives. A listing of all Workshop 3 invitees follows as “Appendix A.” The Workshop 3 Agenda is attached as “Appendix B.” A description of topics for Workshops 1 through 4 is attached as “Appendix C.” We also thank our rapporteurs, Seth Axelrad, Juliana Russo, and Elta Smith, whose summary forms the basis of this report.

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APPENDIX A: Workshop 3 Participants

<p>Frederick R. Bieber <i>Harvard Medical School</i></p> <p>Leslie Biesecker <i>National Human Genome Research Institute, NIH</i></p> <p>Eric Buel <i>Vermont State Police Crime Lab</i></p> <p>Howard Cash <i>Gene Codes Inc.</i></p> <p>R. Alta Charo <i>University of Wisconsin-Madison Law School</i></p> <p>Dave Coffman <i>Florida Department of Law Enforcement</i></p> <p>Irving Gottesman <i>University of Minnesota</i></p> <p>Henry Greeley <i>Stanford University Law School</i></p> <p>Leonard Green <i>Rhode Island Department of Health</i></p> <p>Erica Haimes <i>University of Newcastle on Tyne</i></p> <p>Sheila Jasanoff <i>Harvard University, John F. Kennedy School of Government</i></p> <p>David Kaye <i>Arizona State University College of Law</i></p> <p>Bartha Knoppers <i>University of Montreal</i></p>	<p>David Korn <i>Association of American Medical Colleges</i></p> <p>David Lazer <i>Harvard University, John F. Kennedy School of Government</i></p> <p>Julio Licinio <i>University of California, Los Angeles</i></p> <p>Benjamin W. Moulton <i>American Society of Law, Medicine & Ethics</i></p> <p>Alice A. Noble <i>American Society of Law, Medicine & Ethics</i></p> <p>Mark Rothstein <i>University of Louisville</i></p> <p>Robert Shaler <i>Office of the Medical Examiner</i></p> <p>Tania Simoncelli <i>Technology and Liberty Program, ACLU</i></p> <p>Brion Smith <i>Department of Defense DNA Registry</i></p> <p>Sheri Smith <i>Rhode Island College</i></p> <p>Mervyn Tano <i>International Institute for Indigenous Resource Management</i></p> <p>Sharon Terry <i>PXE International</i></p>
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APPENDIX B: Workshop Agenda

**American Society of Law, Medicine & Ethics
DNA Fingerprinting and Civil Liberties
Workshop #3
May 13-14, 2005
Agenda**

Friday, May 13, 2005

11:30 – 12:00 Registration

**Public Forum: DNA Fingerprinting and Civil Liberties
Land Lecture Hall, Belfer Building (Lunch Provided)**

12:00- 12:05 Welcome/Overview of Project
David Lazer, John F. Kennedy School of Government, Harvard University
Benjamin Moulton, American Society of Law, Medicine & Ethics

12:05 –12:35 Overview of Uses of Human Tissue and DNA in Medical Research
Leslie Biesecker, National Human Genome Research Institute, NIH

12:35 - 1:05 Status of Behavioral Genetics Research
Irving Gottesman, University of Minnesota

1:05--1:35 Ethical and Regulatory Issues in DNA Databases and Repositories
Henry Greely, Stanford University Law School

1:35—2:05 Expanding the Ethical Analysis of Biobanks
Mark Rothstein, University of Louisville

2:05—2:30 Break

2:30--3:30 Q&A to panel of speakers

Plenary Discussion Session (Workshop 3 Invitees)

3:30 –4:30 Discussion Session
Mark Rothstein

4:30—4:45 ASLME grant goals for this and future workshops
Plan for break out sessions

4:45—5:30 Social Hour

6:00 PM Working dinner for invited participants (Harvard Faculty Club)

Saturday, May 14, 2005

8:00 – 8:30 AM Continental Breakfast

Session 1: Widening the Net— Mass Disasters and DNA Collections

Gundle Family Room, Littauer Building 230

Moderator for morning session: Frederick R. Bieber, Harvard Medical School

- 8:30 – 9:00 AM Lessons Learned: DNA Identification of Victims of the World Trade Tower Attack
Robert Shaler, New York City, Office of the Medical Examiner
- 9:00 –10:00 AM Ethical Approaches to Research Using Samples from Mass Disasters
Bartha Knoppers, University of Montreal
Howard Cash, Gene Codes Inc.
- 10:00—10:15 AM Q and A
- 10:15—10:30 AM Break
- 10:30--11:45 AM **Breakout Session 1 (Gundle Family Room, Deland Room Littauer Building 332, and Kahn Room Littauer Building 382)**
Session leaders: Frederick R. Bieber, David Lazer, Mark Rothstein
- 11:45 – 12:00 AM Break/Session Leader Meeting
- 12:00—1:30 PM Lunch/Report Back/Discussion

Session 2: Ownership of Samples

Moderator for afternoon session: David Lazer

- 1:30–2:00 PM Medical Aspects and Ownership of Biological Samples
David Korn, Association of American Medical Colleges
- 2:00 –2:30 PM Legal Aspects and Ownership of Biological Samples
Sharon Terry, PXE International
- 2:30-2:45 PM Q&A
- 2:45 –4:00 PM **Plenary Discussion Session 2 (Gundle Family Room)**
- 4:00-4:30 Discussion summary
Challenges ahead/Preview of future workshop topics
Mark Rothstein
- 4:30 Adjourn

APPENDIX C: Workshop Topics

Workshop 1: Identification Technologies, History, and Law

- ❖ Technology in context
- ❖ Ethical and policy issues

Workshop 2: Policy Issues: Privacy and Justice

- ❖ Access to information
- ❖ Racial identification
- ❖ Partial matches and family relationships
- ❖ Resource allocation and equity
- ❖ Role of federal and state governments
- ❖ Autonomy of science in criminal justice

Workshop 3: Research and Ownership of Samples

- ❖ Who owns the samples?
- ❖ Medical research
- ❖ Behavioral research
- ❖ Epidemiological research
- ❖ Obligations to those who provide samples
- ❖ Collections of DNA for identification in mass disasters, such as TWA flight 800 and the World Trade Center
- ❖ Role of federal and state governments

Workshop 4: Views from the Other End of the Needle: Present and Future Policies

- ❖ Exonerating innocents
- ❖ Families of prisoners (indirect DNA information about family members and families' rights to know medical information)
- ❖ Effects on family relationships
- ❖ Racial identification using DNA
- ❖ National DNA identification cards