

4.1.4 Forensic Genetics

With the exception of genetic information (or material) collected under the jurisdiction of a coroner, medical examiner, or other medical legal officer, the release of genetic information from a physician's records without the patient's informed consent constitutes a breach of confidentiality. However, under limited circumstances with overriding legal and social considerations, all physicians may disclose such information to the criminal justice system.

Physicians from whom genetic information is sought for purposes of criminal justice:

- (a) May ethically carry out DNA analysis on stored tissue samples or release genetic information without the consent of a living or deceased patient (or the patient's authorized surrogate) in response to a warrant or court order.
- (b) Should release only the minimum information necessary for the specific purpose.
- (c) Should not be required to provide genetic information when:
 - (i) a suspect whose location is known refuses to provide a tissue sample for genetic analysis; or
 - (ii) a tissue sample for the suspect can be obtained from other sources (such as the body of a deceased suspect).
- (d) Should decline to participate in the use of information from a genetic database created exclusively for criminal justice for any purpose other than identification.

AMA Principles of Medical Ethics: III,IV

Background report(s):

CEJA Report 3-A-16 Modernized *Code of Medical Ethics*

CEJA Report 6-I-00 Genetic information and the criminal justice system

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AMA Principles of Medical Ethics: III,IV

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 6-I-00

Subject: Genetic Information and the Criminal Justice System¹

Presented by: Herbert Rakatansky, MD, Chair

Presented to: Reference Committee on Amendments to Constitution and Bylaws
(Nelson G. Richards, Jr., MD, Chair)

1 Introduction

2
3 Resolution 513 (I-99), "Use of DNA Testing," instructed the AMA to study the conflicts that
4 arise between the needs for collecting DNA samples for patient care versus the use of DNA
5 information in the criminal justice system. The resolution was forwarded to the Council on
6 Ethical and Judicial Affairs.

7
8 The Use of DNA

9
10 The discovery of the molecular structure of deoxyribonucleic acid (DNA) and the science of
11 molecular biology have profoundly changed medicine's diagnostic capability and promise to
12 transform the therapeutic realm. When some genetic disorders are diagnosed, physicians can
13 intervene for prevention or treatment. While the basic structure of DNA is the same for all
14 human beings, no two individuals other than identical twins have the same DNA sequence. This
15 discovery has had important repercussions in the legal system where DNA can serve as an
16 identification tool.

17
18 At the crossroads of these different uses of DNA, there are great concerns about potential misuse
19 of genetic information. Preventing disease, curing illness, and convicting criminals are all seen as
20 worthwhile uses of the technology by some, but others are concerned that the use could extend
21 much further. Basic health information has been and continues to be the basis of discrimination
22 by employers, insurance companies, and even society. Genetic information is no exception. A
23 1998 AMA study showed that 68% of patients had fears that their genetic test results would be
24 used against them by their employers or insurers.² The possibility that genetic information
25 obtained for diagnostic or therapeutic purposes could be used by the criminal justice system to
26 convict or exonerate a suspect raises important ethical issues. The Council believes that the use
27 of confidential and potentially sensitive medical information should be governed by ethical
28 principles that respect privacy and prevent discrimination.

29
30 While physicians' obligations are first to patients, physicians also "shall recognize a
31 responsibility to participate in activities contributing to an improved community."³ Furthermore,
32 Opinion 9.07, "Medical Testimony" states that "As a citizen and as a professional with special
33 training and experience, the physician has an ethical obligation to assist in the administration of
34 justice." The significant value of genetic information for purposes of law enforcement requires

* Reports of the Council on Ethical and Judicial Affairs are assigned to the reference committee on Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

1 physicians to weigh their responsibilities to safeguard patient confidentiality and their
2 responsibility to assist in the administration of justice. This report provides guidance to
3 physicians by discussing their ethical responsibilities to protect genetic information. Specifically,
4 the report considers (1) the need for genetic privacy; (2) diagnostic and therapeutic use of genetic
5 information; (3) the creation of databanks to store genetic information; (4) the use of genetic
6 information by the criminal justice system; and (5) the circumstances in which physicians may
7 ethically breach patient confidentiality by disclosing genetic information to the criminal justice
8 system.

9 10 11 Genetic Information and Medical Privacy

12
13 It is generally understood that the sensitivity of some medical information warrants higher
14 standards of confidentiality than other medical information. For instance, psychiatric records and
15 HIV status often are protected more rigorously because of social stigmas and the potential for
16 discrimination based on such information.⁴ In fact, current CEJA policy suggests that it may be
17 necessary for physicians to keep separate records for genetic testing results because of the
18 potential for discrimination, particularly by insurance companies.⁵ There are at least two
19 principal arguments for genetic information receiving protection similar to psychiatric records
20 and HIV status.⁶ First, when a patient undergoes genetic testing, the privacy and confidentiality
21 of that individual's entire family is at stake. While the overall medical record of a patient can
22 also contain information about family members, the patient usually discloses this information.
23 Moreover, the patient is not likely to be disclosing information about a family member that is
24 unknown to that family member. In contrast, the results of a patient's genetic test may reveal
25 information about a family member's genetic risk of disease that is unknown to that family
26 member.

27
28 The second principal argument regarding genetic information is that it may provide a forecast for
29 individuals who currently show no sign of disease. We have yet to determine all of the diseases
30 that may be genetic in origin and the predictive power that a genetic abnormality has in disease
31 expression. Furthermore, we will continue to develop diagnostic genetic tests, often ahead of
32 therapeutic interventions. Even though the predictive value of genetic information may not yield
33 certainty, and the treatment options for known genetic diseases may be limited, the knowledge of
34 genetic abnormality alone can have a considerable impact on a patient's decisions regarding
35 health care.

36 37 38 39 Genetic Testing and Patient Care

40
41 In the medical setting, there are many circumstances when genetic testing may provide useful
42 information. Specific genetic tests can be administered prior to implantation, in utero, at any
43 point during a patient's life, and even after a patient's death. Generally speaking, the information
44 gathered from a genetic test can fall into one of four risk categories: (1) inevitable disease onset;
45 (2) heightened risk (susceptibility) for disease onset; (3) carrier status; or (4) no genetic
46 abnormality. Tests have different implications depending on the type of disease being tested for,
47 the severity of the illness, the accuracy of the genetic test, the availability of prophylactic or
48 therapeutic interventions, the social meaning of the disease, the life circumstances of the patient
49 (age, working, contemplating children, etc), the patient's desire to learn about his/her genome,
50 and when the testing is performed (e.g., prenatally versus as an adult).

1
2 Depending on the disease being diagnosed, use of genetic test information may result in
3 preventive measures, changes in reproductive planning, or therapeutic interventions. Scientific
4 progress in the diagnostic realm currently is advancing more rapidly than progress in the
5 therapeutic realm. The impact of diagnostic genetic information will depend on many factors
6 which will continue to evolve with scientific discoveries.
7

8 9 *Physician Involvement in Genetic Testing*

10
11 Physicians are involved in genetic testing as clinicians, laboratory directors, and researchers. In
12 the clinical setting, physicians may order genetic tests to be performed, but most physicians do
13 not directly conduct or interpret genetic tests. The use of DNA for identification purposes does
14 not require the expertise of physicians; however, physicians may act as supervisors of DNA
15 laboratories. The College of American Pathologists, which is among the accrediting bodies for
16 laboratories performing DNA testing, specifies that:

17
18 The technical supervisor of the molecular pathology laboratory (or section) must be a
19 pathologist, certified physician in a specialty other than pathology, or doctoral scientist in
20 a biologic science, with specialized training and/or appropriate experience in molecular
21 pathology. In the case of forensic identity testing, the above or appropriate degree,
22 training or experience in forensic science is required (emphasis added).
23

24 In addition, virtually all clinical laboratories have a physician on staff, or as a supervisor, and
25 physicians may be called for expert testimony regarding DNA.⁷ Finally, physicians may be
26 involved in genetic testing in research (as discussed below).
27

28 29 Genetic Databases

30
31 Physicians, among others, increasingly are involved in the creation or in the use of genetic
32 databases that contain information intended to benefit the health and welfare of patients, their
33 relatives, and society. When parents put a child up for adoption, genetic samples (along with
34 other elements of the parents' medical history) may be taken because of the relevance such
35 information has to the health of the child and his/her future reproductive plans.⁸ Likewise in
36 sperm or egg donation, the genetic information of the donor may be particularly important to the
37 future life of the child. Newborn infants have a blood sample, known as a Guthrie card, that is
38 screened for many genetic abnormalities. Archived blood spots are a potentially extensive source
39 for genetic information. The United States military takes a genetic sample as a routine practice for
40 all military personnel for the principal purpose of identifying human remains.⁹
41

42 Beyond direct DNA samples, the clinical practice of medicine has relied extensively on the
43 sampling of tissue or bodily fluids. The utility of these tissue samples to research is without
44 question. The discovery of leukemia, the advent of blood transfusion and organ transplantation,
45 and virtually every drug produced since 1945 were all possible because of the retention and
46 availability of human tissue samples.⁶ The Council, the AMA, and the courts have addressed
47 some of the rights patients have to their samples, particularly when the physician has the potential
48 to gain financially from the knowledge obtained from the sample.¹⁴⁻¹⁶ Of importance to this
49 discussion is that with the advent of genetic testing, virtually every tissue sample that has been
50 preserved can be used to isolate DNA. The large banks of tissue that exist in many pathology

1 departments are an untapped source for genetic data and a potentially vast resource for law
2 enforcement.

3 4 5 DNA Use in the Criminal Justice System

6
7 As an identification tool, DNA can be valuable in proving or disproving suspects' involvement in
8 criminal activity, and for other identification purposes such as identifying deceased victims. For
9 this reason DNA identification is often referred to as "DNA fingerprinting" and is compared to
10 traditional ink fingerprints.¹⁷ However, DNA is a far more powerful and potentially invasive
11 identification instrument than an actual fingerprint¹⁸ because there is far more information about
12 an individual in his or her DNA than there is in his or her fingerprint. Additionally, as previously
13 discussed, the DNA sample of an individual contains information about every close relative to
14 that person. Even if convicted criminals have diminished rights to privacy, their families' rights
15 should not be affected.

16
17 Unlike a genetic test for medical use, in the United States, a typical genetic test for identification
18 purposes requires analysis of only 13 loci. It is believed that these loci do not code for any
19 known phenotype, and therefore should not be considered as anything more than an elaborate
20 fingerprint. However, the concern is that even after the DNA sample is used to generate the
21 specific ID from the 13 loci, the original genetic sample often is not discarded. The argument is
22 that this sample is kept so that if the technology changes, or replication of the procedure is
23 required, the original sample will still be available. But by keeping the sample, databases are
24 being created which allow for other uses such as research.¹⁸ Such research, if permitted without
25 the consent of the individual, is outside accepted ethical standards. In general, requiring that the
26 genetic sample be destroyed or returned after the analysis necessary for identification is
27 performed affords protection against inappropriate uses.

28 29 30 *Utility of Clinical Genetic Information to the Criminal Justice System*

31
32 Genetic information gathered in the clinical context is likely to be of interest to the criminal
33 justice system in different ways, depending on the circumstances. Usually the criminal justice
34 system will be involved only if physical evidence at the crime scene contains human DNA. Law
35 enforcement personnel may attempt to procure a sample of the suspect's DNA from sources other
36 than the suspect, including the suspect's physician, to compare with the DNA found at the crime
37 scene. Attempts to procure this sample from physicians depend on whether any specific suspect
38 has been identified, and whether the suspect is in custody.

39
40 When a suspect is in custody, the issue is whether a suspect has a Constitutional right to refuse
41 providing a genetic sample. While some have interpreted suspects' Fifth Amendment right to not
42 act as a "...witness against themselves," the Courts have almost universally extended this
43 protection only to a suspect's oral testimony.¹⁹⁻²¹ Suspects do, however, have a due process right
44 as protected by the Fourth Amendment "...against unreasonable searches and seizures," which
45 requires that a warrant be issued to conduct any such search, and that probable cause is necessary
46 to issue the warrant.¹⁴ Thus, in any circumstance where a suspect might be arrested, it is likely
47 that sufficient probable cause would exist to obtain a warrant for a genetic sample with or without
48 the suspect's consent.²¹ It would thus not be necessary for physicians to divulge clinical genetic
49 information, because a sample could be obtained directly from the suspect. If the suspect is

1 deceased, a postmortem genetic sample can still be acquired, although a warrant may still be
2 appropriate.

3
4 In circumstances where a suspect is not in the custody of the court, clinical records may be the
5 only source of comparison for the evidence obtained from the scene of the crime. Society has a
6 vested interest in solving criminal cases, and this may warrant the disclosure of clinical genetic
7 information. In addition, if the suspect is still at large, determining whether their DNA matches
8 DNA from the crime scene can help decide whether to pursue a costly and potentially dangerous
9 manhunt. However, it is important to realize that whether genetic information is gathered directly
10 from the suspect, or from the suspect's physician, it would still be considered a search duly
11 protected by the Fourth Amendment, and requiring a warrant. Physicians should release genetic
12 information only if a warrant is provided.

13
14 Another circumstance that requires careful ethical consideration arises when law enforcement
15 personnel have not been able to identify a suspect but have gathered DNA evidence from the
16 crime scene that may lead to the identification of a suspect. In this instance, they may want to
17 compare the evidence to all the DNA evidence contained in databanks of known offenders. Such
18 databanks exist in individual states and also at the federal level with the Combined DNA Index
19 System (CODIS), a database of the extracted DNA identity from convicted criminals.²² In 1997
20 the CODIS database contained the DNA identity of over 80,000 convicts.²² However, if there is
21 no match from any of the criminal genetic databases, law enforcement personnel may desire to
22 examine other databases of DNA information. The clinical and research databases that were
23 discussed above are one such potential source for examination.

24
25 Although law enforcement personnel may search a forensic database freely, they may not conduct
26 a broad search of a clinical or research database without a court order. Such a search of a genetic
27 database amounts to a fishing expedition.* It has already been established that the appropriation
28 of genetic information by the criminal justice system constitutes a search. The Supreme Court
29 stated in *Chandler v. Miller* that "...to be reasonable under the Fourth Amendment, a search
30 ordinarily must be based on individualized suspicion of wrongdoing."²³ As such, a warrant is
31 required, and sufficient probable cause needed to issue the warrant. There certainly is not
32 probable cause or history of criminal offense for all the individuals in a clinical database.
33 Moreover, there is only a relatively small probability that a suspect would be in the database. It
34 seems unlikely that a court would find there was sufficient probable cause to order the searching
35 of an entire clinical or research database. No suspicion would attach to most members of a
36 database, and the chance that a perpetrator would be part of such a database is normally very
37 small. Physicians should not provide access to such databases as part of a search for a suspect
38 except under a warrant or other court order, which would rarely be issued.

39
40 In instances when a match is found from DNA evidence to a known offender from a criminal
41 database but this offender/suspect is not being held in custody, law enforcement personnel may
42 wish to seek confirmation from a clinical source. In such a case, law enforcement has
43 significantly more evidence that the suspect was involved in the crime, and upon obtaining a
44 warrant, may be able to access clinical genetic information.

* In fact, law enforcement have initiated such "fishing expeditions" in geographic areas where crimes have occurred. In the examples that have occurred in the U.S., law enforcement personnel collected genetic samples from individuals in the proximity of the crime scene. This has only been performed a handful of times and has never resulted in conviction based on genetic evidence. If the practice continues, and a suspect is identified purely from DNA evidence, it is likely that this evidence will eventually be found inadmissible as an unreasonable search and seizure.¹⁶

1 Recent attention has been focused on the high number of convicted felons, many on death row,
2 who have been proven innocent as a result of DNA, or other forensic testing, after lengthy
3 incarceration. The state of Illinois has placed a moratorium on executions until a review of
4 capital cases is completed. Consistent with this effort, the AMA adopted resolution 4-A-00 to
5 indicate its support of the criminal justice system using all appropriate medical forensic
6 techniques to avoid wrongful convictions or executions. However, the issue of exonerating the
7 innocent is fundamentally different from the discussion of suspect identification that has been
8 outlined above. For exoneration purposes, databases are not relevant. Fundamentally, to prove
9 that someone is innocent, the forensic DNA requirement is that his or her DNA does not match
10 the DNA from the crime scene. A database might allow law enforcement to find a new suspect
11 after exonerating the previous one. However, for the reasons discussed above it would be
12 unethical and unlawful to search clinical databanks to find a suspect. One clear exception may be
13 postmortem exoneration. A physician should release genetic information in his or her records
14 after a patient's death in compliance with any court order or warrant and in adherence to the
15 guidelines discussed in CEJA Report 5-A-00, "Confidentiality of Medical Information
16 Postmortem."

17
18 While the above discussion has focused mostly on identification of criminal suspects, it is also
19 possible to have an unidentified deceased victim. Once again clinical records may provide a
20 potential source of genetic information for comparison to the victims' DNA. Physicians should
21 release this information to law enforcement personnel with consent of the appropriate surrogate
22 or as required by warrant or other order of a court.
23

24 25 Privacy Concerns and Ethical Breaches of Patient Confidentiality

26
27 The essential ethical question that must be resolved is under what circumstances should
28 physicians release DNA information to the criminal justice system. At the outset one must
29 recognize that confidentiality of medical information is one of the cornerstones of the patient-
30 physician relationship and that any release of patient information without explicit consent is a
31 breach of patient-physician confidentiality. However, circumstances do exist when physicians
32 may be warranted to breach patient confidentiality. The Fundamental Elements of the Patient-
33 Physician Relationship states that:

34
35 The patient has the right to confidentiality. The physician should not reveal confidential
36 communications or information without the consent of the patient, unless provided for by
37 law or by the need to protect the welfare of the individual or the public interest.²⁴
38

39 According to Opinion 5.05, "Confidentiality," in situations when a patient presents a reasonable
40 threat to himself or herself or to others, and in situations regarding communicable disease or
41 violent injury, it may be permissible to release confidential information.²⁴
42

43 More specifically, AMA policy states that release of genetic information to law enforcement
44 personnel should be provided only with a warrant or court order. Moreover, the onus is upon law
45 enforcement personnel to prove that any requested release meets such sufficient standards of
46 societal necessity. Implicit in this duty is to demonstrate that solving the specific crime under
47 investigation is a societal priority. Opinion 5.05 states:

48
49 Law enforcement agencies requesting private medical information should be given access
50 to such information only through a court order. This court order for disclosure should be
51 granted only if the law enforcement entity has shown, by clear and convincing evidence,

1 that the information sought is necessary to a legitimate law enforcement inquiry; that the
2 needs of the law enforcement authority cannot be satisfied by non-identifiable health
3 information or by any other information; and that the law enforcement need for the
4 information outweighs the privacy interest of the individual to whom the information
5 pertains. These records should be subject to stringent security measures.²⁵
6

7 AMA Policy also states “When breaches of confidentiality are compelled by concerns for public
8 health and safety, those breaches must be as narrow in scope and content as possible, must
9 contain the least identifiable and sensitive information possible, and must be disclosed to the
10 fewest possible to achieve the necessary end.”²⁵ Thus, for purposes of genetic identification,
11 only the genetic information or tissue sample necessary for identification should be provided.
12 Access to other parts of the medical record or results of clinical genetic testing would not
13 typically be necessary.
14

15 In addition, the 1991 Board of Trustees Report “Evaluation of the use of DNA identification
16 testing in criminal proceedings” concludes that “The establishment and use of DNA databanks for
17 convicted criminals is appropriate if usage is limited to law enforcement personnel who are
18 investigating a crime. Any individual or personalized information which may be obtained from
19 DNA prints should be accorded the same confidentiality as medical records.”²⁶
20

21 AMA policy also states that “Genetic information should be kept confidential and should not be
22 disclosed to third parties without the explicit informed consent of the tested individual.”²⁵ While
23 it is clear that consent is preferable, ultimately obeying the law in compliance with court orders
24 does justify disclosing confidential information.
25

26 If a blood or tissue sample must be provided from the physician’s records, this should be done
27 with the understanding that the sample can be used only for identification purposes. It is
28 inappropriate for law enforcement to obtain clinical genetic information for identification
29 purposes and utilize it for another purpose, such as research. While physicians must adhere to the
30 law, they should oppose any additional use of patient information, including genetic information,
31 unless the patient consents to that use.
32

33 34 Conclusion

35
36 Confidentiality is a cornerstone of the patient-physician relationship. While the release of genetic
37 information constitutes a breach of confidentiality, adherence to the law and a societal interest in
38 convicting criminals permit physicians to release a patient’s genetic information with the consent
39 of the patient or when requested by a warrant of the court. When releasing genetic information,
40 physicians should provide the minimum amount of information required, and should not permit
41 general access to clinical or research sources of genetic information or other unauthorized access
42 to confidential health information.
43

44 45 Recommendations

46
47 The Council recommends that the following be adopted and the remainder of the report be filed:
48

49 The release of genetic information from a physician’s records without the consent of the
50 patient constitutes a breach of confidentiality. Opinion 5.05, “Confidentiality,”

1 acknowledges that law and overriding social considerations may permit physicians to
2 disclose confidential information in limited circumstances. However, such circumstances
3 present ethical challenges. The following guidelines are intended to aid physicians in
4 considering the ethical basis for the release of genetic information to the criminal justice
5 system.

- 6
7 (1) Physicians should release a patient's genetic information only with the patient's consent
8 or in compliance with a warrant or other order of a court of law. The circumstances in
9 which law enforcement may seek a suspect's genetic information from the suspect's
10 physician depend on whether any specific suspect has been identified, and if the suspect
11 is in custody.
 - 12
13 (a) If law enforcement personnel have identified a suspect and the suspect cannot be
14 located to provide a genetic sample, physicians should release clinical genetic
15 information only when a warrant or court order mandates such a release.
16
 - 17 (b) When law enforcement personnel have identified a suspect, and the suspect has been
18 located but refuses to provide a sample or is deceased (but his or her body is
19 available), physicians should not be required to release genetic information as in
20 these circumstances a court can authorize collection of a sample from the suspect or
21 from postmortem tissue.
22
 - 23 (c) Searching clinical and research databases of genetic information, or extracting and
24 analyzing DNA from clinical or research tissue repositories, should not be
25 conducted for the mere possibility that there is a match to a suspect's DNA unless
26 there is a warrant or court order to do so.
27
- 28 (2) When genetic information is provided to the judicial system, physicians should provide
29 the minimum amount of information necessary for the explicit identification procedure
30 being performed. Other elements of the medical record, or the results of any genetic
31 testing or genetic diagnosis, should not be released without the patient's consent or
32 further warrant or order of the court.
33
- 34 (3) It is unethical for any genetic information obtained from a physician for identification
35 purposes to be used subsequently for other purposes, such as research, unless
36 appropriate ethical guidelines are followed and the informed consent of the individual is
37 obtained (or the legally appropriate surrogate if the individual is incompetent or
38 deceased, in compliance with Opinion 5.051, "Confidentiality of Medical Information
39 Postmortem").
40
- 41 (4) Databases that contain only the genetic identifiers from the specific loci that are
42 typically used for identification purposes do not present the same ethical concerns that
43 are presented by databases which contain genotypic or phenotypic information.
44 Physicians participating in the creation of genetic databases for the exclusive use of the
45 criminal justice system should ensure that the database is not used inappropriately for
46 purposes other than identification.
47
- 48 (5) In general, requiring that the genetic sample be destroyed or returned after the analysis
49 necessary for identification is performed affords protection against inappropriate uses.
50
- 51 (6) When the criminal justice system seeks genetic information for the purposes of
52 identifying a deceased victim, the above relevant guidelines also apply.

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