

# Life Support for Patients without a Surrogate Decision Maker: Who Decides?

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**Background:** Physicians in intensive care units have withdrawn life support in incapacitated patients who lack surrogate decision makers and advance directives, yet little is known about how often this occurs or under what circumstances.

**Objective:** To determine the proportion of deaths in intensive care units that occur in patients who lack decision-making capacity and a surrogate and the process that physicians use to make these decisions.

**Design:** Multicenter, prospective cohort study.

**Setting:** Intensive care units of 7 medical centers in 2004 to 2005.

**Patients:** 3011 consecutive critically ill adults.

**Measurements:** Attending physicians completed a questionnaire about the decision-making process for each incapacitated patient without a surrogate or advance directive for whom they considered limiting life support.

**Results:** Overall, 5.5% (25 of 451 patients) of deaths in intensive care units occurred in incapacitated patients who lacked a surrogate decision maker and an advance directive. This percentage ranged from 0% to 27% across the 7 centers. Physicians considered lim-

iting life support in 37 such patients or would have considered it if a surrogate had been available. In 6 patients, there was prospective hospital review of the decision, and in 1 patient, there was court review. In the remaining 30 patients, the decision was made by the intensive care unit team alone or by the intensive care unit team plus another attending physician. The authors found wide variability in hospital policies, professional society guidelines, and state laws regarding who should make life-support decisions for this patient population. Thirty-six of 37 life-support decisions were made in a manner inconsistent with American College of Physicians guidelines for judicial review.

**Limitations:** The results are based on physicians' self-reported practices and may not match actual practices. The number of incapacitated patients without surrogates in the study is small.

**Conclusions:** Incapacitated patients without surrogates accounted for approximately 1 in 20 deaths in intensive care units. Most life-support decisions were made by physicians without institutional or judicial review.

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The vast majority of deaths in intensive care units are preceded by a decision to limit life support (1, 2). Most critically ill patients cannot participate in these decisions (1, 3). Consequently, the patients' families generally function as surrogate decision makers (4). However, some patients who lack decision-making capacity do not have a surrogate and have not completed an advance directive. Difficulties in making decisions for this patient population have been documented in skilled-nursing facilities (5, 6), general hospital wards (7), and intensive care units of 1 major medical center (8-10). These cases raise ethical and legal questions about who should make decisions for such patients and under what circumstances it is permissible to limit life-sustaining treatment.

Although one third of physicians who care for critically ill patients have withdrawn life support in at least 1 patient who lacked decision-making capacity, a surrogate,

and an advance directive, little is known about how frequently such decisions are made in intensive care units (11). Professional organization guidelines differ on how decisions should be made for these patients. The American Medical Association (AMA) recommends ethics committee or judicial review, the American College of Physicians (ACP) recommends judicial review, and the American Geriatrics Society (AGS) advises against routine court involvement but recommends that decisions be made by clinicians caring for the patient (12-14). It is unknown what effect these recommendations have had on actual treatment decisions for incapacitated patients who lack a surrogate and an advance directive. Moreover, little is known about how decisions to limit life support are made for these patients.

Therefore, we conducted a multicenter, prospective study to determine the proportion of deaths in intensive care units that occur in patients who lack decision-making capacity, a surrogate, and an advance directive and how decisions regarding life support are made for such patients.

## METHODS

### Design, Patients, and Setting

This multicenter, prospective cohort study included all adults who were admitted to the medical or medical-surgical intensive care units of 7 hospitals in a 6-month period during 2004 to 2005. The hospitals are located in

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Appendix

Conversion of figure and tables into slides

California, Oregon, Washington, Pennsylvania, New York, and New Hampshire. Most of the study hospitals are located in metropolitan areas, and all have an academic affiliation. Several are county hospitals, and all are tertiary care centers. The number of beds in the intensive care units ranged from 8 to 16. Other details regarding the study institutions have been deleted to protect the individual institutions and physicians from legal inquiry. The institutional review board at each hospital approved the study.

We contacted the attending physician twice weekly to determine whether he or she had admitted any patients who lacked decision-making capacity, a surrogate, and an advance directive and, if so, whether there had been consideration of limiting life support in that patient. Patients were eligible if they lacked decision-making capacity and both a written advance directive and a surrogate decision maker. Because some physicians might not consider limiting life support without consent of the patient or a surrogate, we also included patients for whom a physician would have considered limiting life support if a family member had been available to act as a surrogate. Patients were considered to lack decision-making capacity if the attending physician determined that they could not participate in decisions about their medical care. We used the physicians' assessments of decision-making capacity rather than formal cognitive testing to capture how decisions were made in clinical practice, although physicians' assessments of decision-making capacity correlate highly with formal cognitive testing (15). Written advance directives were defined as a document signed by the patient that delineated any aspect of their end-of-life treatment preferences. Patients were considered to lack a surrogate decision maker if they had no family, legally appointed guardian, or health care proxy available to participate in decisions about their medical care.

### Initial Evaluation and Follow-up

If the attending physician indicated that withholding or withdrawing life-sustaining treatment had been considered or would have been considered if a surrogate had been available, he or she completed a questionnaire about the decision-making process that was validated in a separate pilot study for this project (10). The questionnaire addressed patient and physician demographic characteristics, factors that influenced the decision of whether life-sustaining treatment should be limited, persons involved in the decision-making process, and whether the patient died in the intensive care unit. The questionnaire is available from the first author upon request. Physicians were told that the purpose of the study was to understand processes of care for incapacitated patients without surrogates but were not informed of the specific research questions.

At the end of the 6-month study period, we used administrative records from each institution to determine the number of admissions and deaths before discharge from the intensive care unit during the study period. We ob-

### Context

In the United States, what happens to incapacitated patients who lack surrogate decision makers has not been quantified.

### Contribution

This prospective study of 3011 critically ill adults in 7 academically affiliated, geographically diverse intensive care units found that 5.5% of the deaths occurred in patients who lacked a surrogate decision maker and an advance directive. Physicians and unit teams made life-support decisions without a formal hospital or court review for 30 of 37 such patients. Pertinent policies varied widely across hospitals and states.

### Caution

Physicians self-reported information about decision making.

### Implication

Physicians commonly make life-support decisions for patients who lack surrogate decision makers, without formal institutional or judicial review.

—The Editors

tained written hospital policies that addressed how decisions about limiting life support should be made for incapacitated patients who lack a surrogate decision maker or an advance directive. We examined the published guidelines from the major U.S. medical societies (AMA, ACP, and AGS) and critical care organizations (American Thoracic Society, American College of Chest Physicians, and Society for Critical Care Medicine) to determine whether they had a policy for decision making in this population and, if so, what the policy was. In addition, a legal scholar researched state laws to determine if relevant laws that addressed whether it is permissible to limit life support in these patients existed and, if so, the process by which these decisions should be made.

We developed a categorization of groups that might be involved in the decision-making process, including, in increasing level of oversight, other members of the intensive care unit team (nurses, fellows, and residents), another attending physician, hospital review (an ethics committee, multidisciplinary committee, or patient ombudsman), and judicial review (court ruling on the decision or a court-appointed guardian). At the end of the study, 3 investigators (an ethicist, a lawyer, and a critical care physician) together adjudicated whether each decision was made in accordance with hospital policy, professional society guidelines, and state statutes or court rulings.

### Legal Considerations

Physicians may believe that they are in legal jeopardy if they limit life-sustaining treatment in a patient who cannot

provide informed consent and who lacks a surrogate decision maker and an advance directive. Therefore, we took several steps to protect the identities of physicians and patients. First, we removed from our databases all information about the study hospitals, except the state in which they are located. Second, the study was anonymous for patients and physicians. Third, to minimize the chance that study records would allow a direct link between individual physicians and specific treatment decisions, we did not perform a chart review or collect identifying information. To protect individual physicians and institutions from legal scrutiny, we present the data on decision making in aggregate form only. Finally, we obtained a federal Certificate of Confidentiality from the National Institutes of Health that protects research data from subpoena in the event of a legal inquiry (16). The **Appendix** (available at [www.annals.org](http://www.annals.org)) provides more information about this Certificate.

**Role of the Funding Sources**

The funding sources had no role in the design, conduct, or analysis of this study or in the decision to submit the manuscript for publication.

**RESULTS**

A total of 3011 patients were admitted to intensive care units during the study period. **Table 1** shows that the combined mortality rate for all intensive care units was 15.0% (451 of 3011 patients). Overall, 5.5% (25 of 451 patients) of deaths in intensive care units occurred in incapacitated patients who lacked surrogate decision makers and advance directives. The percentage of deaths among incapacitated patients without surrogates ranged from 0% to 27% across the 7 study institutions (**Table 1**).

**Decisions to Write a Do-Not-Resuscitate Order or to Withdraw Life Support**

There were 37 incapacitated patients who lacked decision-making capacity, a surrogate, and an advance directive for whom the attending physician considered or would have considered limiting life support if a surrogate had been available. **Table 2** summarizes the demographic and

clinical characteristics of these patients. They were predominantly male, white, and 40 years of age or older.

In these 37 patients, there were 36 decisions about whether to write a do-not-resuscitate order and 25 decisions about whether to withdraw life support. The **Figure** shows the end-of-life decision-making process and outcomes of each patient. Sixty-eight percent (25 of 37 patients) died in the intensive care unit.

Various persons were involved in decisions about whether to withhold or withdraw life-sustaining treatment (**Table 3**). In 5 of 37 patients, the attending physician did not involve others in the decision-making process and did not consider limiting life support but would have if a surrogate had been available. In 10 of 37 patients, the attending physician sought input from other members of his or her team for at least 1 life-support decision but did not seek review from another attending physician, a hospital review committee, or the courts. In the remaining cases, the attending physician involved another attending physician (15 of 37 patients), a hospital review committee (6 of 37 patients), or the courts (1 of 37 patients).

Physicians cited several reasons why they considered limiting life support. The most common reasons were poor prognosis for hospital survival (28 of 37 patients), predicted poor quality of life (16 of 37 patients), and the belief that treatment was not in the patient’s best interest (7 of 37 patients).

**Hospital Policies, Professional Society Guidelines, and State Laws**

**Table 4** (17–22) summarizes the hospital policies about who should be involved in decisions to limit life support in incapacitated patients without surrogates. At the time of the study, the policies about forgoing life support at 2 of 7 hospitals did not specifically address how to make decisions for patients who lacked surrogates and advance directives. In the remaining hospitals, there were differences in the recommended approach, which ranged from leaving the decision to the health care team to requiring hospital review of such decisions. No hospital policy mandated judicial review. However, in 1 institution, life support could not be withdrawn unless there was clear and convincing evidence of the patient’s wishes, a requirement that is difficult to meet in the study population without specific prior written directives. In the 5 hospitals that had an explicit policy about decision making for incapacitated patients without surrogates, 5 of 14 patients had a life-support decision made for them with less oversight than recommended by the policy.

None of the 3 major U.S. critical care societies has a policy on decision making in this population. Decisions for 30 of 37 patients were inconsistent with the AMA’s policy of ethics committee review or judicial review, and decisions for 36 of 37 of patients were inconsistent with the ACP’s recommendation of judicial review. Decisions for all 37

*Table 1. Admissions and Deaths in the 7 Study Institutions\**

Institution	Admissions, n	ICU Deaths, n (%)	ICU Deaths in Patients Who Lack Surrogates, n (%)
1	315	42 (13.3)	10 (23.8)
2	215	30 (14.0)	8 (26.7)
3	684	54 (7.9)	3 (5.6)
4	423	105 (24.8)	1 (1.0)
5	258	31 (12.0)	2 (6.5)
6	488	101 (20.7)	1 (1.0)
7	628	88 (14.0)	0 (0)
Total	3011	451 (15.0)	25 (5.5)

\* ICU = intensive care unit.

patients had the level of oversight recommended by the AGS.

Table 4 summarizes statutes and case laws that address limiting life support in patients without surrogates in the 6 states under study. The laws vary regarding who should be involved in the decision-making process and under what circumstances it is permissible to limit life support. In institutions in states with laws addressing the issue, 11 of 20 decisions were made with less oversight than recommended by law.

**DISCUSSION**

Patients who lack decision-making capacity, a surrogate decision maker, and an advance directive accounted for approximately 1 in 20 deaths in intensive care units. This proportion varied among institutions. Hospital policies, professional society guidelines, and state laws also varied regarding how decisions should be made for these patients. Most life-support decisions were made by physicians without institutional or judicial review. Decisions were frequently made in a manner different from that advised by the relevant hospital policy, professional society guidelines, and state law.

We established that physicians at a diverse group of hospitals face decisions about whether to continue life sup-

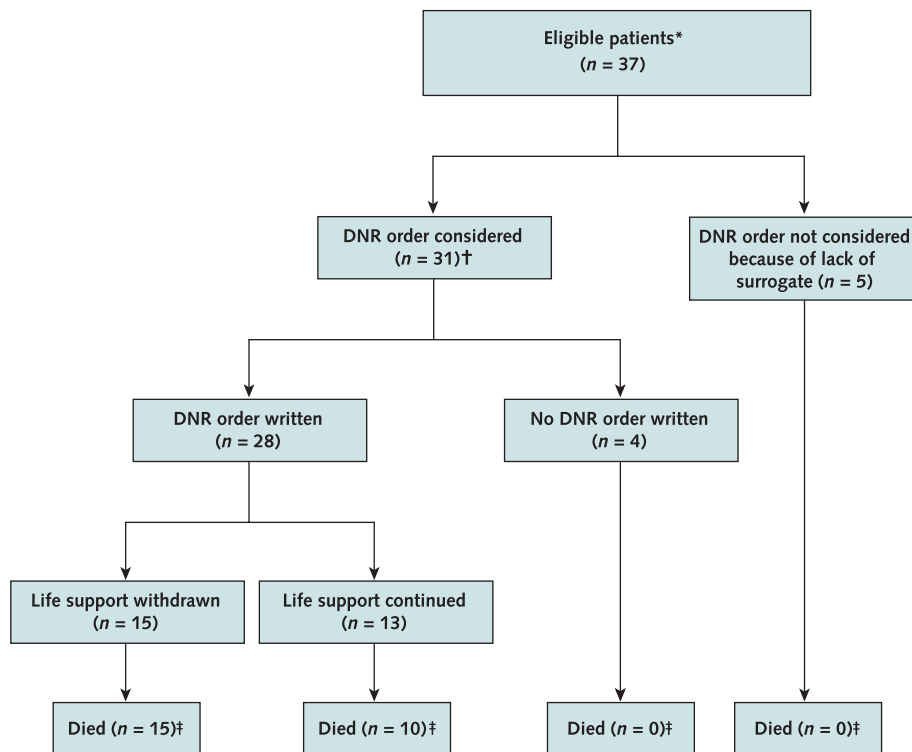
**Table 2. Characteristics of the 37 Incapacitated Patients without Surrogates**

Characteristic	Patients, n
<b>Age</b>	
<40 y	3
40–64 y	21
>64 y	13
<b>Men</b>	
	32
<b>Race/ethnicity</b>	
White	27
Black	7
Hispanic	2
Asian	1
<b>Primary organ dysfunction*</b>	
Respiratory	21
Cardiovascular	8
Neurologic	2
Hepatic	2
Gastrointestinal	2

\* Data were missing for 2 patients.

port in patients who lack decision-making capacity and a surrogate. Three studies from 1 institution documented that life support has been withdrawn in such patients (8–

**Figure. Study flow diagram.**



\*Patients for whom physicians would have discussed forgoing treatment with a surrogate. †For 1 patient, a do-not-resuscitate (DNR) order was not considered but withdrawing treatment was considered. ‡Patients died before discharge from the intensive care unit.

**Table 3. Highest Level of Consultation Sought when Deliberating about whether to Limit Life Support\***

Highest Level of Consultation	DNR Decision (n = 36), n	Withdrawal of Life-Support Decision (n = 25), n	Total (n = 61), n
Intensive care unit team†	14	12	26
Another attending physician	16	10	26
Hospital review‡	6	2	8
Judicial review	0	1	1

\* DNR = do not resuscitate.

† Included the patient's nurses and medical trainees who were supervised by the attending physician.

‡ Included the hospital ethics committee, a multidisciplinary review committee, or a patient advocate or ombudsman.

10). To our knowledge, our study provides the first evidence that the issue occurs elsewhere. Furthermore, approximately 25% of all deaths in intensive care units at 2 institutions occurred in incapacitated patients without surrogates. Given these findings, further research and ethical analysis on how to best make decisions for these patients are warranted.

When patients without decision-making capacity lack a surrogate and an advance directive, it is generally not possible to know whether the decisions made are those that the patients would have made themselves. Because the correct decision is often uncertain, the process by which the decisions are made assumes greater importance (23). Most life-support decisions in our study were made by physicians without input from a hospital review committee or the courts. Physicians clearly play an important role in making decisions for such patients. They understand their patients' medical conditions and prognoses (24, 25) and have an ethical responsibility to act in the patients' best interests (26). A recent study of homeless persons who lacked family revealed that half would want decisions regarding life-sustaining treatment to be made by their physician if they were incapacitated, and 80% would prefer a physician rather than a court-appointed guardian to make these decisions (27).

However, physicians may make widely divergent choices regarding life support when presented with the same clinical situation (28, 29). This variation seems to be related to the physicians' personal characteristics as much as to the characteristics of the patient or his or her illness (28). In addition, some physicians, like some family members (30), are poor judges of the treatments patients would choose for themselves (31). Thus, decisions made solely by the treating clinician could lead to unwarranted variation in life-support decisions for such patients.

The observed variation in hospital policies, professional society guidelines, and state laws indicates that a normative consensus for decision making does not exist for incapacitated patients. Furthermore, there currently are no empirical data on the benefits and burdens of different

approaches. Therefore, it is impossible to draw definitive conclusions about the best approach to decision making in this situation. Nonetheless, in our opinion, it seems prudent for individual physicians to involve multiple perspectives and disciplines in the decision-making process, such as with a hospital ethics committee (32).

Such an approach has many potential benefits. First, in our experience, having such a process often offers the opportunity for additional persons to provide useful suggestions for locating relatives. Second, the treating physicians would be encouraged to articulate the rationale for their decision; others could raise questions, suggestions, and counterarguments. Third, such a process would ensure that individual clinicians, who may have trained in different institutions or states, are not making decisions without knowledge of state laws or hospital policies. In these ways, the process might reduce personal bias, conflicts of interest, and misunderstandings about laws or policies. Finally, by helping to ensure that decisions are based on deliberation and defensible reasons and are consistent across similar cases, such review might also enhance public trust (32–34). Non-judicial review has been advocated by some ethicists, legal experts, and professional societies (13, 35).

The potential benefits of such an approach must be carefully weighed against the potential burdens. In some hospitals, it may not be possible to obtain prompt multidisciplinary consultation, thus subjecting patients to continuation of potentially burdensome treatments and causing frustration for clinicians (36). It also may be difficult to find persons with adequate expertise and skills to substantively improve the decision-making process (37). Furthermore, if all members of a review committee were affiliated with the hospital, there could be institutional biases or pressures (38).

Our study has several important limitations. First, because of the perceived need to protect individual physicians and institutions from legal inquiry, we have not presented detailed information about the individual institutions or the hospital-specific decision-making practices. We believe that assurance of such confidentiality and legal protection, including the federal Certificate of Confidentiality (Appendix, available at [www.annals.org](http://www.annals.org)), may have been necessary to encourage physician participation and honest responses in the study. However, it is still possible that, out of fear of professional or legal scrutiny, physicians reported decision-making practices that differ from what they actually used. Nonetheless, many physicians reported practices that differ from those advocated by professional societies or by state law, suggesting that our efforts to encourage truthful responses were effective. Second, we collected information on the number of incapacitated patients without surrogates for whom there was consideration of limiting life support but did not collect information on the total number of incapacitated patients without surrogates admitted during the study period. Third, because state laws and hospital policies vary, the results from the 7 study institutions may

**Table 4. Hospital Policies and State Laws about Forgoing Life Support in Incapacitated Patients without Surrogates or Written Advance Directives\***

Variable	Description
Hospital	
A	Either a patient advocate, appointed through the hospital's patient advocacy program, or an attending physician who is not involved in the care of the patient will function as surrogate decision maker and can authorize a DNR order or treatment withdrawal.
B	The patient's attending physician, in consultation with the rest of the patient's health care team, can make decisions based on the patient's known values or on what is thought to be in the patient's best interest.
C, D	The patient's attending physician temporarily assumes the role of the patient's surrogate decision maker. Ethics committee review is required before writing a DNR order or withdrawing treatment.
E, F	Hospital policy does not delineate how decisions should be made for patients without surrogates.
G	The attending physician can write DNR orders if a second attending physician concurs that resuscitation would be medically futile or there is clear and convincing oral evidence that the patient would not want resuscitation. The attending physician can withdraw mechanical ventilation if there is clear and convincing oral evidence that the patient would want ventilation withdrawn and the hospital ethics committee reviews and concurs with the decision.
State law	
California	None
New Hampshire	None
Oregon	Physicians may withhold or withdraw life-sustaining treatment from such patients; the physician must first consult with the case manager, if applicable (17).†
New York	Physicians may issue a DNR order if the case is medically futile and another physician agrees in writing (18). Court involvement is required for a DNR order in cases that are not medically futile. Case law holds that physicians may withhold or withdraw life-sustaining treatment only if there is clear and convincing evidence that the patient would have refused such treatment. New York courts have specifically rejected the substituted judgment approach (19, 20).
Pennsylvania	Standards for decision making for patients without surrogates are explicitly not decided (21).‡
Washington	Case law holds that a guardian must be appointed to represent the patient's interests. Life-sustaining treatment may be withdrawn without judicial involvement if "the treating physicians and prognosis committee are unanimous that life-sustaining efforts should be withheld or withdrawn and the guardian concurs." Any conflicts must be resolved by the court (22).§

\* DNR = do not resuscitate.

† Applies to patients who are terminally ill; are permanently unconscious; have "a condition in which administration of life-sustaining procedures would not benefit the patient's medical condition and would cause permanent and severe pain"; or have a condition that is unlikely to substantially improve. Also applies to patients who have a progressive illness that will be fatal and is in an advanced stage, in which the patient consistently and permanently cannot communicate by any means, swallow food and water safely, care for himself or herself, or recognize his or her family or other people and his or her condition is unlikely to substantially improve.

‡ The case addressed a patient who was in a persistent vegetative state.

§ The case addressed a patient who was decisionally incapacitated from birth and at the time of the decision had minimal brainstem activity.

not be generalizable to other institutions with different policies or laws. Nonetheless, because many decisions differed from those suggested by hospital policy and state law, it is likely that this is also an issue at other institutions. Finally, although ours is the largest study of its kind to our knowledge, the relatively small sample size precludes meaningful analysis of whether the degree of oversight recommended by hospital policy or state law was an accurate predictor of how decisions were made in clinical practice. This is an important area for future investigation.

Patients who lack decision-making capacity, surrogates, and advance directives pose ethical and practical dilemmas in intensive care units. Hospital policies, professional society guidelines, and state laws regarding how decisions should be made for these patients vary widely. In practice, most decisions are made by clinicians. Any proposed approach to decision making for these patients should be based on a clear understanding of why current state laws and hospital policies are sometimes not followed (39). Further research, careful ethical analysis, and public debate are needed to determine the relative benefits and burdens of different approaches to these difficult decisions.

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## APPENDIX: CERTIFICATE OF CONFIDENTIALITY

Some research data, if released, could place a participant at legal risk or could damage the participant's social position, em-

ployability, insurability, or financial situation. A Certificate of Confidentiality is a tool for protecting such sensitive, identifiable research data. The Certificate protects against compelled disclosure of identifiable research data in any legal proceeding, including civil, criminal, administrative, or legislative proceedings, at the federal, state, or local level. The federal government issues Certificates through such agencies as the National Institutes of Health, Centers for Disease Control and Prevention, and the Department of Justice. Researchers must apply for each project they seek to protect, but research does not need to be federally funded to be eligible for a Certificate. They are commonly used for research on substance use; sexual attitudes, preferences, and behaviors; mental illness; and genetics (40).

A Certificate does not protect against voluntary disclosures. For example, if a participant consents to disclosure of identifiable research data, a researcher may not rely on the Certificate to prevent disclosure. Similarly, a researcher may choose to disclose data on identifiable research. Many researchers, for example, may reveal such data in connection with reports of child abuse, elder abuse, serious harm to self or others, or communicable diseases (40).

There is only 1 reported legal case involving a Certificate of Confidentiality. That case, decided in 1973, involved a Certificate issued under an earlier version of the statute to a methadone clinic. A witness to a shooting in a murder case indicated that she recognized the shooter from the waiting room of the methadone clinic. Relying on the Certificate, the director of the clinic declined to comply with a subpoena to produce photographs of patients in the clinic. The court agreed that the Certificate protected the photographs from subpoena (41). There are additional reports in the literature of investigators who have been successful in protecting their data using Certificates (16).

40. National Institutes of Health, Office of Extramural Research. Certificates of confidentiality: background information. Accessed at <http://grants2.nih.gov/grants/policy/coc/background.htm> on 30 June 2005.

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