Goals and Realities
Decisionmaking Capacity and Voluntariness

Effective patient participation in health care decisionmaking rests on three foundations that correspond to the traditionally accepted elements of legally effective informed consent: decisionmaking capacity and voluntariness, which are treated in this Chapter, and information, which is discussed in Chapter Four. Throughout, the goals articulated by the Commission are compared with the realities of present practice, as evidenced by the Commission’s studies and other empirical reports.

Capacity to Make Particular Decisions

For patients to participate effectively in making decisions about their health care, they must possess the mental, emotional, and legal capacity to do so. In the Commission’s view, decisionmaking capacity is specific to a particular decision and depends not on a person’s status (such as age) or on the decision reached, but on the person’s actual functioning in situations in which a decision about health care is to be made. Some patients clearly possess such a capacity; others just as clearly lack it. In obvious instances of decisionmaking incapacity—for example, with infants and young children, the comatose, the severely mentally handicapped, and the severely mentally ill\(^1\) the responsibility of the health care professional is to recognize the incapacity and to find another way to reach a decision that will advance the patient’s goals and interests. Such alternative means of decisionmaking are discussed in Part Four of this Report.

\(^1\) This Report does not address the distinctive issues posed by consent to mental health care or consent to health care by the mentally ill, whether or not institutionalized.
In other instances, a patient’s capacity to decide on a course of treatment will be less clear-cut. Professionals may initially be uncertain of a particular patient’s decisionmaking capacity. In such cases, the situation should be evaluated over time, as care providers assess the patient’s understanding of information and reasoning about possible treatment. Efforts can also be made to enhance the patient’s capacity by counseling, providing more information, minimizing untoward effects of psychoactive drugs, and giving other forms of support. Ultimately, however, someone must decide whether the patient is capable of making a particular decision that should then have binding force.

Questions of capacity to make health care decisions may be raised from several perspectives. The law treats the issue under the heading of “competence” and generally presumes that adults can make decisions for themselves unless they have been formally judged to be incompetent. Consent granted by a competent adult normally authorizes a practitioner to provide health care, whereas consent granted by an incompetent individual is usually not legally sufficient to authorize professionals to proceed. Similarly, a competent individual’s refusal of treatment as a rule has legal effect and must be respected, but the refusal of a treatment by an incompetent patient lacks such legal effect (although it may be taken into account in deciding how to proceed).

The legal tests and standards governing determinations of incompetence are discussed elsewhere in this Report, and are not the primary concern here. Rather, the objective is to explain why the patient’s capacity to make health care decisions is important to a sound decision, and to investigate the foundations of that decisionmaking capacity.

Importance of Capacity. The doctrine of informed consent is founded on the premise that self-determination ought not be blind. That is, patients’ interests and well-being are best served when patients understand their medical situation and participate in deciding on treatment or care. This premise is to some degree an empirical proposition and to some degree a statement of faith. Insofar as the premise is an empirical one, there are clearly patients to whom it does not apply. That is to say, some patients (for a variety of reasons) are simply unable to make decisions that will advance their own interests. Following the directives of such patients can be seriously

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3 See, e.g., In re Brooks’ Estate, 32 Ill. 2d 361, 205 N.E.2d 435 (1965).
4 See pp. 169-72 infra.
5 The terms “decisionmaking capacity” and “incapacity” are being used in this discussion to avoid the sometimes confounding legal overtones associated with the terms competence and incompetence.
injurious to their well-being and may fail to respect their own long-term values and objectives.

By not applying informed consent norms to patients who are incapable of joining with professionals to decide on their health care, society seeks to enhance their well-being by protecting them from substantial harms (or loss of benefits) that could result from serious defects in their decisionmaking abilities. The Commission believes that most people would desire such protection if they lost their capacity to participate effectively in medical decisionmaking, and concludes that such societal protection of the well-being of its members is, in principle, appropriate.

Society’s protection does, however, impose certain costs—costs that become particularly clear when the action results in the countermanding or disregard of the expressed preferences of a patient deemed to lack capacity to make a particular decision. At least to some degree, such protection infringes on the patient’s ability to determine his or her own fate. Thus, a conclusion about a patient’s decisionmaking capacity necessarily reflects a balancing of two important, sometimes competing objectives: to enhance the patient’s well-being and to respect the person as a self-determining individual. Commentators have sometimes failed to recognize this balancing element, viewing “capacity” or “competence” as having intrinsic meaning apart from consideration of particular circumstances or situations. Although this view may be appropriate in some instances (with, for example, the comatose or infants and small children), the Commission believes it is inadequate in more ambiguous or troublesome instances. The Commission concludes, therefore, that determinations of incapacity to participate in medical decisionmaking should reflect the balance of possibly competing interests.

**Elements of Capacity.** In the view of the Commission, any determination of the capacity to decide on a course of treatment must relate to the individual abilities of a patient, the requirements of the task at hand, and the consequences likely to flow from the decision. Decisionmaking capacity requires, to greater or lesser degree: (1) possession of a set of values and goals; (2) the ability to communicate and to understand information; and (3) the ability to reason and to deliberate about one’s choices.

The first, a framework for comparing options, is needed if the person is to evaluate possible outcomes as good or bad. The framework, and the values that it embodies, must be

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6 At certain outer limits, an individual’s goals may be so idiosyncratic that they give rise to questions about the person’s capacity for decisionmaking. Assessment of incapacity is further explored in Chapter Eight infra.
reasonably stable; that is, the patient must be able to make reasonably consistent choices. Reliance on a patient’s decision would be difficult or impossible if the patient’s values were so unstable that the patient could not reach or adhere to a choice at least long enough for a course of therapy to be initiated with some prospect of being completed.

The second element includes the ability to give and receive information, as well as the possession of various linguistic and conceptual skills needed for at least a basic understanding of the relevant information. These abilities can be evaluated only as they relate to the task at hand and are not solely cognitive, as they ordinarily include emotive elements. To use them, a person also needs sufficient life experience to appreciate the meaning of potential alternatives: what it would probably be like to undergo various medical procedures, for example, or to live in a new way required by a medical condition or intervention.

Some critics of the doctrine of informed consent have argued that patients simply lack the ability to understand medical information relevant to decisions about their care.

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9 “[I]nformed consent may create delay, apprehension, and restrictions on the use of new techniques that will impair the progress of medicine. It is questionable whether the ‘average prudent man’ will
Indeed, some empirical studies purport to have demonstrated this by showing that the lay public often does not know the meaning of common medical terms, or by showing that, following an encounter with a physician, patients are unable to report what the physician said about their illness and treatment. Neither type of study establishes the fact that patients cannot understand. The first merely finds that they do not currently know the right definitions of some terms; the second, which usually fails to discover what the physician actually did say, rests its conclusions on an assumption that information was provided that was subsequently not understood. In the Commission’s own survey, physicians were asked: “What percentage of your patients would you say are able to understand most aspects of their treatment and condition if reasonable time and effort are devoted to explanation?” Overall, 48% of physicians reported that 90-100% of their patients could understand and an additional 34% said that 7089% could understand.

The third element of decisionmaking capacity—reasoning and deliberation—includes the ability to compare the impact of alternative outcomes on personal goals and life plans. Some
ability to employ probabilistic reasoning about uncertain outcomes is usually necessary, as well as the ability to give appropriate weight in a present decision to various future outcomes.

**Standards for Assessing Capacity.** The actual measurement of these various abilities is by no means simple. Virtually all conscious adults can perform some tasks but not others. In the context of informed consent, what is critical is a patient’s capacity to make a specific medical decision. An assessment of an individual’s capacity must consider the nature of the particular decisionmaking process in light of these developments: Does the patient possess the ability to understand the relevant facts and alternatives? Is the patient weighing the decision within a framework of values and goals? Is the patient able to reason and deliberate about this information? Can the patient give reasons for the decision, in light of the facts, the alternatives, and the impact of the decision on the patient’s own goals and values?

To be sure, a patient may possess these abilities but fail to exercise them well; that is, the decision may be the result of a mistaken understanding of the facts or a defective reasoning process. In such instances, the obligation of the professional is not to declare, on the basis of a “wrong” decision, that the patient lacks decisionmaking capacity, but rather to work with the patient toward a fuller and more accurate understanding of the facts and a sound reasoning process.

How deficient must a decisionmaking process be to justify the assessment that a patient lacks the capacity to make a particular decision? Since the assessment must balance possibly competing considerations of well-being and self-determination, the prudent course is to take into account the potential consequences of the patient’s decision. When the consequences for well-being are substantial, there is a greater need to be certain that the patient possesses the necessary level of capacity. When little turns on the decision, the level of decisionmaking capacity required may be appropriately reduced (even though the constituent elements remain the same) and less scrutiny may be required about whether the patient possesses even the reduced level of capacity. Thus a particular patient may be capable of deciding about a relatively inconsequential medication, but not about the amputation of a gangrenous limb.

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This formulation has significant implications. First, it denies that simply by expressing a preference about a treatment decision an individual demonstrates the capacity to make that decision. The “expressed preference” standard does nothing to preclude the presence of a serious defect or mistake in a patient’s reasoning process. Consequently, it cannot ensure that the patient’s expressed preference accords with the patient’s conception of future well-being. Although it gives what appears to be great deference to self-determination, the expressed preference standard may actually fail to promote the values underlying self-determination, which include the achievement of personal values and goals. For these reasons, the Commission rejects the expressed preference standard for decisions that might compromise the patient’s well-being.  

The Commission also rejects as the standard of capacity any test that looks solely to the content of the patient’s decision. Any standard based on “objectively correct” decisions would allow a health professional (or other third party) to declare that a patient lacks decisionmaking capacity whenever a decision appears “wrong,” “irrational,” or otherwise incompatible with the evaluator’s view of what is best for the patient. Use of such a standard is in sharp conflict with most of the values that support self-determination: it would take the decision away from the patient and place it with another, and it would inadequately reflect the subjective nature of each individual’s conception of what’s good. Further, its imprecision opens the door to manipulation of health care decisionmaking through selective application.

Logically, just as a patient’s disagreement with a health care professional’s recommendation does not prove a lack of decisionmaking capacity, concurrence with the recommendation would not establish the patient’s capacity. Yet, as testimony before the Commission made clear, coherent adults are seldom said to lack capacity (except, perhaps, in the mental health context) when they acquiesce in the course of treatment recommended by their physicians. (Challenges to patients’ capacity are rarer still when family members expressly concur in the decision.) This divergence between theory and reality is less significant than it might appear, however, since neither the self-determination nor the well-being of a patient would usually be advanced by insisting upon an inquiry into the patient’s decisionmaking capacity (or lack thereof) when patient, physician, and family all agree on a course of

14 Of course, extreme care must be exercised lest pronouncements of “what the patient really wants” become a cover for “what I think is best for the patient.” Properly circumscribed, however, a choice made on behalf of a patient who lacks capacity may be a truer example of one fundamental interest undergirding self-determination than following the patient’s preference would be.
treatment. Even if the course being adopted might not, in fact, best match
the patient’s long-term view of his or her own welfare, a declaration of
lack of capacity will lead to a substitute making a decision for the patient
(which means full self-determination will not occur), yet will rarely
result in a different health care decision being made (which means no
change in well-being). Substitution of a third party for an acquiescent
patient will lead to a different outcome only if the new decisionmaker
has a strong commitment to promoting previously expressed values of
the patient that differ significantly from those that guided the physician.
If, as would usually be the case, the substitute would be a family member
or other individual who would defer to the physician’s recommendation,
there would be little reason to initiate an inquiry into capacity. The
existing practice thus seems generally satisfactory. 15

Questions of patient capacity in decisionmaking typically arise only
when a patient chooses a course—often a refusal of treatment—other
than the one the health professional finds most reasonable. 16 A
practitioner’s belief that a decision is not “reasonable” is the beginning—
not the end—of an inquiry into the patient’s capacity to decide. If every
patient decision that a health professional disagreed with were grounds
for a declaration of lack of capacity, self-determination would have little
meaning. Even when disagreement occurs, an assessment of the patient’s
decisionmaking capacity begins with a presumption of such capacity.
Nonetheless, a serious disagreement about a decision with substantial
consequences for the patient’s welfare may appropriately trigger a more
careful evaluation. When that process indicates that the patient
understands the situation and is capable of reasoning soundly about it,
the patient’s choice should be accepted. When it does not, further
evaluation may be required, and in some instances a determination of
lack of capacity will be appropriate. 17

15 Plainly, this conclusion rests on practical and prudential, rather than theoretical,
considerations. A system could be instituted in which all patients facing
significant decisions receive a thorough evaluation of their decisionmaking
capacity. Those showing psychiatric morbidity that might undermine their
decisionmaking capacity could then be channeled through an alternative process
designed to protect their interests and well-being. Though this would undoubtedly
result in “better” decisions for some patients, it would impose substantial
additional costs and burdens on the health care system.
16 Loren H. Roth, Alan Meisel, and Charles W. Lidz, Tests of Competency to
Consent to Treatment, 134 AM. J. PSYCHIATRY 279 (1977).
17 The procedural and substantive standards that apply in this assessment are
discussed in Chapter Nine infra. The factors that prompt an inquiry about a
patient’s capacity are related, but not
Voluntariness in Decisionmaking

A second requirement for informed consent is that the patient’s participation in the decisionmaking process and ultimate decision regarding care must be voluntary. A choice that has been coerced, or that resulted from serious manipulation of a person’s ability to make an intelligent and informed decision, is not the person’s own free choice. This has long been recognized in law: a consent forced by threats or induced by fraud or misrepresentation is legally viewed as no consent at all.18 From the perspective of ethics, a consent that is substantially involuntary does not provide moral authorization for treatment because it does not respect the patient’s dignity and may not reflect the aims of the patient.

Of course, the facts of disease and the limited capabilities of medicine often constrict the choices available to patient and physician alike. In that sense, the condition of illness itself is sometimes spoken of as “coercive” or involuntary. But the fact that no available alternative may be desirable in itself, and that the preferred course is, at best, only the least bad among a bad lot, does not render a choice coerced in the sense employed here. No change in human behavior or institutional structure could remove this limitation. Such constraints are merely facts of life that should not be regarded as making a patient’s choice involuntary.

Voluntariness is best regarded as a matter of degree, rather than as a quality that is wholly present or absent in particular cases. Forced treatment—the embodiment of coercive, involuntary action—appears to be rare in the American health care system.19 Health care professionals do, however, make limited intrusions on voluntary choice through subtle, or even overt, manipulations of patients’ wills when they believe that patients would otherwise make incorrect decisions.

**Forced Treatment.** The most overt forms of involuntariness in health care settings involve interventions forced on patients without their consent (and sometimes over their express objection) and those based on coerced consent. Although rare

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18 See generally RESTATEMENT (SECOND) OF TORTS, American Law Institute Publishers, St. Paul, Minn. (1979) at § 892B; see also Robert E. Powell, Consent to Operative Procedures, 21 MD. L. REV 181, 203 (1961). Indeed, many of the eighteenth, nineteenth, and early twentieth century legal cases often cited as precursors of the modern doctrine of informed consent imposed liability for unauthorized medical procedures on precisely these grounds. See notes 13 to 15 in Chapter One supra.

in mainstream American health care, such situations do arise in certain special settings, and therefore require brief discussion. Society currently legitimates certain forced medical interventions to serve important social goals such as promoting the public health (with, for example, compulsory vaccination laws), enforcing the criminal law (removing bullets needed as evidence for criminal prosecutions), or otherwise promoting the well-being of others (sedating uncontrollable inmates of mental institutions on an emergency basis, for example, to protect other inmates or staff).

Although it is typically not viewed as forced treatment, a good deal of routine care in hospitals, nursing homes, and other health care settings is provided (usually by health professionals such as nurses) without explicit and voluntary consent by patients. The expectation on the part of professionals is that patients, once in such a setting, will simply go along with such routine care. However, the Commission’s study of treatment refusals found that in a hospital setting it was the routine tests that were most likely to be refused. At least some patients expected that participation was voluntary and refused tests and medications ordered without their knowledge until adequate information was provided about the nature, purpose, and risks of these undertakings. Lack of information in such cases may not only preclude voluntary participation but also raise questions about a patient’s rationality, and hence competence.

When a situation offers the patient an opportunity to refuse care, then patient compliance or acquiescence may be viewed as implicit consent. But when the tacit communication accompanying such care is that there is no choice for the patient to make, and compliance is expected and enforced (at least in the absence of vigorous objections), the treatment can be properly termed “forced.” The following conversation between a nurse and a patient regarding postoperative care, obtained in one of the Commission’s observational studies, illustrates forced treatment that follows routinely from another decision (surgery) that was made voluntarily.

Nurse: Did they mention anything about a tube through your nose?
Patient: Yes, I’m gonna have a tube in my nose.
Nurse: You’re going to have the tube down for a couple of days or longer. It depends. So you’re going to be NPO, nothing by mouth, and also you’re going to have IV fluid.

Of course, not all forced interventions that employ medical procedures in such institutions are necessarily intended to promote the well-being of others. Drawing the line between the protection of others and the abuse of inmates is a difficult task. See, e.g., Rogers v. Okin, 778 F. Supp. 1342 (D. Mass. 1979).
Patient: I know. For three or four days they told me that already. I don’t like it, though.
Nurse: You don’t have any choice.
Patient: Yes, I don’t have any choice, I know.
Nurse: Like it or not, you don’t have any choice. (laughter) After you come back, we’ll ask you to do a lot of coughing and deep breathing to exercise your lungs.
Patient: Oh, we’ll see how I feel.
Nurse: (Emphasis) No matter how you feel, you have to do that!21

The interview ended a few minutes later with the patient still disputing whether he was going to cooperate with the postoperative care.

**Coerced Treatment.** Unlike forced treatment, for which no consent is given, coerced treatment proceeds on the basis of a consent that was not freely given. As used in this sense, a patient’s decision is coerced when the person is credibly threatened by another individual, either explicitly or by implication, with unwanted and avoidable consequences unless the patient accedes to the specified course of action.22 Concern about coercion is accordingly greatest when a disproportion in power or other significant inequality between a patient and another individual lends credibility to the threat of harm and when the perceived interests of the individuals diverge.23

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21. Lidz and Meisel, supra note 19.
22. In this respect, threats should be distinguished from warnings of unpleasant occurrences that may be the natural consequences of certain decisions. A physician’s discussion of the natural history of a disease does not constitute threats, while a statement that a physician will discharge the patient from the hospital if the patient requests a second opinion (or asks too many questions, or complains excessively about hospital food) probably does. In many cases, the distinction depends on whether the professional can bring about the unwanted consequences, but this is not always true. For example, a surgeon who tells a breast cancer patient of an inability to continue in charge of her care if she rejects surgery in favor of chemotherapy or radiation is probably not issuing a threat, although in some circumstances the suggestion that a health professional would abandon a highly dependent patient if medical advice were not followed might constitute an improper and coercive threat.
23. These concerns are particularly acute in certain settings, such as so-called total institutions, where whole populations are placed in a special condition of inequality and dependency on powerful others, even for ordinary care and sustenance. Choices made in such settings are particularly subject to coercive influences, and careful scrutiny of their voluntariness is often warranted.
The disparity in power between patient and health care professional may be slight or substantial, depending on the nature of the patient’s illness, the institutional setting, the personalities of the individuals involved, and several other factors. In nonemergency settings, a patient typically can change practitioners or simply forego treatment, thus avoiding the potential for coercion. Further, although health care professionals do have interests distinct from and sometimes in conflict with those of their patients. Strong social and professional norms usually ensure that priority is accorded to patients’ welfare. To be sure, coercion can be exercised with benevolent motives if practitioner and patient differ in their assessments of how the patient’s welfare is best served. Nonetheless, there is little reason to believe that blatant forms of coercion are a problem in mainstream American health care. When isolated instances of abuse do arise, the law provides suitable remedies.

A patient’s family and other concerned persons may often play a useful role in the decisionmaking process. Sometimes, however, they may try to coerce a particular decision, either because of what they perceive to be in the patient’s best interests or because of a desire to advance their own interests. In such instances, since the health care professional’s first loyalty is to the patient, he or she should attempt to enhance the patient’s ability to make a voluntary, uncoerced decision and to overcome any coercive pressures.24

Manipulation. Blatant coercion may be of so little concern in professional-patient relationships because, as physicians so often proclaim, it is so easy for health professionals to elicit a desired decision through more subtle means. Indeed, some physicians are critical of the legal requirement for informed consent on the grounds that it must be mere window dressing since “patients will, if they trust their doctor, accede to almost any request he cares to make.”25 On some occasions, to be sure, this result can be achieved by rational persuasion, since the professional presumably has good reasons for preferring a recommended course of action. But the tone of such critics suggests they have something else in mind: an ability to package and present the facts in a way that leaves the patient with no real choice. Such conduct, capitalizing on disparities in knowledge, position, and influence, is manipulative in character and impairs the voluntariness of the patient’s choice.26

24 The role of the family is discussed in more detail in Chapter Five infra.
26 “In spite of...federal requirements that clients participating as
Manipulation has more and less extreme forms. At one end of the spectrum is behavior amounting to misrepresentation or fraud. Of particular concern in health care contexts is the withholding or distortion of information in order to affect the patient’s beliefs and decisions. The patient might not be told about alternatives to the recommended course of action, for example, or the risks or other negative characteristics of the recommended treatment might be minimized. Such behavior is justly criticized on two grounds: first, that it interferes with the patient’s voluntary choice (and thus negates consent) and, second, that it interferes with the patient’s ability to make an informed decision. At the other end of the spectrum are far more subtle instances: a professional’s careful choice of words or nuances of tone and emphasis might present the situation in a manner calculated to heighten the appeal of a particular course of action.

It is well known that the way information is presented can powerfully affect the recipient’s response to it. The tone of voice and other aspects of the practitioner’s manner of presentation can indicate whether a risk of a particular kind with a particular incidence should be considered serious. Information can be emphasized or played down without altering the content. And it can be framed in a way that affects the listener—for example, “this procedure succeeds most of the time” versus “this procedure has a 40 percent failure rate.” Health professionals who are aware of the effects of such minor variations can choose their language with care; if, during discussions with a patient, they sense any unintended or confused impressions being created, they can adjust their presentation of information accordingly.

Because many patients are often fearful and unequal to their physicians in status, knowledge, and power, they may be particularly susceptible to manipulations of this type. Health care professionals should, therefore, present information in a form that fosters understanding. Patients should be helped to understand the prognosis for their situation and the implications of different courses of treatment. The difficult distinction,

‘subjects’ in research give ‘informed consent,’ and in spite of the legal releases required for such procedures as surgery, it is my impression that clients are more often bullied than informed into consent, their resistance weakened in part by their desire for the general service if not the specific procedure, in part by the oppressive setting they find themselves in, and in part by the calculated intimidation, restriction of information, and covert threats of rejection by the professional staff itself.” Eliot Freidson, THE PROFESSION OF MEDICINE, Dodd, Mead & Co., New York (1970) at 376. See also Jon R. Waltz and Thomas W. Scheuneman, Informed Consent to Therapy, 64 NW. U. L. REV. 628, 645-46 (1970).
both in theory and in practice, is between acceptable forms of informing, discussion, and rational persuasion on the one hand, and objectionable forms of influence or manipulation on the other. Since voluntariness is one of the foundation stones of informed consent, professionals have a high ethical obligation to avoid coercion and manipulation of their patients. The law penalizes those who ignore the requirements of consent or who directly coerce it. But it can do little about subtle manipulations without incurring severe disruptions of private relationships by intrusive policing, and so the duty is best thought of primarily in ethical terms.