

CHAPTER II

THE LEGAL STATUS OF TREATMENT DIRECTIVES: AN INTERNATIONAL SURVEY

In this chapter I present the results of a survey of the legal status of treatment directives in 17 countries, including more than 90 jurisdictions. Almost all western countries where some legal development concerning treatment directives has taken place were included in the survey; a few countries where the situation is still rather underdeveloped were included for purposes of contrast with the rest. For the countries considered I identify common patterns, which allow clustering them in different groups as far as the legal status of treatment directives is concerned. I start the discussion with an analysis of the doctrine of informed consent and its legal recognition in the countries considered, since the acceptance of the principle of informed consent is a prerequisite to legal recognition of treatment directives.

1. Respect for autonomy and informed consent in the medical sphere

The principle of (respect for) autonomy is considered one of the foundational principles of western societies.¹ The situations in which the principle is considered relevant are various, from economic transactions to sexual relations. For example, under Dutch criminal law, the presence of an autonomous authorization of a potential victim to acts in areas such as sexual activities (including those involving violence) and euthanasia, makes these acts not criminal offences.²

¹ Beauchamp and Childress 1999: 120-132.

² Kelk 2001.

A direct translation of this principle in the area of health-care is the doctrine of informed consent. Generally, informed consent is seen as an absolute pre-condition of medical treatment: no treatment can be performed without the consent of the patient. In other words, doctors have no inherent prerogative to treat just because in their medical judgment treatment is indicated. Put negatively: a competent patient is entitled, for whatever reasons are important to him, to refuse any medical treatment, including treatment necessary to continued life.³ The fact that withholding consent may shorten a patient's life is not usually considered a sufficient ground for qualifying the right.⁴

The first formulation of the doctrine of informed consent appeared already at the beginning of the twentieth century,⁵ and was formulated in terms in which we now understand it in the 1950s in several decisions of US courts.⁶ The cultural background of this development was the individualistic bias of American society, in the framework of an abiding suspicion of state power and changes in the relation between doctors and patients.⁷ The doctrine quickly received international attention and in a relatively brief period achieved widespread acceptance. Nowadays, the informed consent of the patient is widely regarded as, under normal circumstances, a precondition of any medical treatment and the doctrine is accepted almost everywhere in western countries. Despite this widespread acceptance, the doctrine of informed consent has different consequences depending on the precise way it is understood. For example, the requirements of disclosure of medical information, which is one of the key elements of informed consent as we will see later, can be associated with different standards that reflect substantially different interpretation of the principle. Another point of variability concerns the weight autonomy and informed consent should have in medical decision-making, as against other principles such as beneficence and nonmaleficence.⁸

Because of different views on such matters, it is difficult to find a broadly accepted definition of informed consent. Here, I follow the position expressed in the influential book on informed consent by Faden and Beauchamp.⁹ These authors acknowledge a certain level of ambiguity about the concept of informed consent. Therefore, instead of proposing a unique definition, they make a distinction between two common but very

³ See for example Meisel 1998.

⁴ See Cantor 1993: 1, note 2.

⁵ Cardozo, J., in *Schloendorff v. New York Hospital*, 211 N.Y. 127, 129, 105 N.E. 92, 93 (1914), reported in Katz 1972.

⁶ See Faden and Beauchamp 1986: 235-273.

⁷ For US cultural background of informed consent, see Schuck 2000: 899-959, especially pages 900-901.

⁸ Beauchamp and Childress 1999: 128, 146-150.

⁹ Faden and Beauchamp 1986: 276 and following.

different conceptions of informed consent: the first, that I will label *ideal* consent, is rooted in moral theory and focuses on the idea of *autonomous* authorization; the second, labeled *effective* consent, reflects a policy-oriented perspective and deals with the cultural and policy rules that together define the requirements for effective consent.

Ideal informed consent is defined as follow: “An informed consent is an autonomous action by [...] a patient that authorizes a professional [...] to initiate a medical plan for the patient.”¹⁰ A necessary condition of the validity of the patient’s consent is proper disclosure, which entails that the patient must be properly informed about his situation, the treatment alternatives, the possible outcomes, and the effects of proposed treatment. Consent is autonomous, if the patient:

- (1) substantially understands the disclosed information;
- (2) is in a situation of substantial absence of control by others;
- (3) acts voluntarily.¹¹

If these conditions are fulfilled, but the patient withholds authorization, we can speak of *informed refusal*.

Effective informed consent refers to “a legally or institutionally *effective* authorization by a patient.” The rules that govern legally-effective exercises of the right to grant or withhold consent focus “on regulating the behavior of the *consent-seeker* and on establishing *procedures and rules* for the context of consent”.¹² Ideally, the requirements for *effective* consent should result in an autonomous authorization as defined in the *ideal* definition. But this is in practice not always straightforward, especially because several elements of the *ideal* definition remain abstract and contested, and it is difficult to translate them unambiguously into concrete requirements.¹³

The following paragraph analyses the situation concerning informed consent in several countries from the point of view of the *effective* definition: it identifies the main legal and/or institutional requirements to which informed consent is subjected.

¹⁰ *Idem*: 278.

¹¹ *Idem*: 278.

¹² *Idem*: 280.

¹³ As Schermer notes, the differences between the two conceptions makes the presentation of Faden and Beauchamp problematic: they acknowledge the distinction between the two conceptions of informed consent, but focus mostly on the moral requirements derived from the *ideal* definition without specifically discussing the practical requirements required to implement it. Schermer 2001: 47.

2. Informed consent in several countries

Some requirements concerning informed consent are common to all the countries surveyed (if we exclude Japan, where the principle is not recognized at all). In all countries, the doctrine of informed consent is qualified by the condition that the patient who expresses it must be competent and not subject by law to restrictive measures (e.g. mentally ill persons under guardianship). A minor who is competent at the time he gives or withholds consent is generally regarded as falling within the scope of the right. The most frequent solution is to identify a specific age (the lowest is 12, in the Netherlands) above which a minor patient is considered competent to express a legally binding consent or refusal.

Another important qualification of the principle concerns situations of emergency. In all the countries surveyed, if a person is in a condition threatening his life and temporarily incompetent to express consent, and no representative is available as a surrogate decision-maker, a doctor is expected to make treatment decisions in the person's best interests. This exception does not apply if the doctor knows of the patient's rejection of a particular form of treatment. The typical case of such knowledge is objection to blood transfusions for religious reasons.

Leaving aside these generally accepted qualifications, we can distinguish three groups of countries as far as implementation in law of the requirement of informed consent is concerned:

- a first group, consisting of the Anglo-American countries (USA, England, Canada, Australia, New Zealand) together with the Netherlands, Belgium, and Denmark, exhibit a relatively unqualified commitment to the requirement;
- a second group, including the other European countries (Germany, Switzerland, Austria, France, Norway, Sweden, Italy, Spain, France), accept the requirement in principle;
- a third group, of which Japan is the only example in our survey, rejects the requirement of informed consent.

In countries of the first group, the requirement of informed consent is explicitly recognized at common law and/or by statute. In the common-law countries, many judicial decisions affirm the almost absolute character of the requirement and its priority over the principle of the sanctity of life. The patient's granting or withholding of consent does not have to be grounded in rational considerations and no reasons have to be given to justify a particular choice. The right to refuse treatment is explicitly accepted even when death is the likely effect of the decision, including the situation in which this is the patient's reason for refusing consent. A doctor who performs treatment without consent is potentially liable both criminally and civilly. The three continental European countries included in this group (the Netherlands, Belgium, and

Denmark) have enacted specific statutes on patient's rights. These statutes exhibit a strong commitment to the autonomy of the patient, comparable to that seen in common-law countries. In the Netherlands and Belgium, for example, consent must in principle always be secured and a patient is presumed to be competent.

The countries belonging to the second group do recognize the requirement of informed consent, usually through official statements of national medical associations or in codes of medical ethics. In principle this recognition is more or less unqualified, but the legal status of the recognition is not entirely clear and in practice a more paternalistic approach seems to be widely accepted. The possibilities of legal enforcement are unclear.

Japan alone represents the legal situation where the requirement of informed consent is not officially recognised and medical practice is still rooted in a paternalist approach. Information concerning his condition is said rarely to be supplied to a dying patient and decisions are taken by doctors and the family in the supposed best interests of the patient.

This brief classification suggests how varied is the translation of the doctrine of informed consent into specific legal rules. Especially the difference between the first and second groups is of interest. The countries belonging to both groups subscribe to the doctrine of informed consent in some official way. However in the countries of the first group, the legal recognition of the doctrine at the level of common law or statute includes the possibility of enforcing it, at least in civil proceedings. In the countries of the second group, the possibility of enforcement is much more dubious. Despite a rather general adherence to the idea of informed consent, implementation in specific legal rules is problematic. For this reason it is often possible to speak of a 'rhetoric of informed consent', whereby the doctrine is strongly asserted in abstract declarations, while its legal status is unclear and compliance by the medical profession uncertain. My hypothesis is that this situation has an influence on the legal recognition of treatment directives in the sense that in jurisdictions where the legal status of informed consent is strong, we can expect the chance to be greater that there will be provision for the exercise of prospective autonomy.¹⁴

¹⁴ Nys 1997 comes to the same conclusion. From a bioethical perspective, applying the logic of Faden and Beauchamp to the case of treatment directives, it should be considered wrong, in jurisdictions that fully accept the requirement of informed consent, to deny a person the fundamental right to refuse treatment just because he is not capable of exercising the right at the critical time (Faden and Beauchamp 1986: 285). From their position, it follows that the situation of a set of rules requiring doctors to honor treatment directives is morally preferable to one in which such documents are not recognized.

3. Autonomy for incompetent patients: the legal status of treatment directives

The legal recognition of treatment directives is a practical answer to the question whether incompetent people can retain some autonomy in the medical sphere, despite their being currently unable to give informed consent. Since the 1970s, treatment directives have become accepted in many countries as a way in which a person who anticipates incapacity can prospectively exercise his right to informed consent. But because the legal recognition of the underlying doctrine of informed consent is a relatively recent matter in all countries, some still interpret the principle of informed consent in a restrictive or qualified way, as applicable – at least in full force – only to a competent patient with respect to a current situation.

An additional distinction concerning the legal status of treatment directives can be made on the basis of the nature of the legal rules dealing with them. The law recognising treatment directives can *require* a doctor to follow a valid one (‘must’ rules) or it can *allow* him to do so (‘may’ rules). In the latter case legal recognition protects a doctor against possible civil or penal sanction when the death of the patient is the result of following an advance directive.

Moreover, in the legal and medical literature, the possibility to appoint a representative in advance is seen as a reinforcement of the prospective autonomy of an individual, since a person selected by the author can warrant a more accurate and reliable implementation of the instructions contained in the document. Therefore, the existence of a legal provision allowing the appointment of a representative for health-care (proxy directives) will be considered as a strengthening of the legal status of treatment directives.

In the following paragraphs, we give an overview of the legal status of treatment directives in the countries surveyed. For each country considered, the legal status of treatment directives is assessed on the basis of the following elements:

- the existence of specific legislation or common-law rules recognizing treatment directives;
- the binding nature of the rules (‘must’ rather than ‘may’);
- the absence of substantial limitations on the right to give instructions in advance;
- the absence of substantial formal requirements;
- the possibility of appointing a representative for health-care decision-making.

The details for each country based on these elements are available from the author. Here I present a comprehensive table that summarizes the main results. To simplify the

discussion, I have divided the countries surveyed into three groups, depending on the strength of the legal status of treatment directives. The composition of the three groups is similar to that of the three groups identified above in connection with the recognition of the requirement of informed consent, but some adjustments are needed, as shown on Table 1 and Table 2.

Group 1 contains the Anglo-American countries (USA, England and Wales, Canada, Australia, New Zealand)¹⁵ plus the Netherlands, Denmark, Spain, and Belgium. The countries in this group are characterised by a strong legal status of treatment directives, which are recognised by statute and/or at common law.

Group 2 includes the German-speaking countries (Germany, Austria, Switzerland), Norway and Sweden. In these countries some official steps (mainly by the national medical associations) have been taken in the direction of the recognition of treatment directives and debate on the subject is currently active. But the legal status of treatment directives remains uncertain and there is no clear indication that legislation will be enacted soon.

Group 3 includes France, Italy and Japan. These countries do not (explicitly) recognize the legal validity of treatment directives and public discussion of the subject is characterised by a high degree of vagueness.

¹⁵ For USA, Canada and Australia it is not always possible to give a uniform picture of the situation due to the differences between various jurisdictions (states, provinces or territories). Where important for the discussion, these differences will be mentioned.

Table 1. Summary of the legal status of treatment directives (TD) across countries where the legal status is strong

	USA (a)	Canada (b)	Australia (b)	New Zealand	England and Wales	Netherlands	Belgium	Spain	Denmark
Acceptance of Informed consent	Strong	Strong	Strong	Strong	Strong	Strong	Strong	Dubious	Strong
Legal status of treatment directives	Strong	Strong (variable)	Strong	Strong	Strong	Strong	Strong	Strong	Strong
Coverage of legal regulation	TD and Proxy directives	TD and Proxy directives	TD and Proxy directives	TD and Proxy directives	TD and Proxy directives	TD and Proxy directives	TD and Proxy directives	TD and Proxy directives	TD and Proxy directives
Source of legal status	Statute + common law + constitutional	Statute	Statute + common law	Statute	Common law + statute (d)	Statute	Statute	Statute	Statute
Limitations	Extensive but doubtful	Medium (variable)	Extensive	None	Medium	Mild	Mild	Medium	Mild
Competent author	X	X	X		X	X	X		x
Age	Majority	Usually majority	Majority		Majority	Always over 16 12-16 if competent	Always over 16 12-16 if competent	Majority	Majority
Specific treatment excluded	Artificial feeding and hydration (c)		Palliative care		Basic care				
Condition of applicability	Terminal phase (?)		Terminal phase or current condition					Terminal illness	Terminal illness
Pregnancy	X		X		X				
Formal requirements	Extensive	Medium (variable)	Medium	Minimal	Medium	Minimal	Minimal	Minimal	Mild
Legal force accorded to treatment directives (kind of rules)	Must	Must	Must	Must	Must	Must	Must	Must	Must

(a) In USA the situation varies among the states. Table 1 gives the most common situation. Despite the variability, the federal constitutional rights of the patient afford a fairly homogenous framework in all states.

(b) In Canada and Australia the situation differs slightly between the various jurisdictions. Table 1 therefore gives only a rough picture of the situation.

(c) Only in few States, and the status of such limitation is unclear.

(d) In England the legal binding force of treatment directives has recently been recognized by statute. See following note 1, page 30.

Table 2. Summary of the legal status of treatment directives (TD) across countries where the legal status is weak or none

	Germany	Switzerland	Austria	Norway	Sweden	France	Italy	Japan
Acceptance of Informed consent	Dubious	Dubious	Dubious	Dubious	Dubious	Dubious	Dubious	Absent
Legal status of treatment directives	Weak	Weak	Weak	Weak	Weak	None	None	None
Coverage of legal regulation	Proxy directives	Proxy directives (analogy)	None	None	Proxy directives	None	None	None
Source of legal status	Medical association	Medical association	Legal literature	Legal literature	Governmental papers	None	None	None
Limitations	Not well-defined	Mild	Not defined	Not defined	Not defined	Not defined	Not defined	Not defined
Competent author	X	X						
Age		Competent minors >=14						
Binding request for treatment explicitly not included	X	X						
Specific treatment excluded		No						
Condition of applicability	Terminal illness or PVS							
Pregnancy								
Formal requirements	Minimal	Minimal	Minimal	Minimal	None	None	None	None
Legal force accorded to treatment directives (kind of rules)	May	May	May	May	May	None	None	None

Group 1: Strong legal status

In the countries belonging to this group, the legal rules designed to protect the autonomy of the patient should he become incompetent are binding on doctors: the refusal of treatment in a valid treatment directive must be respected. The following description is based on the information reported on Table 1.

The Anglo-American countries, members of a single common-law family, are easily located in this group. In most of these countries statutes also deal with treatment directives, but the common law gives a sufficient basis and may even supersede statutory limitations. In England, where the legal status of treatment directives is rather strong, until 2004 there was no statute dealing with them and the Government stated that it did not regard such a statute as desirable since the regulation at common law was considered to be sufficiently clear and had the advantage of flexibility.¹ Nonetheless, a bill providing for negative treatment directives was passed in June 2004. The act does not fundamentally change the legal status of treatment directives, although the source of legitimation became more secure.² In some provinces of Australia and Canada and in a few states of the United States, the situation is comparable to the previous situation in England, that is, there is no statutory recognition of treatment directives. Where statutes impose conditions, limitations or formal requirements, the courts often regard treatment directives not fulfilling these constraints as nevertheless binding at common law.³

As far as continental Europe is concerned, treatment directives have a particularly strong legal status in the Netherlands, Belgium, Denmark and Spain. Except for Spain, my hypothesis that there is an increasing chance of a strong legal status for treatment directives, given a strong commitment to the principle of autonomy of the patient, is confirmed. As far as Spain is concerned, the process of legal recognition presents some peculiarities. Before the enactment of a national statute, treatment directives were legally recognised at a regional level, the regional parliaments of Catalonia, Extremadura and Galicia having enacted laws that explicitly provide for both treatment directives and appointment of a representative. Legal recognition of treatment directives was strongly backed by the Catholic church, which sees in treatment directives an acceptable alternative to euthanasia.⁴ Thus the legal recognition

¹ This was in the past the position held by the Lord Chancellor's Department, *Making Decisions – The Government's Proposals for Making Decisions on Behalf of Mentally Incapacitated Adults* (1999).

² See Mental Capacity Act, June 2004, www.publications.parliament.uk/pa/cm200304/cmbills/120/2004120.htm, accessed on 6/4/2005.

³ See Cantor 1993.

⁴ The strong opposition of the Spanish church to any form of legalization of euthanasia is depicted in a recent movie of Alejandro Amenábar (*Mar adentro*, 2003), inspired by the real story of Ramon Sampedro, a Spanish quadriplegic man after an accident in his youth, who undertook a cultural and legal battle for acknowledgement of his right to die (and ultimately was helped by a friend to commit suicide).

of treatment directives has been not only a logical consequence of the recognition of a patient's right to autonomy, but sometimes also the expression of the local assertion of self-determination, and supported by local ideological concerns.

With the sole exception of Denmark, all the countries belonging to this group have also recognised the appointment of a representative for health-care decision-making, often in the same statute recognising treatment directives. In these countries the coverage of legal regulation is therefore complete. The powers of the appointed representative are generally as extensive as those of a competent patient, but his decisions are constrained if there is also a treatment directive.

The conditions of validity differ in minor ways among the various jurisdictions. In general, only a competent patient, adequately informed and free from undue pressure can make a valid treatment directive. Concerning the age of the author, statutes providing for treatment directives are sometimes more restrictive than for informed consent. Generally the author must have reached the age of majority. The doctrine of 'competent minor' holds only in New Zealand, in one province of Canada (Manitoba) and in the Netherlands. In the Netherlands, the low age limitation for informed consent apparently also holds in the case of a treatment directive: patients 12 years or older are presumed competent to make medical decisions.⁵

The degree to which a patient can express instructions in a treatment directive can be affected by a variety of limitations (see Table 1). A typical case of such limitations is represented by various states in the USA, where the three most common limitations provided for in statutes concern the medical state of the patient (a directive is only effective in the case of terminal illness or a permanent vegetative state), the treatment that can be refused (artificial nutrition and hydration sometimes being excluded or limited), and pregnancy.⁶ Despite such restrictive legislation, however, non-statutory treatment directives are usually considered by American courts to be a valid expression of the wishes of the patient and therefore binding on doctors because of the common law requirement of informed consent. Moreover, the validity conditions specified in a statute can be overruled by the constitutional 'right of privacy'. Thus references to terminal illness or permanent unconsciousness are not necessarily considered by the courts as exhausting the conditions under which a treatment directive can be valid. Similarly, restrictions on the treatment that can be refused are constitutionally dubious. The exclusion of pregnant women has been held unconstitutional, at least before the foetus is viable.⁷

⁵ However, the age of majority (18) is required to make a valid appointment of a representative; below that age the person's parents are his representatives.

⁶ Thus in some statutes, the previously written request of an incompetent pregnant woman should not be fulfilled if the consequence of such a course of action will endanger the development of the fetus.

⁷ See Meisel 1998.

A case similar to the USA is represented by Australia, where the legislation in the jurisdictions that have enacted statutes on treatment directives includes quite extensive limitations, but the appeal to common law serves to weaken the statutory limitations. In effect, once the right to consent to or refuse medical treatment in advance is recognised, it seems to be difficult for common-law legal systems to subject this right to limitations that do not apply to a competent patient in a current situation.

In some other countries belonging to the first group there are potentially serious limitations on patient autonomy. For example, in Spain the only instructions binding on doctors are those which conform to good medical practice. Clearly, if taken at face value, such a provision significantly weakens the force of the right to refuse medical treatment in advance. In Denmark a doctor is obliged to comply with a treatment directive only if the patient is terminally ill; if the patient's condition is one of serious impairment causing grave invalidity but not terminal,⁸ a treatment directive only guides but does not bind a doctor.

At the opposite end of the spectrum are New Zealand, the Netherlands and Belgium, where there are no limitations on the validity of a treatment directive, except the general requirement of identity and competence of the author. In these countries the right to express instructions in advance is extensive and unconstrained. However, in the Netherlands, an escape provision is offered: a doctor can deviate from the instructions contained in a treatment directive if he has "well-founded reasons" (in Dutch: *gegronde redenen*) to do so. A broad interpretation of this provision could undermine the force of treatment directives. However, the provision is interpreted in a restrictive way, and seems not to undermine the legal strength of treatment directives.⁹

As far as formal requirements are concerned, the differences among jurisdictions run parallel to the situation concerning limitations: on the one hand is the USA, where state statutes often impose extensive formal requirements,¹⁰ on the other hand is New Zealand, where no formal requirements are specified. There seems to be a common denominator underlying the differences: some documentation of a treatment directive (not necessarily writing) and at least one witness is generally required. Interestingly, a requirement of periodic renewal is usually not imposed, despite the common expert opinion that regular renewal is highly desirable.

⁸ E.g. dementia; more examples are described in guidelines issued by the National Health Care Directorate. See Hybel 2000.

⁹ See more details in Chapter 4, specifically dedicated to the legal situation in the Netherlands.

¹⁰ As an example of a set of formal requirements, we can refer to the West Virginia Living Will Law (1994): "A living will (...) shall be : in writing; executed by the declarant or by another person in the declarant's presence at the declarant's express direction if the declarant is physically unable to do so; dated; signed in the presence of two or more witnesses at least eighteen years of age; and signed and attested by such witnesses". This is followed by the conditions for being a valid witness. Reported in Zucker 1999: 77.

Group 2: Weak legal status

This group is characterized by a rather uncertain and weak legal status of treatment directives. Nonetheless, discussion of the issue is active and some steps toward legal recognition have been taken. In these countries, the main point of discussion concerns the binding nature of the directives. The usual position, held especially by the medical associations, is that a treatment directive gives relevant information on which a doctor can determine the presumed will of an incompetent patient, but in itself is insufficient to bind a doctor's hands. A certain degree of freedom remains, within which a doctor can decide whether the instructions given in advance by a patient should be followed or not. It is clearly accepted, on the other hand, that a doctor may legally carry out a treatment directive without fear of civil or criminal liability ('may' rule).

A common argument used in these countries against giving treatment directives binding legal force is that they are necessarily expressed in such general terms that they can hardly be decisive in a concrete situation. This can indeed be a serious problem in the implementation of treatment directives.¹¹ However, this does not seem to afford a sufficient reason for a categorical rejection of their binding force when they are clearly applicable. Moreover, considerable improvement in the interpretation of treatment directives can be obtained by coupling them with the appointment of a representative. Appointment of a representative for health-care decision-making is legally recognized in three of the five countries: in Germany by a specific law and in Switzerland and Sweden by analogy with the appointment of a representative for financial matters.¹²

The role played by the arguments against binding force differs among the countries belonging to this group. On the one hand we have Germany, Sweden and Norway, where the arguments are seen as insurmountable objections to giving treatment directives binding force and the medical associations and/or the governments concerned have officially declared that such a legal development would be undesirable. On the other hand, Switzerland and Austria seem to exhibit a more pragmatic approach and legislative change to give treatment directives binding force appears more likely.

Something more should be said about Germany, where the literature takes the position that treatment directives apply in only two cases: when the incompetent patient is in a terminal phase and treatment can only prolong the process of dying, and when a patient is in a permanent vegetative state. A treatment directive refusing treatment if the author becomes incompetent due to a disease such as Alzheimers would apparently

¹¹ See Chapter 3, paragraph 4.

¹² Despite this official recognition, in Sweden the legal status of an appointed representative is weak and the binding force of his decision is far from certain. See Westerhall 2000: 877-949.

not be considered binding, because German law emphasises the welfare and current will of the patient above prior written expressions of the patient's will. However, given the weak legal status of treatment directives, the meaning of limitations on what a patient can request in advance is unclear. This is the crucial point of difference with the countries of Group 1, where similar limitations draw the line between binding and non-binding treatment directives.

Group 3: No legal status

The countries belonging to this group do not legally recognize either treatment directives or the appointment of a representative. Together with two European countries, we find Japan in this group. The strong opposition of the medical profession may help explain the legal situation in these countries. However the situation is not uniform in the group. Japan does not recognize the principle of informed consent at all, while France and Italy do so at least in theory, and in both countries bills to recognize treatment directives have been introduced in the legislature. Recognition of the requirement of informed consent is weakened in these countries by the context of a paternalistic medical profession.

4. Summary

The question whether incompetent people have a right to respect for their autonomy has not been answered positively from a legal point of view in many of the countries surveyed. For those countries that do give legal recognition to treatment directives, formal legal support for the doctrine of informed consent seems almost always to be a prerequisite. For countries where informed consent has a weaker legal status (mostly through being mentioned in ethical codes of the medical profession), the legal status of treatment directives is, at best, weak.

Even in the countries with strong legal status of treatment directives, several differences exist in the translation of the principle of autonomy into actual rules. In some countries, like New Zealand, the right to express informed refusal in advance is almost unconditional: there are no constraints on the contents of a treatment directive and such a document is binding on care-givers. In other countries, a number of limitations and formal requirements are imposed on valid treatment directives.

The next step in my research will be to evaluate how such legal arrangements work in practice. This will be done in the following chapter, analysing the existent empirical literature on the subject. In the second part of the book (chapters 5 to 8), I will report on the results of my surveys on the working of treatment directives in the Netherlands.