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**The previously expressed wishes relating to health care
Common principles and differing rules in
national legal systems**

**Report to the Council of Europe based on the 18-22 June 2008
“Exploratory Workshop on Advance Directives” organized by the
Institute of Biomedical Ethics of the University of Zurich with the
support of the European Science Foundation (ESF)**

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1. Introduction

The Institute of Biomedical Ethics of the University of Zurich convened between 18 and 22 June 2008 an “Exploratory Workshop on Advance Directives” with participants from 19 European countries and one from the USA.¹ This event was financed with the support of the European Science Foundation (ESF), the Research Priority Program Ethics (*Universitärer Forschungsschwerpunkt Ethik*) of the University of Zurich, and <http://www.esf.org/activities/exploratory-workshops/medical-sciences-emrc.html> the Swiss National Science Foundation (SNF/FNS). The convenors of the Workshop were Susanne Brauer, PhD, Prof. Nikola Biller-Andorno, and Dr. Roberto Andorno.²

The aim of the Zurich Workshop was to bring together experts from different disciplines (mainly law, medicine, and ethics) related to advance directives to present the role and legal efficacy of such documents in their respective countries, to identify the most pressing concerns in this field, and to explore the opportunity and the possibility of reaching a greater consensus on this issue across Europe.³

The topic is becoming increasingly important for two main reasons. First, the growing value attached to patient autonomy in health care decision making, which goes in parallel with the rejection of the medical paternalism that dominated the doctor-patient relationship until the 1970's. Second, the extraordinary advancements in clinical treatment and in life-sustaining technologies, which may allow physical survival for years, but which, in some circumstances, could be no longer of real benefit for the patient, and becoming futile.

Respect for patient autonomy, which is crucial in modern medical ethics and law, embodies in the requirement of informed consent for any medical intervention.⁴ This certainly includes the possibility for patients to refuse what they may regard as disproportionate or futile treatment, that is, when its burden outweighs any benefit. But what about those patients who cannot give (or refuse) consent because of physical or mental incapacity? Who shall decide for them? The physician? The family? What if family members disagree about treatments to be provided or withheld? What if doctors and patient's relatives have different views on what is best for the patient?

¹ The 19 European countries represented at the Workshop were: Austria, Belgium, Bulgaria, Finland, France, Germany, Greece, Hungary, Italy, Lithuania, The Netherlands, Norway, Portugal, Serbia, Slovakia, Spain, Switzerland, Turkey, and United Kingdom.

² The Country Reports is available online at: http://www.ethik.uzh.ch/ibme/news/advance-directives/Country_Reports_AD.pdf

³ The expression “advance directives” is used in this report as synonymism with “advance declarations”, “advance decisions”, “previously expressed wishes concerning medical treatment”, and other similar terms, and does not necessarily presuppose the *binding* legal status of such documents.

⁴ See the general rule provided by the Council of Europe's Convention on Human Rights and Biomedicine, which states that “an intervention in the health field may only be carried out after the person concerned has given free and informed consent to it” (Article 5).

Here is where advance health care directives come in. These can take two different forms, which are not necessarily exclusive of each other, but can be complementary:

a) The *living wills*, which are written documents designed to allow people to express their preferences regarding the provision –or the withholding– of specified treatments, and to avoid confusion later on, in the event that they become unable to make decisions in the future. Although living wills are usually designed to *refuse* treatments, they can also be used to express the wish of *receiving* some treatments (for instance, artificial nutrition and hydration).⁵

b) The *power of attorney for health care*, which allow individuals to appoint someone (for example a trusted relative or friend) to make health care decisions on their behalf once they lose the ability to do so. The power of attorney has the significant advantage of providing a way –a personal voice– for clarifying the patient’s preferences when they have been formulated in ambiguous terms in a living will, as well as for dealing with unexpected developments that have not been specifically addressed by the patient.

What is the real use of advance health care documents in current medical practice? Interestingly, while they are legally accepted and widely recognized in the clinical practice of the United States, in most European countries it is still unusual to base clinical decisions on patient’s previously expressed wishes. This explains why, from a legal point of view, the validity of advance directives still remains unclear in many European states, which are just beginning to recognize the potential utility of advance decisions and to legislate on this matter.

At present, the only European legal framework on this issue is provided by Article 9 of the Council of Europe’s Convention on Human Rights and Biomedicine (“Oviedo Convention”) of 1997. According to it,

“[t]he previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes *shall be taken into account.*”

This norm is of great importance as it embodies the first significant effort made by European institutions to set up a binding legal framework relating to advance health care documents. However, it is not without some shortcomings. First, it has been drafted having in mind only one of the forms that advance directives may take (a living will), but ignoring the other one (the health care power of attorney). Second, it remains highly vague on the legal effect of such documents, as several scholars have pointed out.⁶ Article 9’s statement according to which previously expressed wishes “shall be taken into account” (in French: “seront pris en compte”) is particularly problematic. This seems to indicate that advance directives should have, *at least*, an advisory effect. It other

⁵ This could be important, for instance, in countries where it is not legally mandatory to continue artificial nutrition and hydration in patients in persistent vegetative state, and the individual would like to ensure that, if he/she is diagnosed with such a condition, those life-sustaining treatments will not be withdrawn.

⁶ See for instance: Dominique Manaï, “Images du droit du patient au miroir de la Convention européenne pour les droits de l’homme et la biomédecine”, in: Franz Werro (ed.), *L’européanisation du droit privé? Vers un code civil européen?*, Fribourg, Editions Universitaires de Fribourg, 1998, p. 120; Hans-Ludwig Schreiber, “The European Ethical Convention: Legal Aspects”, in: Alfred Schauer, Hans L. Schreiber and Zdzislaw Ryn (eds.), *Ethics in Medicine*, Göttingen, Vandenhoeck & Ruprecht, 2001, p. 247; Gilbert Hottois, “A Philosophical and Critical Analysis of the European Convention of Bioethics”, *Journal of Medicine and Philosophy*, 2000, n°2, p. 139.

words, European countries are not required to assign to these documents a legally *binding* status. But this provision fails to provide any clear guidance as to what extent, or under what conditions, advance directives must be really “taken into account”. Because if health care professionals can freely decide, without any clear reason, to not comply with patients preferences, one may wonder what the real utility of drafting such documents is.

The Explanatory Report to the Convention does not resolve the ambiguity of Article 9. It only states that the expression “taken into account” “does not mean that previously expressed wishes should necessarily be followed” and provides two examples to illustrate why in some circumstances the practitioner may have good reasons not to follow the patient wishes on the grounds that they do not apply anymore to the situation at hand: a) when they have been expressed a long time before the intervention; b) when medical technology has made significant progress since the time where the advance directive was signed and it can be reasonably assumed that, in the present circumstances, the will of the patient would have been different.⁷

This gives the impression that, in the mind of the Convention’s drafters, doctors cannot act arbitrarily, i.e., they need to have *good reasons* to disregard the patient’s legitimate wishes expressed in an advance directive. The problem is that this basic principle has not been explicitly stated in the Convention itself, nor there is any indication as to what reasons can be validly given by health care professionals for not complying with the patient’s explicit will. Some of the countries having in recent years introduced specific legislation on this matter take care of addressing this fundamental point.

The key issue is whether it would be possible -and desirable- to elaborate common European standards (for instance, to be included in an additional protocol to the Oviedo Convention) addressing the two following questions:

- *What are the minimal formal requirements for the validity of an advance directive?* For example: the individual’s legal capacity and freedom of choice at the time of its making; his/her incompetence at the time of its implementation; absence of revocation in the meantime; the need of a previous consultation with a health care professional, etc.
- *What should be the legal effect of advance directives?* In other words, what does the expression “taken into account” used by the Oviedo Convention mean in legal terms? This is equivalent to ask: what *reasons* could health care professional legitimately give for not complying with patients’ preferences? Among the reasons given by some domestic law to allow doctors to disregard advance directives are the following: that the patient’s will is contrary to law; that the document was written too many years before its implementation; that there have been significant advances in medical sciences that are relevant to the advance directive in question; that there are some other good reasons from which it might be inferred that the patient would have a different view had he/she had adequate knowledge of the current circumstances, etc.

⁷ Explanatory Report to the Convention on Human Rights and Biomedicine, paragraph 62.

2. An overview of the legal status of advance health care decisions in Europe

At present, the legal status of advance directives in the national legislation of European states is very disparate. However, as it will be indicated below, several countries show a clear trend towards a greater recognition of the value of patients' previously expressed wishes. Currently, four groups of countries can be distinguished:⁸

a) Countries where specific laws on the issue have been adopted assigning binding force to previously expressed wishes (UK, Austria, Spain, Hungary, Belgium, The Netherlands, Finland);

b) Countries where specific laws on the issue have been adopted in recent years, but without assigning binding force to such documents (France);

c) Countries where there is no specific legislation yet, but which are planning to introduce it in the next few years in order to attach to AD a binding effect (Germany, Switzerland);

d) Countries where there is no specific legislation yet and which do not have any concrete plans to introduce it in the coming years (Norway, Italy, Portugal, Greece, Turkey, Serbia, Slovakia, Bulgaria, Lithuania).

The following pages are intended to offer a brief overview of the role and validity of advance directives in the above mentioned countries.

a) Strong legal status of advance directives

United Kingdom⁹

The *Mental Capacity Act* of 2005, which entered into force on 1st October 2007, allows every competent adult to make advance decisions relating to medical treatments. Such decisions need not be in writing, unless life sustaining treatment is refused, in which case it must be in writing, witnessed and signed, and include an explicit, signed statement indicating that the refusal applies "even if life is at risk" (Section 25.5).¹⁰ The refusal can extend to artificial nutrition and hydration (ANH), but not to "basic or essential care" (warmth, shelter, hygiene measures, and the offer of oral food and water).¹¹

An advance refusal is legally binding in the sense that it is as valid as a contemporaneous refusal made by a competent patient (Section 26.1). On the contrary, advance *requests for treatment* are not strictly binding, although they

⁸ It should be noted that this report is not exhaustive in the sense that it is limited to a review of the legal status of advance directives in those countries that have been represented by an expert at the Zurich Workshop.

⁹ The following information only relates to the specific legal situation in the jurisdiction of England and Wales (Scotland has a different legal system).

¹⁰ It is interesting to note that whether a treatment falls into the category of a "life-sustaining" one will sometimes depend on the circumstances. For example, in some situations, the provision of antibiotics may be life-sustaining, but in others they can be used to treat conditions that do not threaten life. See Code of Practice for the Mental Capacity Act (Section 9.25). Available online at: <http://www.justice.gov.uk/docs/mca-cp-plain2.pdf>

¹¹ See Code of Practice for the Mental Capacity Act: "An advance decision cannot refuse actions that are needed to keep a person comfortable (sometimes called basic or essential care). Examples include warmth, shelter, actions to keep a person clean and the offer of food and water by mouth" (Section 9.28).

may help guide health care professionals in determining what is in the best interests of the patient.

Importantly, to be valid, an advance refusal should be applicable to the situation that has now arisen, i.e. where there are no “reasonable grounds for believing that circumstances exist which the person did not anticipate and which would have affected his decision had he anticipated them” (Section 25.4.c). More generally, an advance decision cannot require health care providers to act contrary to the law and therefore, for instance, an advance request for euthanasia would be invalid.

The *Mental Capacity Act* also allows for the appointment of a health care proxy, known as “lasting power of attorney” (Sections 9 to 14). Through this instrument, individuals can empower a person of their choice to make health care decisions on their behalf, should they lose the capacity to decide by themselves. The donee of the power of attorney can give or refuse consent to life-sustaining treatment, but only if this is explicitly stated in the instrument of authorisation (Section 11.8). In any case, the attorney is required to make decisions in the best interests of the patient (Section 1.5).¹²

Austria

The Austrian Law on Advance Directives (*Patientenverfügungsgesetz*), which entered into force on 1st June 2006, enables patients to make a living will which is *binding* for physicians if certain criteria are met: a) A previous consultation with a physician has taken place in order to be comprehensively informed about the nature and consequences of the living will; b) The document was drafted in the presence of a lawyer, a notary, or a legally trained associate of the patient advocacies; c) The treatments that are refused are described in precise terms; d) The living will has not been drafted more than 5 years before its implementation.¹³ If one or more of these conditions are not met, the living will is not binding. However, the more they are fulfilled, the more the living will must be taken into account by physicians.¹⁴

The binding nature of the living will is however not absolute, because according to Article 10, the document is considered invalid if: a) There has been “an essential change” of medical sciences relating to the content of the document since the time it has been drawn up; b) Its content is contrary to the law (for instance, a request for active euthanasia, or the rejection of the basic provision of liquid and food by natural means, which are considered “care measures”, and not medical treatments).¹⁵

¹² The law sets out a very detailed checklist for determining what is in a patient's best interests (Article 4).

¹³ See the full text of the Law on Advance Directives (in English) at: http://www.patientenanwalt.com/pdf/FEDERAL_LAW_GAZETTE.pdf

¹⁴ In addition to this, it should be mentioned that since 1 July 2007, patients are allowed to give a power of attorney for health care matters (new Article 284f of the Civil Code).

¹⁵ Maria Kletecka-Pulker, “Grundzüge und Zielsetzungen des Patientenverfügungsgesetzes”, in: Ulrich H.J. Körtner, Christian Kopetzki, Maria Kletecka-Pulker (eds.), *Das österreichische Patientenverfügungsgesetz. Ethische und rechtliche Aspekte*, Vienna, Springer, 2007, p. 82.

Spain

Advance directives are regulated in Spain by Law n° 41/2002 on Patient's Autonomy and on the Rights and Obligations Concerning Health Information (*Ley básica reguladora de la autonomía del paciente y de derechos y obligaciones en materia de información y documentación clínica*), adopted on 14 November 2002.¹⁶ Article 11 of the Law, which deals specifically with the so-called “previous instructions” (*instrucciones previas*), provides that health care services must establish adequate procedures “to guarantee that the previous instructions are complied with”. However, to be valid, advance directives must be in written form and not being contrary either to the law (for instance, a request for active euthanasia) or to good clinical practice (*lex artis*). In addition, the factual circumstances at the time of their implementation must correspond with the ones that the patient had envisaged at the time of drafting the document.

The law also allows, as a complement to the living will, the designation of a health care proxy (*representante*), who will act on behalf of the patient as interlocutor with the health care professionals, in order to endeavour to ensure that the patient's preferences are complied with.

An originality of the Spanish law is the creation of a National Registry for Advance Directives so as to guarantee nationwide efficacy of such documents. At present, each Autonomous Region has, or is on the way to having, an official registry where citizens can register their advance directives. One of the main tasks of the National Registry will be precisely that of setting up a coordination mechanism between the Registries of each Autonomous Region via informatic tools.¹⁷

Belgium

Advance directives are regulated in Belgium by two laws: the Act on Patients Rights of 22 August 2002,¹⁸ and the Act on Euthanasia of 28 May 2002.¹⁹ According to the former, the patient has the right to refuse treatments in advance. Such refusal, which have to be in written form, “must be respected by the health care professional as long as it has not been revoked by the patient” (Art. 8.4). The Explanatory Report states that the advance directive has in principle the same binding effect as a currently expressed refusal. In order to be binding, two conditions should however be met: a) It must apply to a “well-defined medical service”, which means that a refusal formulated in vague terms would not be binding; b) There should be no doubt that the document really comes from the patient.

The Act on Euthanasia allows individuals to include a request for euthanasia through an advance directive insofar as some conditions are fulfilled: the patient suffers from a serious or incurable disorder; he/she is no longer conscious; and

¹⁶ See the full text of the Law N° 41/2002 (in Spanish) at: http://www.isciii.es/htdocs/terapia/legislacion/Terapia_Ley_41_2002.pdf

¹⁷ Pablo Simón Lorda, María Isabel Tamayo Velázquez, Inés María Barrio Cantalejo, “Advance directives in Spain. Perspectives from a medical bioethicist approach”, *Bioethics*, 2008, vol. 22, n°6, p. 346-354.

¹⁸ See the full text of the Law on Patients Rights (in French) at: <http://www.health.fgov.be/EMDMI/fr/legislation/loi-droitsPatient.htm>

¹⁹ See the text of the Law on Euthanasia and Assisted Suicide (in English) at: <http://www.kuleuven.ac.be/cbmer/viewpic.php?LAN=E&TABLE=DOCS&ID=23>

the condition is irreversible (Art. 4). Such advance directives are however non binding, which means that no physician could be obliged to perform euthanasia (Art. 14).²⁰

The Act on Patients' Rights also enables individuals to appoint a proxy decision maker (the so-called "patient-designated representative", in French: "mandataire désigné par le patient") to act on behalf of the patient (Art. 14).

The Netherlands

Similarly to Belgium, also The Netherlands allow the use of advance directives both for refusal of treatments and for euthanasia. Advance treatment refusals have been attached legally binding effect since 1995, when some provisions of the Civil Code were modified by the Medical Treatment Contract Act (*Wet op de Geneeskundige Behandelingsovereenkomst, WGBO*).²¹ Article 450.3 of the Civil Code provides that a competent patient can refuse treatments in advance through a written statement. However, the health care provider is authorized not to comply with the patient instructions "if he deems that there are good reasons for so doing." As the law does not indicate what reasons could be legitimately given by the physician, the experts discuss how this exception is to be interpreted.²²

The Law on Euthanasia and Assisted Suicide (*Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*), adopted in 2001 and which entered into force on 1 April 2002, allows people to make a written declaration requesting that their life be terminated in the event they will not be able to make such a request in the future, insofar as the legal requirements for the practice of euthanasia are fulfilled (Art. 2.2).²³ This kind of living will is however non-binding, which means that it is not mandatory for any physician to perform an euthanasia. The possibility of making advance directives for euthanasia has been criticized by some experts on the grounds that such a request is neither feasible nor ethically justifiable, since doctors cannot at the same time perform an euthanasia and fulfill the duty of "due care" imposed by the law.²⁴ In practice, a case of euthanasia based on an advance directive has never been reported to the authorities.²⁵

Hungary

According to the Health Care Act of 1997, every competent person can make a written statement before a notary public in order to refuse specified medical

²⁰ The practice of euthanasia following an advance directive remains very rare and represents no more than 2% of all cases of euthanasia. See: Chris Gastmans, "Belgium" in: S. Brauer, N. Biller-Andorno, R. Andorno (eds.), *Country Reports on Advance Directives*, ESF- Exploratory Workshop on Advance Directives, Zurich, 18-22 June 2008, p. 17. Available online at: http://www.ethik.uzh.ch/ibme/news/advance-directives/Country_Reports_AD.pdf

²¹ See the full text of the Medical Treatment Contract Act (in English) at: <http://www.healthlaw.nl/wgboeng.html>

²² See Mette Rurup, "The Netherlands", in: S. Brauer, N. Biller-Andorno, R. Andorno (eds.), *Country Reports on Advance Directives*, op. cit., p. 55.

²³ See the full text of the Dutch Law on Euthanasia and Assisted Suicide at: http://www.healthlaw.nl/eutha_e.html

²⁴ Johannes J.M. van Delden, "The unfeasibility of requests for euthanasia in advance directives", *Journal of Medical Ethics*, 2004, vol. 30, p. 447-451.

²⁵ See: Mette Rurup, op. cit., p. 53.

treatments (Art. 22.1).²⁶ This is interpreted by legal scholars as meaning that the advance directives are legally binding.²⁷ The refusal may include life-supporting or life-saving interventions if the patient has an incurable disease and, as a consequence of it, is unable to care for himself or herself, or suffers pain that cannot be relieved with appropriate therapy (ibid.). For an advance directive to be valid, it must be accompanied by a written statement made by a board-certified psychiatrist indicating that the person made the decision in full awareness of its consequences (Art. 22.3).

If the advance directive is to refuse life-supporting or life-saving treatments, a three-member committee of physicians should examine the patient to verify that the conditions specified by the law are fulfilled (in particular, that the patient suffers from an incurable disease leading to death in a short period of time).²⁸ In addition, the advance directive should have been made (or renewed) no more than two years before its implementation (ibid.).

The 1997 Act also allows individuals to appoint a health care proxy who will act on behalf of them in the event they become unable to decide by themselves (Art. 22.2). However, the rules governing the decision-making process in such a situation are not specified in the law.

Finland

Advance directives are, in principle, legally binding. According to Article 8 of the Act on the Status and Rights of Patients of 1992, "if a patient has steadfastly and competently expressed his/her will concerning treatment given to him/her, he/she must not be given a treatment that is against his/her will".²⁹ The patient has the right to refuse any, even life sustaining treatment. However, there seems to be consensus that the health care professional is not obliged to comply with the advance directive if there are reasons to believe that the patient's will has changed since completing the living will.³⁰

There are no formalities for making advance directives, but they should be recorded in the patient's medical file. There is no maximum time limit for their validity.

An amendment made in 1999 to Article 6 of the law allows the designation of a health care proxy, who should act in conformity with the patient's will. If no wishes have been expressed by the patient, he/she should be treated "in accordance with his or her best interests" (ibid.).

²⁶ See the full text of the Health Care Act of 1997 (in English) at: http://www.szozolo.hu/53/rights_and_obligations_of_patients.htm

²⁷ See Judit Sandor, "Hungary", in: S. Brauer, N. Biller-Andorno, R. Andorno (eds.), *Country Reports on Advance Directives*, op. cit., p. 41.

²⁸ The governmental decree N° 117/1998 provides more detailed rules regarding the tasks of the three-member committee.

²⁹ See the full text of the 1992 Law with the 1999 amendments (in English) at: <http://www.finlex.fi/en/laki/kaannokset/1992/en19920785.pdf>

³⁰ See Pekka Louhiala, "Finland", in: S. Brauer, N. Biller-Andorno, R. Andorno (eds.), *Country Reports on Advance Directives*, op. cit., p. 25.

b) Weak legal status of advance directives

France

Advance directives (*directives anticipées*) are regulated by Law N° 2005-370 of 22 April 2005 relating to patients rights and end of life issues (*Loi relative aux droits des malades et à la fin de vie*).³¹ According to the Law, advance directives expressing the patient's wishes relating to the withdrawing or withholding of treatments "must be taken into account by the doctor" (Art. 1111-11 of the Public Health Code). They are therefore merely advisory, not binding. This means that advance directives are "an element among others of the medical decision".³² However, they must necessarily "be consulted" before a decision relating to the withdrawing or withholding of treatments (Art. 1111-13 of the Public Health Code). The time limit of validity of advance directives is three years. After that period, they should be renewed. They can be revoked at any time (Art. 1111-11 of the Public Health Code).

The Law N° 2002-303 of 4 March 2002 relating to the patients' rights and the quality of the health system (*Loi relative aux droits des malades et à la qualité du système de santé*) enables individuals to appoint a "trustworthy person" (*personne de confiance*) as a health care proxy, who must be consulted about the decision to be taken in case the patient becomes unable to decide by him- or herself (Art. 1111-6 of the Public Health Code).

c) No legal status of advance directives yet, but with immediate plans to put it in place

Germany

The right of every individual to decide in advance about medical treatments in the event that he or she will not be able to make decisions in the future is recognized by the German jurisprudence and by legal scholars as an expression of the right to self-determination regarding one's own body which can be derived from various provisions of the Constitution (*Grundgesetz*).³³ Nevertheless, since no specific legislation on advance directives exists yet, there are uncertainties about the degree of bindingness, scope and limits of such documents.

The German Parliament is currently discussing three draft bills on the matter and is expected to come with a law by 2009. One of the bills restricts the use of advance directives to patients with an irreversible terminal condition or suffering from an irreversible loss of consciousness. It also stipulates a mandatory consultation between the physician, the guardian or attorney, and the patient's closest relatives before any decision concerning withdrawing or withholding treatment is made. The two other bills recognize a broader scope to advance directives, which are not restricted to certain diseases or medical conditions. These latter require however court approval for limiting or withdrawing life-

³¹ See the full text of the Law (in French) at: <http://www.senat.fr/dossierleg/pp104-090.html>

³² Frédérique Dreifuss-Netter, "Les directives anticipées : de l'autonomie de la volonté à l'autonomie de la personne", *Gazette du Palais*, 9-10 juin 2006, Doct., p. 1693-1695.

³³ In particular, Articles 1.1 (human dignity), 2.1 (right to the free development of one's personality), and 2.2 (right to physical integrity and personal freedom).

sustaining treatments when there is disagreement between the doctor and the patient's representative. In spite of these differences, all three bills agree in attaching a binding force to advance directives and in allowing the appointment of a health care proxy.³⁴ Similarly, the German National Ethics Council (*Nationaler Ethikrat*) has expressed the opinion that a specific law on advance directives is needed in order to clarify the scope of such documents and that they should have legally binding character.³⁵

Switzerland

Because of the very decentralized political system of Switzerland and the extensive competencies assigned to cantons (which in principle include health-policy issues), there is no specific federal legislation relating to advance directives yet. While some cantons have already adopted laws on this matter attaching binding force to advance directives, others do not even mention them in their local regulations.³⁶ Therefore, at present, unless there is a specific cantonal law recognizing that advance directives are legally binding, such documents are merely regarded as the *starting point to determine the presumed will of the patient*³⁷

Nevertheless, the Parliament is currently preparing a reform of the Civil Code (future Articles 370 to 373) in order to explicitly recognize, at the federal level, the right of every competent individual to make advance health care directives (*directives anticipées; Patientenverfügungen*). The directives should be in written form, dated and signed. The reform is expected to come into effect in 2010. According to the draft bill under discussion, the physician “must respect” advance directives (future Art. 372.2). However, they are no valid if: a) they are contrary to the law; b) there are serious doubts that they still reflect the patient’s free will, or his/her presumed will in the particular circumstances (future Article 372.2). Individuals are also enabled by the law to appoint a health care proxy, who will act on behalf of them in case they become unable to make decisions by themselves (Art. 370.2).³⁸

³⁴ Ralf J. Jox, Sabine Michalowski, Jorn Lorenz, and Jan Schildmann, “Substitute decision making in medicine: comparative analysis of the ethico-legal discourse in England and Germany”, *Medicine, Health Care and Philosophy*, 2008, vol. 11, n° 2, p. 153-163.

³⁵ Nationaler Ethikrat, *The advance directive. An instrument of self-determination*, Berlin, 2005. Available at: http://www.ethikrat.org/_english/publications/opinions.html

³⁶ For instance, the Patients’ Law (*Patientinnen- und Patientengesetz*) of the Canton of Zurich provides that advance directives “must be respected, except when they are contrary to the law or there are reasons to believe that the patient has in the meantime changed his/her mind” (Art. 32); the Health Law of the Canton of Neuchâtel provides that “health care professionals must respect advance directives” (Art. 25a.3).

³⁷ Thomas Gächter and Irene Vollenweider, *Gesundheitsrecht. Ein Kurzlehrbuch*, Basel, Helbing Lichtenhahn Verlag, 2008, p. 159.

³⁸ See the draft bill (in French) at: <http://www.admin.ch/ch/f/ff/2006/6767.pdf>

d) No legal status of advance directives, without any immediate plans to put it in place

Portugal

Portugal has already ratified the European Convention of Human Rights and Biomedicine (Oviedo Convention). Therefore, Article 9 of the Convention relating to advance directives has become part of the domestic law. Nevertheless, no specific legislation on the matter has been adopted yet, and there are no concrete plans to introduce it in the next few years.

Legal scholars point out that, at present, “there is nothing to prevent a person making what is called a Living Will; on the other hand, appointing a proxy to take care of health issues could, by analogy, be framed within the civil discipline of the institution of power of attorney”.³⁹ However, the efficacy of such documents is unclear. For some authors, physicians should *prima facie* respect advance directives, while others think that they have a merely advisory value.⁴⁰

Italy

In 2001, the Italian Parliament ratified the Oviedo Convention. Nevertheless, as the Government did not formally submit the ratification instrument to the Council of Europe, the Convention’s entry into force in Italy is still pending. Certainly, people can *de facto* make advance directives. However, such documents are not considered to be legally binding, or to have any serious legal effect. Nor it is possible to appoint a health care proxy: if a patient becomes incompetent, health care decisions will be taken by relatives, even if they disagree with the personal preferences of the patient.⁴¹

In 2003, the Italian National Bioethics Commission expressed the opinion that there are no objections of principle against advance directives, and that a specific law on the matter is desirable. The Committee rejects a strict bindingness of advance directives, but at the same time insists that, in case health care professionals decide not to comply with patients’ preferences, they are obliged to give adequate reasons for their decisions.⁴²

Turkey

As Turkey has ratified the Oviedo Convention, Article 9 on previously expressed wishes relating to health care has already entered into force in the country. However, in the absence of any specific law regulating the issue, there is great uncertainty about the legal efficacy, scope and limits of such documents. In any case, the use of advance directives in the medical practice is practically non-

³⁹ André Dias Pereira, “Country Report Portugal”, in Jochen Taupitz (ed.), *The Convention on Human Rights and Biomedicine of the Council of Europe – a Suitable Model for World-Wide Regulation?*, Berlin, Springer, 2002, p. 712.

⁴⁰ See Herman Nys, Sarah Defloor, Kris Dierickx, Tom Goffin, “Patient Rights in the EU: Portugal”, *European Ethical-Legal Papers*, N° 13, Leuven, Center for Biomedical Ethics and Law, 2008, p. 15.

⁴¹ See Fabrizio Turollo, “Italy”, in: S. Brauer, N. Biller-Andorno, R. Andorno (eds.), *Country Reports on Advance Directives*, op. cit., p. 45.

⁴² Comitato Nazionale per la Bioetica, *Direttive anticipate di trattamento*, 18 December 2003. Available online (in English) at: <http://www.governo.it/bioetica/eng/opinions.html>

existent because of the strong paternalism that dominates the doctor-patient relationship.⁴³

Norway

Although the Norwegian Law on Patients' Rights of 1999 allows "dying patients" (sic) to refuse life-prolonging treatments (Section 4-9), nothing is said about the possibility of expressing such refusal in advance in anticipation of the possibility that one may become unable to make such decision in the future.⁴⁴ According to the same legal provision, if the patient is unable to communicate his or her wishes, the health care professional "shall refrain from providing health care if the patient's next of kin express similar wishes *and* if they find that this is also the patient's wish and that the wish should clearly be respected." Therefore, when the patient is unable to express his or her preferences regarding treatment, the priority is given to the wish of family members. This is why advance directives are not regarded as having legally binding effect. This also explains why the use of advance directives in medical practice is very rare.⁴⁵

Bulgaria

Bulgaria has ratified the Oviedo Convention and passed a Health Act in 2005. However, the 2005 Law does not include any specific provisions relating to advance directives.⁴⁶ In addition to this, as some scholars point out, beyond the formal requirement of informed consent for any medical treatment, the fact is that the doctor-patient relationship is dominated by "a long-standing culture and tradition of medical paternalism. (...) Physicians do not routinely discuss treatment options with patients."⁴⁷

Serbia

There is no law in Serbia enabling people to make living wills. The Health Care Law of 2005 acknowledges the patient's right to refuse treatments, even those that are life-saving or life-sustaining (Art. 33.1). It also allows the designation of a health care proxy (Art. 32.4). But it does not specify who may be a proxy, how he/she can be appointed, and, most importantly, if the health care proxy can make decisions regarding withdrawing or withholding life sustaining treatments.⁴⁸ Serbia has signed but not ratified the Oviedo Convention.

Greece

In Greece, the only relevant legal provision regarding advance directives is Article 9 of the Oviedo Convention, which was already ratified by the country in 1998. In 1997, a Law on health care was passed that includes important

⁴³ See Tolga Guven, "Turkey", in: S. Brauer, N. Biller-Andorno, R. Andorno (eds.), *Country Reports on Advance Directives*, op. cit., p. 93-96.

⁴⁴ See the full text of the Norwegian Patients' Rights Act (in English) at: <http://www.ub.uio.no/ujur/ulovdata/lov-19990702-063-eng.doc>

⁴⁵ See Per Nortvedt, "Norway", in: S. Brauer, N. Biller-Andorno, R. Andorno (eds.), *Country Reports on Advance Directives*, op. cit., p. 59-61.

⁴⁶ Tom Goffin, Darina Zinovieva, et al., "Patient Rights in the EU: Bulgaria", *European Ethical-Legal Papers*, N°8, Leuven, Center for Biomedical Ethics and Law, 2007, p. 18.

⁴⁷ See Assya Pascalev, "Bulgaria", in: S. Brauer, N. Biller-Andorno, R. Andorno (eds.), *Country Reports on Advance Directives*, op. cit., p. 21-22.

⁴⁸ See Violeta Besirevic, "Serbia", in: S. Brauer, N. Biller-Andorno, R. Andorno (eds.), *Country Reports on Advance Directives*, op. cit., p. 75-77.

provisions relating to patients' rights (Law N° 251 9/21-8-97).⁴⁹ However, it does not have any specific provisions on living wills or allowing people to appoint a health care proxy.⁵⁰

Slovakia

In 2004, Slovakia passed a comprehensive Health Care Law, which acknowledges the right to consent or to refuse to medical treatments (Art. 6). Nevertheless, such a right is only recognized to competent patients or, in case they are incompetent, to their legal representatives. Nothing is said about the possibility of making advance directives or appointing health care proxies.⁵¹ Slovakia has already ratified the Oviedo Convention.

Lithuania

Like some of the above mentioned countries, Lithuania has ratified the Oviedo Convention but has not enacted any specific law to clarify the scope and efficacy of advance directives. The Law on the Rights of Patients of 1996 affirms the general principle according to which patients have the right to refuse medical treatments (Article 8.1). However, nothing is said about advance refusals that are only applicable when the patient becomes unable to make decisions. Nor the right to designate a health care proxy is explicitly recognized by the law.⁵²

3. Conclusions of the Zurich Workshop

Participants in the Zurich Workshop were divided into three Working Groups (WG) to examine the *ethical*, *medical*, and *legal* aspects of advance directives, respectively.⁵³ Interestingly, all participants agreed that Article 9 of the Oviedo Convention is the appropriate starting point for a cross-culture agreement on the matter in Europe. At the same time, they pointed out the current lack of empirical data about the acceptance, advantages and shortcomings of advance directives across European countries.

WG 1 was rather sceptical about the possibility of reaching in the next future a more substantial agreement on the issue due to the great social, political, economic and cultural differences between European countries. It also pointed out that Article 9, according to which patient's prior wishes "shall be taken into account" is too vague, and that the expression "shall be respected" would

⁴⁹ Koula Merakou and Ellie Tragakes, "Developments of Patients' Rights Legislation", *European Journal of Health Law*, 1999, vol. 6, n° 1, p. 71-81.

⁵⁰ See Takis Vidalis, "Greece", in: S. Brauer, N. Biller-Andorno, R. Andorno (eds.), *Country Reports on Advance Directives*, op. cit., p. 37-39.

⁵¹ See the full text of the Slovak Health Care Law N° 576 of 2004 (in English) at: http://www.privireal.org/content/rec/documents/Slovakia_ActNo576_Healthcare_2004.pdf

⁵² See the full text of the Lithuanian Law on the Rights of Patients and of Compensation of the Damage to their Health of 1996: http://www3.lrs.lt/pls/inter3/dokpaieska.showdoc_e?p_id=111935

⁵³ The Working Groups were composed of the following participants: WG 1: Assya Pascalev, Violeta Besirevic, Tolga Guven, Julia Inthron, Judith Sandor, Pekka Louhiala, and Fabrizio Turoldo; WG 2: Anne-Marie Slowther, Chris Gastmans, Arnd May, Lisa Lehmann, Per Nortvedt, Claude Regamey, and Pablo Simón; WG 3: José A. Seoane, Mette Rurup, Jean-René Binet, João Carlos Loureiro, Margot Michel, Eimantas Peicius, Katarina Glasova, and Takis Vidalis.

perhaps be more adequate. On the other hand, the group emphasized the need to prevent possible abuses of advance directives, for instance, by insurance companies, nursing homes, or proxies tainted by a conflict of interests. The group also expressed its doubts whether there is really a difference in the use of advance directives between those countries where advance directives are legally binding and those where they lack such a legal force, because moral recognition is sometimes independent of legal status. This is why the group considered that the important thing would be to disseminate information among patients about the possibility of making advance directives, and to motivate practitioners to respect patients' autonomous decisions.

WG 2 considered that a more substantial agreement on the issue was desirable and possible, insofar as it is described in terms that are broad enough to be compatible with the socio-cultural differences that exist between European countries. It also recommended to adopt a broader terminology, which is not limited to patient's "wishes" but also includes patient's "goals and values." According to the group, the *medical* focus of the Convention should be broadened to a *care* focus. The group also suggested that patient's preferences should be binding, not only "taking into account". In addition, the group stressed the opportunity of developing common standards relating to the designation of a health care proxy. Among the practical problems that need to be addressed, the group mentioned the following: How to define quality criteria for advance directives? How to ensure confidentiality of such documents? How to prevent undue pressure on patients to sign a living will which could be motivated, for instance, by the desire to reduce health care costs?

WG 3 concluded that a consensus about some minimal requirements for the recognition of a binding status to advance directives could be reached between European countries. At the same time, such agreement should indicate what reasons could legitimately be given by doctors to disregard patient's preferences. In this respect, some participants expressed the view that the distinction between the "binding" and "non-binding" status of advance directives is maybe more semantic than real: What is the practical difference between arguing that advance directives should be "respected" and arguing that they should be "taken into account"? Especially, when in both cases the law accepts that there could be good reasons for not complying with patient's preferences. The group also discussed the need to develop various models of a common form of advance directives, which could be translated into different languages in order to facilitate its implementation across Europe. For this purpose, the group also suggested the need to establish a European network of registries on advance directives, in order to guarantee self-determination for travelling people, who may become unable to make health care decisions in a country other than the one in which they live.

4. Final Remarks

Comparing the legal norms relating to advance directives of European countries, it is evident that they adopt different approaches, based on their diverse legal, socio-cultural and philosophical traditions. Some countries attach a prominent value to patient autonomy and to the possibility of making advance directives, while others, which rely more on paternalistic decision-making structures, are still reluctant to legislate in this field.

Nevertheless, all countries seem to agree that advance directives could eventually play a positive role in health care practice, for instance, in order to prevent futile or disproportionate treatments, and that Article 9 of the Oviedo Convention is the starting point that provides the minimal basis for a common European understanding on this matter.

In conclusion, the Zurich Workshop proved to be helpful, first, in collecting valuable information about the strengths and shortcomings of implementing advance directives across Europe, and second, in putting in evidence that an increasing number of countries show a clear trend to reinforce patients' ability to make health care decisions in advance, either by allowing them to write a living will or to designate a health care proxy (or by using both options combined). Further studies, discussion and consultation with stakeholders are needed to determine whether this trend of convergence may actually extend to Europe as a whole, and if so, what could be the conceptual, ethical and legal basis for such a greater substantive consensus.