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Articles

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How Can Be Increased the Accessibility and Effectiveness of Advance Directives?*

Jak zwiększyć dostępność i skuteczność testamentów życia?

ABSTRACT

One or more forms of advance directives are regulated in the majority of legal systems. However, people generally do not create advance directives. The main reason for this problem is that people do not have enough information about this legal institution, and it is too difficult or expensive to create one. Furthermore, it is also questionable if someone has an advance directive whether it will be able to achieve the aimed legal effect. Similarly, the enforcement of the advance directives could be problematic, especially if litigation is required to enforce these wills. The situation of advance directives

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is more or less the same in the majority of legal systems. Our aim is to show that these problems could be solved using the already existing, e.g. in Austria or Hungary, digital health databases and by introducing a non-litigation legal dispute framework.

Keywords: advance directive; private litigation; register; healthcare law

INTRODUCTION

Today informed consent is a widely acknowledged normative standard in medical ethics: the will of the patient overrides what the doctor considers best for the patient. Advance directives are the necessary consequences of the idea of informed consent.[1] The idea of advance directives became known first in the USA in the late 1960s by Kutner, a human-rights lawyer from Chicago[2] who elaborated the concept of living will.[3]

The function of advance directive is to give instructions to the medical staff on how the patient should be treated in such a situation when he or she is not able to make medical decisions because of incapacity or illness. There are more known forms of advance directives. The first one is the living will which is a written, legal document that contains those medical treatments which should and which should not be used to keep the patient alive. The patient can subscribe other preferences about the medical treatment as well, e.g. organ donation or pain management. The second one is the healthcare proxy (or medical or healthcare power of attorney) in which the patient appoints an agent to make healthcare decisions on behalf of the patient, when the patient is not able to make medical decisions because of incapacity or illness.

Although today the advance directives are regulated by most legal systems, their status is controversial. For example, the knowledge of patients and medical professionals on advance directives is not satisfactory[4] or it could be questionable who should be allowed to make an advance directive.[5]

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[1] See A. Simon, *A Historical Review of Advance Directives*, [in:] *Advance Directive*, eds. P. Lack, N. Biller-Andorno, S. Brauer, Dordrecht 2014, pp. 3–4.

[2] See C.P. Sabatino, *The Evolution of Health Care Advance Planning Law and Policy*, "The Milbank Quarterly" 2010, vol. 88(2), p. 212.

[3] See L. Kutner, *Due Process of Euthanasia: The Living Will, a Proposal*, "Indiana Law Journal" 1969, vol. 44, pp. 549–554.

[4] For example, a survey (published in 2017) showed that even health professionals have a low level of knowledge on advance directives in Lithuania, although the majority of these health professionals agreed that advance directives improved end-of-life decision making. See E. Peicius, A. Blazeviciene, R. Kaminskas, *Are Advance Directives Helpful for Good End of Life Decision Making: A Cross Sectional Survey of Health Professionals*, "BMC Medical Ethics" 2017, vol. 18, p. 40.

[5] For example, it is not clear whether someone who has already symptoms of Alzheimer's disease should be allowed to subscribe his or her preferences about medical treatment for the case when the symptoms become more serious. See C. Porteri, *Advance Directives as a Tool to Respect Patients'*

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The method of our analysis is based on the jurisprudential methodology. Our analysis focuses mainly on the examination of the regulatory framework, and mainly on the dogmatics of these rules. Secondly, the comparative – especially the legal – comparative method is applied, and the regulations and practices of different countries are compared. We have focused on the solutions of two civil law systems: Hungarian and Austrian regulations (however, there are other countries based on civil law systems, which have been partially examined by us, e.g. Germany, France and Italy). Because the advance directive evolved originally in the United States of America – which has a common law legal system – therefore, we have mentioned the main elements of the regulatory approach of the US on the analyzed issue. Thirdly, the methods of the administrative sciences have been applied, the effectiveness of the regulation is similarly examined.

We would like to summarize the typical regulatory approaches on advance directives. Also, we try to explain using these typical regulatory methods why the accessibility and effectiveness of advance directives is low or moderate in the majority of the legal systems. Then we draw up a possible solution which could increase the accessibility and effectiveness of advance directives. In conclusions, we point out why we have serious doubts about the realization of our idea.

ABOUT THE TYPICAL REGULATORY SOLUTIONS ON ADVANCE DIRECTIVES

The most important regulatory questions of advance directives are as follows:

1. The complexity of the regulation and delimitation issues.
2. Who can make an advance directive and who can be a healthcare proxy.
3. The legal binding force of an advance directive.
4. The formal conditions of an advance directive.
5. The obligatory content of an advance directive.
6. The registry of the advance directives.
7. The period of validity of an advance directive.

1. If we compare the complexity of regulation on advance directives of several legal systems, we can find important differences. On the one hand, the concerning regulation of living wills and healthcare proxies can be the same in a country (e.g.

Values and Preferences: Discussion on the Case of Alzheimer's Disease, "BMC Medical Ethics" 2018, vol. 19, p. 9. We have to mention that there are several other critics about advance directives: not enough people use them; people do not understand the forms they complete; the preferences of the patients can change after forming an advance directive; the proxies often do not know or understand the wishes of the patient; even those advance directives which are known by the healthcare providers effect barely the treatment of the patient. See C.P. Sabatino, *op. cit.*, pp. 221–224.

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in Hungary, see Section 22 of Act CLIV of 1997 on Healthcare and the Government Decree No. 117/1998 on the Detailed Regulation about the Rejection of Medical Treatments). In this case, we can speak about a simpler regulation scheme. On the other hand, in other legal systems we can find differences not just between the regulation of living wills and healthcare proxies, but the regulation can be varied in the same legal system. Each country has different rules about the forms and requirements of advance directives.[6]

There are different types of advance directives. Our analysis focuses on the advance directives in healthcare, but it should be emphasized that advance directives have been institutionalized by several countries as a general legal institution and as part of the guardianship reforms. The "general" advance directives can be interpreted as a tool for the preservation of personal autonomy: those adults who have full active legal capacity could have made advance directives for those cases if their active legal capacity would be a limited one, because of their later situation. The scope of these advance directives is partly different and focuses on the guardianship issues. The advance directives could name one or more persons whom the patient proposes to be appointed as his/her custodians or may exclude one or more persons from being a custodian. Similarly, it can be specified by the advance directives how the custodian should act in certain personal and property affairs. The institutionalization of the advance directives has accelerated ratification of the UN Convention on the Rights of Persons with Disabilities[7] because it has been interpreted as a special tool of supported decision-making.[8] However, the healthcare advance directives can be interpreted as a specialized form of these general tools,[9] but they have a much more limited scope; as we have mentioned, they focus on healthcare treatment.[10]

It should be emphasized that the legal relationships between healthcare institutions and patients are interpreted by the vast majority of the legal systems

[6] It is a good example of the complexity of the regulation of the USA that the concerning rules of the states use different expressions for the person who is authorized to make the medical decisions instead of the patient, e.g. health care agent, health care proxy, health care surrogate, health care representative, health care attorney-in-fact, patient advocate. See Mayo Clinic, *Living Wills and Advance Directives for Medical Decisions*, https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303 (access: 12.12.2023).

[7] See J. Bodio, *Guardian Appointed for a Disabled Person and Guardian Appointed for a Partially Incapacitated Person*, "Studia Iuridica Lublinensia" 2021, vol. 30(4), p. 53.

[8] See F.E. Morrisey, *The Introduction of a Legal Framework for Advance Directives in the UN CRPD Era: The Views of Irish Service Users and Consultant Psychiatrists*, "Ethics, Medicine and Public Health" 2015, vol. 1(3), p. 326.

[9] See H. Molnár, *Az ellátás visszautasítása jogának egyes kérdései – az Alkotmánybíróság határozataira és a Ptk. cselekvőképességre vonatkozó megújult szabályaira figyelemmel*, "Állam- és Jogtudomány" 2016, vol. 63(4), pp. 84–87.

[10] See Á. Dósa, P. Hanti, Z. Kovácsy, *Kommentár az egészségügyi törvényhez*, Budapest 2016, p. 63.

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as legal institutions governed by civil law.[11] However, in those countries which have universal healthcare systems or a social security healthcare system, the provision of these services is interpreted as a legal relationship governed by public law, and therefore, the legal disputes on the provision of the services are mainly defined as administrative disputes (administrative court procedures or specialized administrative procedures), because the personal relationship between the healthcare provider (institution, doctor, etc.) and the patient is interpreted as a private relationship. Therefore, if there is a dispute whether the healthcare institution has or has not followed the advance directives and whether the advance directives can be interpreted as valid or not, this dispute is mainly a civil (court) procedure, especially civil litigation.[12] This means that as a general civil litigation it can be interpreted as a time-consuming process, therefore it is partially effective because decisions on advance directives should be made quite rapidly and these litigations do not offer a short dispute solution.[13]

2. In the majority of the legal systems those people can create advance directives who are over 18 years old and have full legal capacity. However, we can find some exceptions, e.g. even minors who are over 16 years old are entitled to make an advance directive in some regions of Spain.[14]

The regulations are more different in that aspect of who can be a healthcare proxy. The concerning acts of some countries contain a strict order list of the closest relatives who are entitled to act as a healthcare proxy if the patient did not appoint someone in an advance directive before.[15] However, we can find examples of such solutions as well, when only those relatives can act as healthcare proxies who were appointed before by an advance directive or a court (e.g. Germany).[16]

3. It is a very important question when an advance directive has a legal binding force. In some jurisdictions the legislator regulates just those advance directives which are legally binding (e.g. Hungary).[17] We can find such countries where advance directives are not legally binding (e.g. France or Italy), as well. Furthermore, the Austrian regulation distinguishes the legally binding and non-binding living

[11] See M. Karpiuk, J. Kostrubiec, *The Voivodeship Governor's Role in Health Safety*, "Studia Iuridica Lublinensia" 2018, vol. 27(2), pp. 65–67.

[12] See U. Wiesing, R.J. Jox, H.-J. Heßler, G.D. Borasio, *A New Law on Advance Directives in Germany*, "Journal of Medical Ethics" 2010, vol. 36(12), pp. 779–781.

[13] Similarly M. Calder, *Chapter 765 Revisited: Florida's New Advance Directives Law*, "Florida State University Law Review" 1992, vol. 20(2), pp. 293–295.

[14] A. Simon, *op. cit.*, p. 10.

[15] See, e.g., Section 16 (2) of the Hungarian Healthcare Act. According to this rule, the strict order of the relatives as a healthcare proxy in case of no appointment is the following: 1) spouse or cohabiting partner; 2) child; 3) parent; 4) sibling; 5) grandparent; 6) grandchild. The cohabiting relatives always precede the non-cohabitating relatives.

[16] A. Simon, *op. cit.*, p. 9.

[17] See, e.g., Section 22 of the Hungarian Healthcare Act.

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wills.[18] The legally binding solution should fulfill strict procedural and formal conditions. If these conditions are not fulfilled, the living will is not legally binding for the doctors but they must be considered by the decisions about the patient's treatment: the more the prescribed conditions are fulfilled, the more the legally non-binding advance directive shall be considered.[19]

4. The legislators normally prescribe strict formal conditions, but we can find several solutions.[20] It is typical that the simple written form does not fit the required criteria, but the advance directive must be witnessed or notarized.[21] Furthermore, other conditions could be required, e.g. Section 22 (3) of the Hungarian Healthcare Act prescribed till 2014 in Hungary that an advance directive can be valid only in that case if a psychiatrist certifies in an expert opinion, which is not older than one month, that the decision of the patient was made in the knowledge of its possible consequences.[22] We have to mention that comprehensive medical advice which confirms the mental capacity of the patient is still required for an advance directive in Austria (see Section 5 of PatVG).

5. It is also typical that the concerning acts prescribe the obligatory content of an advance directive. However, the details can differ a lot. The most important part of this aspect is how the patient shall formulate how he or she can be treated by the medical staff. For example, according to the concerning Hungarian Government Decree No. 117/1998 the patient shall declare that he or she "does not consent to the use of the following diagnostic and/or therapeutic procedures in the event of illness/accident". However, the Decree offers several options for the patients how to phrase their wishes.[23]

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[18] See Federal Act No. 55/2006 on Living Wills (Bundesgesetz über Patientenverfügungen), hereinafter: PatVG.

[19] A. Simon, *op. cit.*, pp. 7–9.

[20] For example, we can distinguish five solutions among the US states about the formal conditions of a legally binding healthcare proxy. These are the following: 1) health care power of attorney must be witnessed; 2) health care power of attorney must be notarized; 3) health care power of attorney must be witnessed or notarized; 4) health care power of attorney must be witnessed and notarized; 5) health care power of attorney need not be witnessed or notarized. See *Health Care Powers of Attorney – Witness and Notary Requirments*, https://web.archive.org/web/20130608064700/http://www.lawserver.com/maps/health-care-powers-of-attorney-witness-and-notary-requirments (access: 12.12.2023).

[21] The advance directive in Austria must be signed by the patient in the presence of a notary or a representative of a patient advocacy organization. See A. Simon, *op. cit.*, p. 8.

[22] The Hungarian Constitutional Court abolished this prescription in 2014 because it found that this restricting condition is a unique one in the Hungarian law and it is not reasonable comparing it with other legally binding documents (e.g. testaments or other medical declarations). See A. Makács, *Néhány gyakorlati gondolat az élő végrendeletről*, 2019, https://jogaszvilag.hu/szakma/nehany-gyakorlati-gondolat-az-elo-vegrendeletrol (access: 18.5.2023).

[23] The denied treatments can be defined by the following ways: defining an intervention group (e.g. amputation) or excluding a specific intervention (e.g. breast amputation); with the help of phrase commonly used in the Hungarian language (e.g. taking blood test, medication in general or with

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Another example: Section 4 of PatVG prescribes that the medical treatments that are the subject of the rejection must be specifically described in a binding advance directive or it must be clear from the overall context and the advance directive must also show that the patient correctly evaluates the consequences of the advance directive. However, if the advance directive is interpreted as a legally binding institution, its effectiveness can be decreased by the dispute solution approach of them. As we have mentioned earlier, the relationship between the patient and the healthcare institutions is interpreted as a relationship governed by private law, therefore, the disputes on following the instructions are mainly civil litigations.

6. It is a crucial question whether the advance directives shall be registered although it is not typical. A very good example for a register is the German one,[24] the so-called "Das Zentrale Vorsorgeregister" (ZVR). Everyone who has drawn up an advance directive can register that fact in the ZVR. It is an online register operated by the German Federal Chamber of Notaries. The registration is cheap (the prices are between 10 and 20 euros) and it can be made online or by post. However, the registration does not prove the validity of the advance directive (e.g. whether it fulfills the legal conditions or it has not been revoked). Thus, the patient should ask to help a notary or an attorney to make a valid advance directive. The ZVR is used by the courts.[25] It contained more than 5 million registrations in the first half of 2021.[26]

7. The regulation on the validity period of advance directives is also diverse. They are always revocable and it is typical that the revocation can be done without fulfilling those formal criteria which are prescribed for the creation.[27] It is also not a unique solution if the advance directive must be renewed (e.g. in France after 3 years,[28] in Austria after 8 years[29]); in other case it automatically expires.

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certain drugs only, exclusion of surgery in general or only for specific surgeries, artificial feeding or respiration, etc.); by the name in the International Classification of Procedures in Medicine, but in this case each intervention must also be indicated by the commonly known name; instead of naming the interventions by naming the specific disease in general (e.g. "If I have a malignant cancer, I do not consent to its treatment", or "If I have a disease or accidentally become unable to take care of myself, I do not consent to my treatment").

[24] Another example is the Austrian solution, where the advance directive will be able to registered among the electronic health records (ELGA). See ELGA, https://www.elga.gv.at/faq/wissenswertes-zu-elga (access: 12.12.2023).

[25] For example, if a doctor needs a consent to a life-threatening operation and the patient is unconscious, the doctor shall apply to the court to appoint a supervisor. If the health care proxy is registered, the court shall inform the doctor that there is an authorized representative to whom he can turn.

[26] See Das Zentrale Vorsorgeregister der Bundesnotarkammer, https://www.vorsorgeregister.de (access: 12.12.2023).

[27] See, e.g., Section 22 (3) of the Hungarian Healthcare Act. Moreover, the revocation is valid if the patient does not have full mental capacity.

[28] See A. Simon, *op. cit.*, p. 8.

[29] See Section 7 of PatVG. The patient may choose a shorter period of expiration.

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ABOUT THE ACCESSIBILITY AND EFFECTIVENESS OF ADVANCE DIRECTIVES

The above-mentioned aspects of regulation significantly influence the accessibility and effectiveness of advance directives. First, we should speak about the complexity of the regulation. It does not need much explication to understand: the simpler the regulation is, the easier the patients can use advance directive effectively. If the regulation is complex, the chance of the invalidity of the advance directives is higher, etc.

The second aspect is who can make an advance directive and who a healthcare proxy can be. The more restrictions the concerning regulation contains in this field, the less people will make a valid advance directive what decrease the accessibility.

As the third point we shall examine the legal binding force of an advance directive. Those which are legally binding could be much more effective which are not. And if the patients have no chance to make one with legal binding force (e.g. in France or Italy), they will not be interested that much to create an advance directive.

Fourth, we shall focus on the formal criteria. As we mentioned before, these conditions are normally quite strict because of the importance of the content. However, if you have to use the service of a notary or an attorney to fulfill these requirements, it can be expensive – not just in money but in time, too – what decrease the accessibility.

The obligatory content of an advance directive as the fifth aspect is connected more to the effectiveness. On the one hand, if this requirement is too strict, in that case a huge amount of advance directive could be invalid which do not fulfill the prescribed conditions. On the other hand, if the legislator does not determine the obligatory content, the patients should write their will without any guideline what increase the numbers of such advance directives which are hard to understand. Both extremities decrease the effectiveness.

Our sixth point, the registry of advance directives is perhaps the most crucial one. Without a register an advance directive can easily remain hidden from those to whom it concerns: the medical staff and the courts. In this case, an advance directive cannot be effective at all. However, we have to mention that the cost of registration shall not be high because the high costs decrease the accessibility.

Last, we shall speak about the validity period of an advance directive. The legislators apply this tool because the will of the patients can be changed with time and those advance directives must not prevail which do not meet the wishes of their creator. However, those people who do not change their mind can forget to extend the validity of their advance directive. This real danger decreases the effectiveness.

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POSSIBLE SOLUTIONS

1. Using the already existing open access health databases

In our opinion, if we want to establish an effective system of advance directive, we have to create an easily accessible – and free of charge – surface where the patients can place their advance directives which are automatically controlled to avoid the danger of invalidity and the doctors can easily find them. This surface already exists in several countries: this is the health record database (e.g. it is the electronic healthcare service space – the so-called EESZT[30] in Hungary or ELGA in Austria).

Our idea is the following: all patients have free direct access to their electronic health records on a website. They can find there all the reports about their medical treatments, the electronic recipes which were prescribed by their doctors, etc.[31] Therefore we cannot see why the patients could not create their advance directives on this electronic surface. The advantages of this solution are as follows:

- it is completely free for the patients;[32]
- this surface is safe because the users must identify themselves with the help of several safety steps[33] what could substitute all the formal conditions which are typically prescribed;[34]
- the invalidity of the advance directive could be avoided if the patients should choose by a click among the possible contents of their directive (of course, it must be offered to the patient to amend the offered options if they want to do it);[35]
- the advance directive can be revoked easily;[36]
- the doctors can easily find the advance directives because they use the same database during the treatment;[37]
- the possibility of creating of an advance directive can also be cheaply promoted on this electronic surface.

[30] EESZT Lakossági Portál, https://www.eeszt.gov.hu/hu (access: 12.12.2023).

[31] Another example: people who want to be vaccinated against COVID-19 have to register on EESZT in Hungary.

[32] If there is an independent register, it is normally not free of charge. See the ZVR.

[33] Similarly to the case if someone wants to reach an online bank account.

[34] The planned and partly existing Austrian solution just facilitates to register the advance directives on ELGA, but the declarations cannot be made directly on the online surface and they must fulfill several formal conditions.

[35] The German ZVR only certifies the fact that the patient has made an advance directive, but it does not guarantee its validity.

[36] The patients use this surface frequently because it has many functions as we mentioned before. This fact can guarantee that if someone changed his or her mind about his or her advance directive, the patient can easily modify it when he or she enters the database because of any reason.

[37] The medical staff cannot reach the ZVR directly in Germany, just the courts have access to it.

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2. A non-litigation procedure

As we have mentioned, another risk on the effectiveness of the advance directives is the approach of the dispute solutions. The doctor–patient relations are interpreted as relationships governed by private law. Therefore, as a principle, these disputes are civil litigations which are mainly time-consuming procedures. Because the "living wills" require rapid decisions – having regard the nature of the application – therefore a civil litigation can be ineffective, because it can be longer, as the disputed situation. Thus, the traditional civil litigation could be a barrier to the wide application of the advance directives. However, this issue can be solved by interpreting these procedures as public disputes, but it is not fitting into the dogmatics of the patient–doctor relationship, which is really a private one.[38] Therefore, such a solution should be founded which maintains the private nature of the relationship, but by which a rapid solution is offered. Therefore, we recommend introducing a non-litigation procedure for the dispute solution. It could be similar to such solutions which are introduced by several legal systems on the disputes on the obligatory psychiatric treatments.[39] Therefore, the private nature of the relationship can be preserved, but a rapid, e.g. a 72-hours, decision making procedure controlled by a judge can be established.

CONCLUSIONS

Despite the fact that the implementation of an accessible and effective registry system of advance directives does not seem to be expensive or difficult – see our suggestion above – we have serious doubts that it could be realized soon in one or more legal systems. The main reason of this thought is not the lack of demand. According to several research a lot of people make an advance directive under such conditions that it is questionable whether their wish could be fulfilled our not.[40]

In our opinion, the problem is the lack of the political intention. The acceptance of the advance directive was a long process, and we are far away from the end of it. As we mentioned before, there are still several doubts about advance directives, thus the legislators do not want to facilitate the patients to create one and it is not a political aim, either, to build up a register which could be easily accessed by the patients and the medical staff.

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[38] See O.O. Cherednychenko, *Fundamental Rights and Private Law: A Relationship of Subordination or Complementarity?*, "Utrecht Law Review" 2007, vol. 3(1), pp. 2–4.

[39] See M. Asbóth, M. Fazekas, J. Koncz, *Egészségügyi jog és igazgatás*, Budapest 2020, pp. 47–48.

[40] For example, approx. 30% of the US citizens had an advance directive in 2008 (see C.P. Sabatino, *op. cit.*, p. 221) or the German ZVR contained more than 5 million registrations in the first half of 2021 (see Zentrales Vorsorgeregister, ZVR-Statistik 2021, https://www.vorsorgeregister.de/fileadmin/user_upload_zvr/Dokumente/Statistiken_ZVR/2021-Statistik-ZVR.pdf, access: 12.12.2023).

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As long as this approach will not be changed, the concept presented above will stay just an idea.

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ABSTRAKT

Większość systemów prawnych reguluje jedną lub więcej form testamentu życia. Generalnie jednak ludzie ich nie sporządzają. Główną przyczyną tego problemu jest niedoinformowanie o tej instytucji prawnej oraz fakt, że sporządzenie takiego aktu jest zbyt trudne lub zbyt kosztowne. Ponadto nawet w sytuacji, gdy ktoś sporządził taki akt woli, rodzą się wątpliwości, czy wywoła on zamierzony skutek prawny. Podobnie problematyczna może być egzekucja testamentów życia, zwłaszcza gdy wymaga postępowań sądowych. Sytuacja dotycząca testamentów życia jest mniej więcej podobna w większości systemów prawnych. Naszym celem jest wykazanie, że można rozwiązać te problemy z wykorzystaniem już istniejących (np. w Austrii lub na Węgrzech) baz danych medycznych oraz poprzez wprowadzenie nieprocesowych rozwiązań w zakresie rozstrzygania sporów prawnych.

Słowa kluczowe: testament życia; postępowanie prywatnoprawne; rejestr; prawo medyczne