CNS 27/2021

Opinion in relation to the consultation of a healthcare entity regarding access to the clinical history of deceased patients

A letter from an entity in the health sector is submitted to the Catalan Data Protection Authority, requesting a report from this Authority on requests for access to the clinical history of deceased patients.

The consultation refers to the regulatory provisions on access to the clinical history of deceased patients (article 18.4 of Law 41/2002, of November 14, basic regulation of patient autonomy and rights and obligations in matters of 'information and clinical documentation'), and raises the following questions:

> **"Case 1. We are asked by the HC of a deceased, a brother or a nephew of this one. The patient has a living spouse and children. The copy of the HC of the successful patient can be given to this sibling who attests to the kinship relationship or, considering that there are closer relatives, they have a better right.**
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> **Case 2. If this were the case and only close people could request the HC, would a brother or nephew have to certify that the deceased had no close relatives?**
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> **Case 3. In the case of a person who is not related to the deceased but is an heir, is he entitled to a copy of the HC justifying it as a de facto relationship?**

Having analyzed the request, (...), in view of the current applicable regulations, and in accordance with the report of the Legal Counsel, the following is ruled.

I

(...)

II

The consultation refers to access to the clinical history of deceased patients (hereafter, HC), by people related to them, taking into account the regulatory provisions on this matter.

At the outset, it should be borne in mind that, according to article 4.1 of Regulation (EU) 2016/679, of April 27, general data protection (RGPD), personal data is "all information about a person identified or identifiable physical person ("the interested party"); Any person whose identity can be determined, directly or indirectly, in particular by means of an identifier, such as a number, an identification number, will be considered an identifiable natural person.

location data, an online identifier or one or more elements of the physical, physiological, genetic, psychological, economic, cultural or social identity of said person;

According to article 4.15 of the RGPD, it is data relating to health: "personal data relating to the physical or mental health of a natural person, including the provision of health care services, which reveal information about their state of health" .

The processing of data (art. 4.2 RGPD) of natural persons who receive assistance in health centers is subject to the principles and guarantees of the personal data protection regulations (RGPD and Organic Law 3/2018, of December 5, of protection of personal data and guarantee of digital rights (LOPDGDD)).

Given the terms of the consultation, it should be taken into account that, according to recital 27 of the RGPD:

> **"This Regulation does not apply to the protection of personal data of deceased persons. Member States are competent to establish rules relating to the treatment of their personal data."**

According to article 2.2 of the LOPDGDD:

> **"2. This organic law will not apply: (...) b) To the data processing of deceased persons, without prejudice to what is established in article 3. (...)."**

Article 3 of the aforementioned LOPDGDD provides the following:

> **"1. Persons linked to the deceased by family or de facto reasons, as well as their heirs, may contact the person responsible for the treatment to request access to their personal data and, where applicable, their rectification or deletion.**
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> **As an exception, the persons referred to in the previous paragraph will not be able to access to the data of the causer, nor request its rectification or deletion, when the deceased person had expressly prohibited it or so established by law. Said prohibition will not affect the right of the heirs to access the property data of the deceased.**
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> **2. The persons or institutions to which the deceased had expressly designated for it may also request, according to the instructions received, access to his personal data and, where appropriate, their rectification or deletion.**
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> **By royal decree, the requirements and conditions will be established to certify the validity and validity of these mandates and instructions and, where appropriate, their registration.**

3. In the event of the death of minors, these powers may also be exercised by their legal representatives or, within the framework of their powers, by the Public Prosecutor's Office, which may act ex officio or at the instance of any interested natural or legal person.

In the event of the death of persons with disabilities, these powers may also be exercised, in addition to those mentioned in the previous paragraph, by those who had been designated for the exercise of support functions, if such powers are understood to be included in the support measures provided by the designated."

Although the data protection regulations (RGPD and LOPDGDD) are not applicable to the processing of data of deceased persons, said regulations expressly provide that certain persons linked to them "for family or de facto reasons", and also their heirs , or those persons or institutions designated by the holder of the information (in the case at hand, the patient), can access the information relating to the deceased person and, where appropriate, request its rectification or deletion (art. 3.1 LOPDGDD).

This, unless there is an express prohibition of the owner of the information or certain legal provisions may limit the exercise of this faculty. In the event that the deceased person is a minor or a person with a disability, the specific provisions regarding the exercise of these powers must be taken into account (art. 3.3 LOPDGDD).

Regarding this, we note that the provision of article 3 of the LOPDGDD refers to access and, where appropriate, rectification (art. 16 RGPD) or deletion (art. 17 RGPD) regarding the personal information of a dead person, without establishing specific conditions or differences depending on whether the persons linked to the holder wish to access one or another type of personal information or on the basis of the type of data.

The aforementioned regulations, when referring to people linked by family or de facto reasons, or the heirs who can exercise the right of access in relation to personal data of deceased owners, also do not establish an order of priority between these people, rather, it only establishes categories of third parties that in principle must be able to access the deceased's information, in accordance with the regulations.

The regulations also do not establish a limited number of people who can access the personal data of a deceased owner, so it can be one or several people who, proving their identity and the link with the owner of the data for family reasons or in fact, or their status as an heir of the deceased, could access the latter's data.

The provisions of the aforementioned data protection regulations are fully applicable to access to health data, such as the data contained in the HC (art. 9.1 of Law 21/2000), in this case, of dead people , case to which the query refers.

III

Having said that, the content of the clinical history (henceforth, HC) is detailed in the patient autonomy regulations (article 10.1 Law 21/2000, of December 29, on the rights of information concerning health and patient autonomy, and clinical documentation; article 15 Law 41/2002, of 14

November, basic regulation of patient autonomy and rights and obligations in terms of information and clinical documentation).

As this Authority has highlighted on previous occasions (among others, Opinions CNS 36/2018, CNS 37/2018 or CNS 8/2019, which can be consulted on the website: www.apdcat.cat), the regulations 'patient autonomy provides for the communication of patient health data related to the healthcare process to the people linked to it, either for family or factual reasons (arts. 3.1 Law 21/2000 and 5.1 Law 41/2002).

Thus, in cases of physical or mental incapacity of the patient, the regulations provide that it is necessary to inform "relatives or people who are linked" (art. 3.2 Law 21/2000, and art. 5.3 Law 41/2002). Even, in exceptional cases, the regulations on patient autonomy provide that consent to carry out interventions in the field of health must be obtained, by substitution, "from the relatives of this person or the persons that are linked to it" (art. 7.2 Law 21/2000, and art. 9.3 Law 41/2002). Obviously, in this case - or in cases where a "state of therapeutic necessity" is present (art. 5.4 Law 41/2002) - the people linked to the patient should receive certain information about the patient from the health center, when the circumstances described.

The legal system recognizes the people linked to the patient for family reasons or in fact, a certain degree of involvement or participation in the patient care process and, as a logical consequence, recognizes them in certain circumstances a right to receive information about the patien

In line with these regulatory provisions on access to the HC by other people, and for the purposes that concern them, article 18.4 of Law 41/2002, specifically provides for access by people linked to deceased patients, in the following terms:

> **"4. Health centers and individual practitioners will only provide access to the clinical history of deceased patients to persons related to them, for family or de facto reasons, unless the deceased had expressly prohibited it and this is proven. In any case, the access of a third party to the clinical history motivated by a risk to your health will be limited to the relevant data. No information will be provided that affects the privacy of the deceased or the subjective notes of the professionals, nor that harms third parties."**

It is worth saying that Law 21/2000, of December 29, on the rights of information concerning the patient's health and autonomy, and clinical documentation, does not contain specific provisions on access to the HC of patients deceased In any case, State Law, 41/2002, has the character of basic legislation, as specified in its first additional provision. Therefore, we must refer to the provisions of said article 18.4 in relation to the question raised.

As this Authority has agreed (CNS Opinion 28/2009, regarding access to medical data of a deceased patient by his relatives, which is of particular interest in this case), article 18.4 of the Law 41/2002 establishes a series of criteria that must be taken into account by those responsible for the treatment of the information of patients who have died, when assessing a request for access to this information.

At the outset we note that access is limited, in general, only to people who are linked to the deceased patient "for family or de facto reasons", so that general knowledge by third parties who are not have a connection with the deceased. In general, if the kinship or de facto relationship is documented (depending on the case, for example, through the family book, the entry in the register of de facto partners, deed of cohabitation, notarial document, among others), these people should, in principle, have access to the information, notwithstanding that there may be other reasons for limiting access that we will see later.

Thus, in the face of the request for access to the HC from people related to a deceased patient (and, where appropriate, for the rectification or deletion of personal data), it will be necessary that the identity of these people and their relationship with the deceased being duly accredited, verification that would correspond to the person responsible (art. 4.7 RGPD), in principle, the health center that attends the patient as responsible for the HC in the terms of the patient autonomy legislation. Thus, according to article 9.4 of Law 21/2000: "Health centers must take the appropriate technical and organizational measures to protect the personal data collected and avoid its destruction or accidental loss, and also access , alteration, communication or any other processing that is not authorized."

As this Authority has agreed in the "Data protection guide for patients and users of health services" (June 2020), people who request access to a third party's HC must identify themselves and prove their relationship with the patient, on the basis of which they request access.

Therefore, people linked to a deceased patient, for family or de facto reasons, or their heirs, in principle must be able to ask the person in charge (a healthcare facility) for access to the patient's HC data and, where appropriate, the rectification or deletion of patient data, since this is recognized by the patient autonomy regulations and the data protection regulations (art. 3 LOPDGDD and art. 18.4 Law 41/2002).

IV

Once the general framework in which the questions are framed has been set out, it is appropriate to refer to the specific questions posed by the consultation:

Case 1. "We are asked by the HC of a deceased, a brother or a nephew of this one. The patient has a living spouse and children. The copy of the HC of the successful patient can be given to this brother who attests to the kinship relationship or, considering that there are closer relatives, they have a better

The regulations studied (art. 3 LOPDGDD and art. 18.4 Law 41/2002) do not specify an order of priority between people related to the deceased patient who, in principle, could request access to the HC. Nor does it appear from the regulations studied that only a single person (a family member or person linked to the patient) can have access to the HC of the deceased.

However, without prejudice to this, the fact that the regulations studied refer to people linked by family and de facto reasons, and to heirs, without further specification, does not seem to have to

result in any person related to a deceased patient, who can prove any family or de facto relationship, must be able to access the patient's HC.

First of all, because the health information contained in the HC is information deserving of special protection (art. 9 RGPD) and affects, among others, the right to privacy of patients and their family environment. Taking this into account, it does not seem that this information should be accessible to an indeterminate number of people, just because they have some connection with the patient, or a more or less distant relationship, and can prove it.

As has been said, the patient autonomy legislation allows the patient's health data to be communicated during the care process, to the people who are linked, either for family reasons or in fact, who accompany them during this process , unless the patient objects.

This access to patient information during the care process is not recognized to "any person" more or less related to the patient, but to the people linked to the patient, who assist him, who usually accompany him, or who take care of him , as these are the ones who, if applicable, will have to make decisions on behalf of the patient.

With regard to access to data of the deceased patient, if we take into account what the purpose of accessing their HC may be (to manage personal, patrimonial, family matters, of the deceased or his family environment, to file a claim or manage issues related to the health benefits received by the deceased, exercise inheritance rights, etc.), it seems logical that the relatives closest to the deceased, those who accompanied and assisted him during the care process and who took care of him , are those who in principle must be able to access the HC of the deceased, since it is these people who will have to make these arrangements and, therefore, the ones who need to have the deceased's information.

Therefore, although the aforementioned regulatory provisions make general mention of "related persons" without establishing exclusions, nor a specific order, the special nature of health information, and the provisions of the patient autonomy legislation regarding the access to the patient's information, lead to consider that the people linked for family reasons or in fact closest to the deceased patient (such as the spouse, children or parents, although not exclusively) would have, as the inquiry points out , a “better right” or a preferential right to access the HC, in relation to other people linked to the patient but with a less close link.

Thus, in relation to the people usually closest to the patient, who in principle would have preferential right of access to the HC (spouse and children, parents, de facto partner or, where appropriate, other close relatives of the first or second degree, if applicable, or other cohabitants of the deceased of whom the center has evidence that accompanied and attended on a regular basis), it seems that this link can be presupposed. In these cases, in principle it would be necessary to give access to the HC. Beyond checking the identity of the applicants, and the relationship of kinship or de facto, or the status of heir, it does not seem that the center has to make further checks in this regard, nor request a more specific accreditation or justification of the purpose

However, without prejudice to the fact that, in principle, a preferential right of access must be recognized for these people with a closer link to the patient, it cannot be ruled out that the aforementioned relatives (a nephew or a brother) may access to the HC, for example, if it was these relative

they usually accompanied and assisted the patient, and those who had to manage issues relating to the deceased (financial, patrimonial issues, etc.).

For example, it may be that, although the deceased had a spouse and living children, it was another family member who took care of them instead of them, or who usually accompanied them in the care process, or even who was in regular contact with the health center instead of the closest relatives. So, for example, in cases where it is a more distant relative, such as a nephew or a brother, or another cohabitant, who took care of the deceased, it cannot be ruled out that they must have access to the HC.

In these cases, the center should consider the circumstances of the request to assess whether it is relevant to grant access to these people. A check that should be even more accurate if the center is aware that there are relatives closer to the deceased. Thus, if there are people closely related to the deceased (such as spouse, children or parents, although not exclusively), giving access to other people could be disproportionate, given the special nature of health information, unless the applicants prove the link with the deceased and the center can determine the relevance of the access.

In short, it will be necessary to take into account the casuistry that may be presented in each case, in order to determine which people it may be relevant to give access to the HC, taking into account the considerations that have been made.

It does not seem to be required that, beyond this, the center should make disproportionate efforts in order to resolve what the accesses to the HC of a deceased patient could be in each case.

All this without prejudice to the fact that if the deceased patient had expressed his opposition to certain relatives or close people accessing his HC (art. 3.1, second paragraph, LOPDGDD, and art. 18.4 Law 41/2002), it will be necessary to have into account, since this circumstance may mean that certain family members or people linked to the deceased patient cannot access the HC.

Case 2. "If that were the case and only the closest people could request the HC, would a brother or nephew have to certify that the deceased had no next of kin?"

If certain people related to the deceased, but with a family link that a priori is not the closest - such as a brother or a nephew -, request access to the HC, they will have to prove the link with the deceased.

The fact of certifying that there are no other close relatives, as the inquiry points out, or that the applicants have usually accompanied the patient during the care process, or that they took care of him despite not having such a relationship close as well as other more direct relatives, among others, can allow to prove the required link for the purposes of giving these people access to the HC of the deceased.

Case 3. "In the case of a person who is not related to the deceased but is an heir, is he entitled to a copy of the HC justifying it as a de facto relationship?"

Article 18.4 of Law 41/2002 does not mention heirs as persons who can request access to the HC of a deceased patient.

However, people who have the status of heirs (art. 411-1 of Law 10/2008, of July 10, of the fourth book of the Civil Code of Catalonia, relating to successions, and other regulations resulting from 'application) of a deceased patient, they can exercise the right of access to their personal data, as this is provided for in article 3 of the LOPDGDD.

In addition, regardless of whether or not they are relatives of the deceased, the designation of a person as heir by the deceased already highlights the existence of a de facto relationship derived from the deceased's own will.

It should be borne in mind that the purpose of the access request may respond to issues that affect the applicant in his capacity as an heir (exercise or defense of inheritance rights, claims related to health care for the deceased, etc.). Considering this, and the specific provision of Article 3 of the LOPDGDD, it is clear that the heirs must in principle have access to the HC of the deceased, even if there is no binding for family reasons.

In accordance with the considerations made in this opinion the following are made,

Conclusions

Case 1: Given the special nature of health information and the provisions of the patient autonomy and data protection legislation, in principle a preferential right of access to the HC of the deceased should be recognized for people with a link, for family or de facto reasons, closer to the deceased, such as a spouse, children or parents.

Case 2: The preferential access of people with a closer link to the deceased does not exclude the possibility of other access given the specific circumstances.

Case 3: Given the regulatory provisions (art. 3 LOPDGDD), and that in principle the heirs have a link for reasons of fact with the causer, it seems clear that they must have access to the HC of the deceased, although not there is a connection for family reasons.

Barcelona, May 18, 2021