CNS 10/2018

Opinion in relation to the consultation on access to clinical data of minors by their parents

A consultation is submitted to the Catalan Data Protection Authority in which a report is requested to this Authority on the possibility for parents to access the clinical data of their children under the age of 18, given the large number of requests which, according to the query, they receive in this regard.

The consultation considers that "in application of the law, a minor under the age of 14 who is not incapacitated can directly exercise his ARCO rights", and asks "if the fact that parents can exercise it until the minors are 18 years old violates at some point its confidentiality or it could be incardinated in the exercise of its functions of paternal authority."

Having analyzed the request, given the current applicable regulations and the report of the Legal Counsel, the following is ruled.

I

(...)

II

The consultation, referring to parents' access to the clinical data of their minor children, mentions that "in application of the law, a minor under the age of 14 who is not incapacitated can directly exercise his ARCO rights". and asks "if the fact that parents can exercise it until the minors are 18 years old violates their confidentiality at some point or could it be incardinated in the exercise of their parental authority functions."

Given the consultation in these terms, from the perspective of data protection, it is necessary to agree that the personal data of natural persons under the age of majority is personal information (art. 3.a) Organic Law 15/1999, of December 13, on the protection of personal data (LOPD)) and, as such, is protected by the principles and guarantees of the regulations on the protection of personal data (LOPD, and Royal Decree 1720/2007, of 21 of December, by which the Development Regulation of the LOPD (RLOPD) is approved).

It is also necessary to take into account the General Data Protection Regulation (EU) 2016/679 (RGPD), which entered into force on 25 May 2016, and which will be applicable from 25 May 2018 (art. 99 RGPD)).

The query refers to the "clinical data" of minors. Information relating to the health of natural persons is subject to special protection (art. 7.3 LOPD and art. 4.15 and 9 RGPD). The information contained in the clinical history of each patient is found

regulated and protected by a specific regulation (Law 21/2000, of December 29, on the rights of information concerning the patient's health and autonomy, and clinical documentation, and Law 41/2002, of November 14, basic, regulating the patient's autonomy and rights and obligations regarding information and clinical documentation).

III

The consultation refers to access by parents to the information of minor children, who would be the holders (art. 3.e) LOPD), and also refers to the exercise of the rest of the so-called "ARCO rights ” (rights of rectification, cancellation and opposition), collected in the LOPD and the RLOPD.

We agree that the RGPD, which will be applicable from May 25, 2018, in addition to the right of access (art. 15), the right of rectification (art. 16), the right to deletion or "right to 'oblivion' (art. 17), and the right of opposition (art. 21), incorporates new rights that must also be considered as part of the right of informational self-determination. Thus, the RGPD establishes the right to limit treatment (art. 18), the right to data portability (art. 20), or the right of every person not to be subject to automated individual decisions (art. 22).

In any case, given that the usual denomination of "ARCO rights" would not incorporate all the rights of the personality that make up the right to the protection of personal data or the right to informative self-determination given the provisions of the RGPD, for the purposes of this opinion we will not refer to "ARCO rights", but to the rights inherent in informative self-determination or habeas data rights. This, without prejudice to the particularities that, in relation to the exercise of each of these rights, may establish the RGPD.

Having said that, article 15 of the LOPD, in relation to the right of access, determines the following:

> "1. The interested party has the right to request and obtain free of charge information about their personal data being processed, the origin of the data and the communications made or planned to be made.
> 2. The information can be obtained through the mere consultation of the data through visualization, or the indication of the data that is the subject of treatment through writing, copying, telecopy or photocopy, certified or not, in a legible and intelligible form legible, without using keys or codes that require the use of specific mechanical devices.
>
> 3. The right of access referred to in this article can only be exercised at intervals of no less than twelve months, unless the interested party proves a legitimate interest for this purpose, in which case they can exercise it earlier."

For its part, article 27 of the RLOPD, in its first and second sections, provides the following regarding the right of access:

> "1. The right of access is the right of the affected person to obtain information on whether their own personal data is being processed, the purpose of the processing that, if applicable, is being carried out, as well as the information available on the origin of the aforementioned data and the communications made or planned for this data.
>
> 2. By virtue of the right of access, the affected person can obtain from the controller information relating to specific data, to data included in a certain file, or to all their data subjected to processing.

However, when reasons of special complexity justify it, the person in charge of the file may request the affected person to specify the files in respect of which he wishes to exercise the right of access, and for this purpose he must provide him with a list of all the files."

Regarding the rest of the rights referred to in the query (right to rectification, cancellation and opposition), we refer to the provisions of the regulations (Title III LOPD, Title III RLOPD, and arts. 15 et seq. RGPD).

According to the data protection regulations, the rights of access, rectification, cancellation and opposition are very personal rights, and must be exercised by the affected person (art. 23.1 RLOPD), although, in relation to persons under age that cannot exercise their rights by themselves, the regulations provide for the exercise of these rights by representation.

Thus, article 23.1.b) of the RLOPD establishes that, with regard to the exercise of the rights of access, rectification, cancellation and opposition, when the affected person is in a situation of incapacity or "minority of age that makes the personal exercise of these rights impossible", they can be exercised by their legal representative, in which case it is necessary to prove this condition.

As this Authority has ruled on previous occasions (among others, Opinion CNS 13/2015, CNS 33/2015, CNS 33/2017 or CNS 58/2017, which can be consulted on the Authority's website, www.apdcat.gencat.cat), the regulations provide that the parents are the holders of parental authority over unemancipated minor children (Article 236-1 of Book Two of the Civil Code of Catalonia, hereinafter CCC).

The exercise of authority over the children involves their legal representation (art. 236-18 CCC). The second section of the same article 236-18, excludes from the legal representation of children, among others, "the acts relating to the rights of personality, unless the laws that regulate them establish something else."

In this regard, it should be borne in mind that the regulations in the health field expressly provide for the possibility that the patient's right of access to the clinical history can also be exercised by representation, as long as it is duly accredited (article 13.3 of Law 21 /2000, of December 29, on the rights of information concerning the patient's health and autonomy, and clinical documentation, and article 18.2 of Law 41/2002, of November 14, basic, regulating the patient autonomy and rights and obligations regarding information and clinical documentation).

Therefore, at the outset, it is clear that the parents of minors, to the extent that they exercise their legal representation based on the provisions of the regulations, can exercise the rights of habeas data in the name and representation of the minors and, consequently, must be able to have access to minors' health information.

Having said that, as the consultation points out, with regard to minors from the age of 14, the regulations recognize a certain capacity for action in relation to their right to informational self-determination.

Article 13.1 of the same RLOPD recognizes minors who are over 14 years of age the ability to consent to the processing of personal data, so it should be concluded that minors who are over 14 years of age can also exercise the rights inherent in informative self-determination, because it would not make sense to recognize the capacity to consent to the treatment and not to access to consult the treated information, or to exercise the rest of the aforementioned rights.

We note that, although the consultation mentions that "a minor under the age of 14 who is not incapacitated" could exercise their rights of informative self-determination, the data protection regulations recognize the right to exercise the rights by themselves mentioned to minors over the age of 14 (and not to those under 14).

In any case, having made this clarification, according to the aforementioned regulations, as a general rule, minors who are over 14 years of age and who are not incapacitated must be able to exercise the rights of informative self-determination for themselves.

However, as this Authority has also agreed, the fact that the regulations provide for the exercise of the aforementioned rights by minors over the age of 14 should not lead to the conclusion that parents who have parental authority cannot access the clinical documentation of the minor child, even when he is over 14 years old.

In this sense, it must be borne in mind that the aforementioned parental authority is an inexcusable function that is exercised in the interest of the children (art. 236-2 CCC), and that this function justifies access to the minor's information.

To this it should be added that article 236-17 CCC, which regulates relations between parents and children, states that: "1. Parents, by virtue of their parental responsibilities, must take care of their children, provide them with food in the broadest sense, live with them, educate them and provide them with a comprehensive education. (...).” This duty of care regarding children obviously includes care regarding their state of health.

In fact, Law 21/2000 itself provides that "if the patient, in the judgment of the doctor responsible for the assistance, is not competent to understand the information, because he is in a physical or mental state that does not allow him to -if you are in charge of your situation, you must also inform your family members or the people who are related to you" (art. 3.3). Obviously, this situation in many cases will be predictable with respect to minors.

For all this, it is clear that the duties that the legal system attributes to the holders of parental authority, enable them to access the clinical documentation that affects the minors subject to their authority and, by extension, the exercise of the rest of the informational self-determination rights referred to in the query (rectification, cancellation and opposition), on behalf of minors, including minors over 14 years of age.

This, without prejudice to the fact that minors over the age of 14 can also exercise their rights of informative self-determination directly, a possibility that, as has been explained, is also provided for in the regulations, and which is not incompatible with the exercise of rights by parents or legal representatives.

In conclusion, for the purposes of the query formulated, the possibility of exercising informational self-determination rights, on the one hand, by the minor himself or herself over 14 years of age, and on the other, by the parents or legal representatives of this minor , are not incompatible or exclusive, since both are provided for in the regulations. Therefore, the exercise of the aforementioned rights by the parents or legal representatives of the minors, which is foreseen and enabled by the aforementioned regulations, would not entail, from the perspective of the protection of personal data, a violation of the rights of the minor, nor does it involve illegitimate access to the minor's information, nor a "violation of the confidentiality" of the minor's information, in the terms mentioned in the query.

IV

Having said that, it cannot be ruled out that, in specific cases, and given the circumstances of the case, the regulations allow limiting the access of parents or legal representatives to certain health data of the minor and, ultimately, the exercise of the rights referred to in the query.

As this Authority has agreed, it is necessary to take into account article 17.1 of Law 14/2010, of 27 May, on rights and opportunities in childhood and adolescence (LDOIA), according to which: "children and adolescents can exercise and defend their rights themselves, unless the law limits this exercise. In any case, they can do it through their legal representatives, **as long as they don't have interests that conflict** with their own."

According to article 5 of the LDOIA:

> "1. The best interest of the child or adolescent must be the inspiring and foundational principle of public actions.
>
> 2. Rules and public policies must be evaluated from the perspective of children and adolescents, to ensure that they include relevant objectives and actions aimed at satisfying the best interests of these people.
> Children and adolescents must actively participate in this assessment.
>
> 3. The best interests of the child or adolescent must also be the inspiring principle of all the decisions and actions that concern them adopted and carried out by the parents, by the guardians or guardians, by the public or private institutions in charge of protecting and assisting him or by the judicial or administrative authority.
>
> 4. In order to determine the best interests of the child or adolescent, their needs and rights must be taken into account, and their opinion, their wishes and aspirations must be taken into account, as well as the their individuality within the family and social framework."

In accordance with these regulatory provisions, the exercise of the rights of informative self-determination on behalf of the minor without the need for his authorization, which the parents or legal representatives must be able to exercise in general, may be limited if there a conflict between them and the minor himself, in which case the general principle of protection of the minor's best interests must prevail (art. 5 LDOIA), in the terms provided for in the regulations.

The prevalence of this principle could underpin the limitation of parents' or legal representatives' access to minor's data and, in short, the exercise of their right to informational self-determination, in relation to health data from
minor

It is worth saying that the query is formulated in general terms, and not in relation to a specific problem or situation related to the exercise of the rights of informative self-determination by parents or guardians of minors (situations of helplessness or risk of minors, conflicts between the parents regarding the exercise of parental authority or custody of the minor, problems in relation to certain medical interventions on the minor, etc.).

Therefore, we note that it will be necessary to be aware of the circumstances of each case, in order to consider whether there are factual and regulatory elements that can justify the limitation or exclusion of the exercise of the rights of informative self-determination by parents or legal representatives, in relation to certain health data of the minor.

For example, it should be borne in mind that the regulations provide for the possibility of depriving parents of parental authority (art. 236-6 CCC). Thus, as this Authority has highlighted (Opinion CNS 58/2017), in the event that parental authority is suspended - as may happen, for example, as a result of the instruction of a procedure of destitution in the terms provided for in regulations (article 228-1 CCC, and arts. 106 et seq. LDOIA)-, the exercise of the rights in question by the person or persons exercising said parental authority would be impossible, at least, while the suspension lasts or the deprivation of said power.

Nor can it be ruled out that, in specific cases and with respect to specific medical procedures, the minor himself who is over 14 years of age may exercise the right, as the owner of his personal data, to limit or even to prevent the access of their parents or guardians to certain health data. This is what this Authority has done in Opinion CNS 33/2017 (Legal Basis V), to which we refer.

Also by way of example, Organic Law 2/2010, of March 3, on sexual and reproductive health and the voluntary termination of pregnancy, provides (art. 13) that information about this fact to the parents of women aged 16 or 17 who have decided on the voluntary termination of pregnancy can be limited to one of the parents or none of them when circumstances arise that could generate a conflict to the detriment of the minor:

> "Fourth In the case of 16- and 17-year-old women, consent to the voluntary termination of pregnancy corresponds exclusively to them in accordance with the general regime applicable to older women.
> At least one of the legal representatives, father or mother, persons with parental authority or guardians of the women in those ages must be informed of the woman's decision.
>
> This information will be dispensed with when the minor alleges that this will cause a serious conflict, manifested in the certain danger of domestic violence, threats, coercion, ill treatment, or a situation of uprooting or helplessness occurs.

If this assumption is made, and the minor alleges the existence of a conflict in a well-founded way, this should mean that the parents or guardians cannot access certain health information of this minor, in the terms provided for in the regulations

The legal system, in these and other rules, foresees certain situations or circumstances in which the principle of the best interests of the minor - which must inform all actions carried out towards minors and, therefore, also the actions in the health field-, would allow parents or guardians to exclude access and knowledge of certain medical information of the minor (information to which, in principle, they should have access for the fulfillment of the duties required by the legal system itself, in the terms indicated) and, in short, the exercise of the rights of informative self-determination by the parents or guardians, in relation to the minor's personal health data, in the terms provided for in the regulations.

For all this, it cannot be ruled out that, in specific cases, and given the concurrent circumstances, the applicable regulations must lead to the data controller (art. 3.d)

LOPD and art. 4.7 RGPD) to deny the minor's parents or legal representatives access to certain health information of the latter, either directly or, where appropriate, through the person in charge of the treatment (arts. 3.g) and 12 LOPD , arts. 20 to 22 RLOPD, and arts. 4.8 and 28 et seq. RGPD).

In any case, the person responsible for the treatment must take into account the circumstances that may arise in each case, in relation to the limitation of the exercise of the rights inherent in informative self-determination by the parents or legal representatives in relation to the data of the minor, in the terms provided for in the regulations.

In accordance with the considerations made in this opinion in relation to the query raised, the following are made,

Conclusions

Minors over the age of 14, who are not incapacitated, must be able to exercise the rights inherent in informative self-determination for themselves.

The exercise of the rights by the parents or legal representatives of the minor - including the minor who is over 14 years old -, in relation to the personal information of the latter, which is foreseen and enabled by the regulations, would not imply illegitimate access to the child's information or a "breach of the confidentiality" of the child's information.

Without prejudice to this, in those cases in which there is a conflict between the parents or legal representatives and the minor himself, by application of the principle of protection of the best interests of the minor (art. 5 LDOIA), the exercise of the rights on the part of these regarding certain health data of the minor, may be limited, depending on the circumstances of the specific case.

Barcelona, March 19, 2018