

The Grey Digital Divide and the Right to be Forgotten: An Inter-American Approach

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Abstract

To exercise several human rights, old persons must know about the existence of records containing personal information, who keeps them, for which purpose, and in which format. However, this is not always the case. Hence, how can states guarantee the right to be forgotten in the health care system when people do not understand how digital archives work? To answer this question it is necessary to review what informed consent implies in the digital era. In this paper, I present the Inter-American approach to this issue. The Inter-American Convention on Protecting the Human Rights of Older Persons (IACPOP) entered into force in January 11, 2017, and among others, it promotes the rights to health and freedom of expression of the elderly. It establishes in articles 11 and 19 that states parties must obtain access to appropriated health-related information as a mechanism to ensure that older people provide informed consent in any type of medical procedure. However, because it does not contain an express reference to the right to be forgotten, in the article I also review the Inter-American Convention of Human Rights, and the principles developed by the inter-American system regarding the right to access information and the right to be forgotten. After the explanation of the effects of the digital divide among the elderly in Latin America and the analysis of the scope of protection granted by the informed consent, I discuss how older people can initiate *habeas data* procedure to exercise their right.

Keywords: Older People, Right to be Forgotten, Access to Information, Health-related Information, Inter-American System

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I. Introduction

The right to health “must be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health.”¹ To obtain it, people need to exercise other human rights, especially the right to freedom of expression. In fact, access to information is an essential element for the exercise of the right to health. Any person not only has the right to seek, receive and impart ideas on health issues but also has the right “to have personal health data treated with confidentiality.”² Technological developments contribute to the achievement of these obligations, but they also pose several challenges.

Older people face various problems derived from the uses of new technologies in health care systems, especially new information and communication technologies (ICT). The digital divide impedes them from accessing ICT and educational programs designed to teach them how to use these technologies. This situation creates a barrier for the exercise of the right to health in the digital era. Furthermore, if elder people cannot understand how information is stored and used they cannot exercise their right to freedom of expression or the right to be forgotten.

Obligations related to the exercise of the right to access to information require that old persons get information regarding the existence of records containing personal information, who keeps that information, for which purpose, and in which format. In the digital era this is a growing barrier that we need to overcome. Hence, it is necessary to question how states can fulfill these international obligations when people do not understand how digital archives work. In this paper, I analyze Inter-American human rights law to find a legal solution to this problem.

I start with the discussion of the effects of the digital divide for older people in Latin America. To map the situation and describe some of the factors that impede the exercise of the right to be forgotten, I illustrate the situation through the use of

¹ UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)*, 11 August 2000, E/C.12/2000/4. Para 9.

² *Ibid.*, para. 12.

statistics and examples. Then, I continue with the legal analysis of the obligations adopted by Latin American states to specify the relationship between the right to freedom of expression and informed consent. In this part, I pay special attention to the characteristics of the information shared and the consequences of its classification as public or private, not only to determine what informed consent implies but also to examine which type of information can be removed from records. To conclude I discuss the legal mechanism developed by Latin American states to ensure the exercise of the right to be forgotten.

Throughout the paper I consider the Inter-American Convention on Protecting the Human Rights of Older Persons (IACPOP), the American Convention of Human Rights (ACHR), and the principles developed by the Inter-American system regarding the right to access information and the right to be forgotten. This approach favors the discussion of the existing legal alternatives than can improve the protection of this right. Moreover, given the fact that the exercise of the right to be forgotten by older persons will set the basis for the development of legal standards in the future, in this article I also contribute ideas that can prevent states from violating the right to health and the right to be forgotten in the years to come.

II. The Grey Digital Divide in Latin America

The importance of the Internet and other ICT is increasing all over the world. The “Network Society” depends on the availability of information, and health-related data is not the exception.³ Technology developers and health practitioners are continuously searching for new forms to improve health standards. For that reason, digital platforms to provide or gather health-related information are more common every day. The availability of these technologies has numerous benefits and several consequences for different groups. Nevertheless, for the purpose of this article I only consider those related to the impacts of the digital divide for older persons.

³ Manuel Castells, *The Information Age: Economy, Society and Culture*, vol. 1 of *The Rise of the Network Society*. (Massachusetts: Blackwell Publishers, 1996).

The digital divide is usually related to the gap between those who can have access to the Internet and ICT and those who cannot.⁴ However, this approach is over-simplistic. Scholars argue that there are two types of divide. The first corresponds to access to the technology, and the second refers to the development of the capabilities needed to use it.⁵

Even though scholars tend to consider restrictions based on age, the study of the effects of these gaps among elder people remains understudied.⁶ One reason could be the lack of international definition of who is an older person.⁷ Yet, it was only until the adoption of the IACPOP⁸ that this situation changed. For this reason, it is difficult to obtain disaggregated data that considers the effects of age differences all over the world.⁹

Nonetheless, the Economic Commission for Latin America and the Caribbean (ECLAC) has conducted research in the region, and in 2017 it found that Latin American societies are aging and that “on average, in the period 2015-2020 a person aged 60 has 22.4 years left to live.”¹⁰ It also indicated that older people represented approximately 11.8% of the population in 2017, and that by 2030 the number is expected to

⁴ UN Human Rights Council, *Report of the Special Rapporteur on the Promotion and Protection of the Right to Freedom of Opinion and Expression: Addendum, Communications to and from Governments*, May 16, 2011, A/HRC/17/27. Para. 61.

⁵ Nnenna Ajufo, “Technology and Human Rights: Revisiting the Role of ICT in Bridging Gender Inequality in Sub-Saharan Africa,” in *Human Rights and Technology: The 2030 Agenda for Sustainable Development*, ed. Mariateresa Garrido V., (San Jose: University for Peace, 2017), 139-162; Martin R. Hilbert, *Latin America on its Path into the Digital Age: Where Are We?* (Santiago: United Nations, 2001); Jan van Dijk, “A Theory of the Digital Divide,” in *The Digital Divide*, ed. Massimo Ragnedda and Glenn W. Muschert (London and New York: Routledge, 2013), 29-51.

⁶ Thomas N. Friemel, “The Digital Divide has Grown Old: Determinants of a Digital Divide among Seniors,” *New Media & Society* 16, no. 4 (June 2014): 4.

⁷ United Nations Office of the High Commissioner for Human Rights, *Normative Standards in International Human Rights Law in relation to Older Persons*. Analytical Outcome Paper (New York: United Nations Office of the High Commissioner for Human Rights, 2012), 6.

⁸ IACPOP, Article 2 (“Older person”: A person aged 60 or older, except where legislation has determined a minimum age that is lesser or greater, provided that it is not over 65 years. This concept includes, among others, elderly persons).

⁹ André C. Medici, “How Age Influences the Demand for Health Care in Latin America,” in *Population Aging: Is Latin America Ready?*, ed. Daniel Cotlear (Washington D.C.: World Bank, 2011), 135-189; Peter Millward, “The ‘Grey Digital Divide’: Perceptions, Exclusion and Barriers of Access to the Internet for Older People,” *First Monday* 8, no. 7 (July 2003).

¹⁰ Economic Commission for Latin America and the Caribbean [ECLAC], *Challenges to the Autonomy and Interdependent Rights of Older Persons* (Santiago: United Nations, 2017), 18.

increase to 17%. Furthermore, approximately 41% of Latin America older people have some form of disability, and women are among the most affected.¹¹

In relation to ICT, in 2001 half of the Latin-American Internet users were men, younger than 25 years old, living in urban areas, from upper and middle classes.¹² This led scholars to focus on the effects of the digital divide in younger generations.¹³ The situation has not changed. In fact, in 2016 the Organization of American States Special Rapporteur for Freedom of Expression (OASSR) found that one-third of the population did not have access to the Internet. He indicated that the divide “is most likely to impact upon poor, isolated and remote communities who can therefore be doubly disadvantaged by losing access to all communication services, not just digital ones.”¹⁴ Older persons are among the most vulnerable. They are an understudied group and possibilities to obtain updated information of the grey digital divide are scarce.

In relation to digital skills, it is noticeable that the statistics elaborated by ECLAC show a diminution on the illiteracy rate among older people, with considerable differences between men and women, and between those living in rural and urban areas.¹⁵ Nonetheless, these numbers do not reflect the reality regarding the creation of digital skills or health literacy (i.e. management of the medium and access to digital information, comprehension of medical recommendations or treatments).¹⁶ Actually, in 2009 the U.S. Department of Health and Human Services reported that health literacy skills among citizens older than 65 years were very deficient. Twenty-nine per cent of participants reported to have skills below basic, 30% basic knowledge, while only 3 percent considered themselves proficient.¹⁷ Both skills are indispensable. There is no

¹¹ Ibid. 29, 39-42.

¹² Hilbert, 12, 43, 46.

¹³ cf. Daniela Trucco, “The Digital Divide in the Latin American Context,” in *The Digital Divide*, ed. Massimo Ragnedda and Glenn W Muschert (London and New York: Routledge, 2013) , 251-269.

¹⁴ Edison Lanza, *Annual Report of the Office of the Special Rapporteur for Freedom of Expression* (Washington DC: Inter-American Commission of Human Rights, 2017), 406.

¹⁵ ECLAC, *Challenges to the Autonomy*, 35-36.

¹⁶ Digital skills are known as information skills, and in accordance to van Dijk they are “the skills to search, select, and process information in computer and network sources. They can be defined as the capacities to use computer and network sources as the means for particular goals and for the general goal of improving one’s position in society” (van Dijk, 40).

¹⁷ Centers for Disease Control and Prevention, *Improving Health Literacy for Older Adults: Expert*

point in accessing the Internet if the person cannot research health-related information, or fully comprehend medical terms, because in the end, it is like not having any information.

The U.S. Department of Health and Human Services also indicated that, besides the problems related to accessing ICT, there were problems linked to the use of these technologies. In fact, health practitioners reported that:

... there are specific skills required to use the Internet to obtain health information. Older adults may have problems with technical jargon, scientific terms, and search engines that do not return suitable results. They may not be able to discern the quality of the information presented.¹⁸

Several countries have addressed this situation. For example, in 2009, the government of Panama launched the program “*Info Plazas*” to develop digital skills among older persons, and Telecom Argentina developed a free training program for older persons.¹⁹ However, the efficacy of these initiatives on health-related issues has not been tested.

Hence, although it is difficult to map the situation with updated data, it is possible to affirm that in Latin America the grey divide is a reality that affects millions of people. In the era of big data and increasing dependence on ICT, this situation presents many challenges for the protection of their human rights.

III. The Right to Freedom of Expression and the Right to Health

To exercise the right to health and the right to be forgotten, it is essential that people can seek, receive, and impart information. These three rights are internationally guaranteed as the right to freedom of expression.²⁰ And, although it seems obvious,

Panel Report 2009 (Atlanta: U.S. Department of Health and Human Services, 2009), 2.

¹⁸ *Ibid.*, 6.

¹⁹ cf. CETAL, *Programas de Alfabetización Digital en América Latina* (Santiago: Centro de Estudios de Telecomunicaciones de América Latina, 2014).

²⁰ United Nations General Assembly, 1966. “International Covenant on Civil and Political Rights,”

older person enjoy this right. Article 14 of the IACPOP expressly indicates that:

Older persons have the right to freedom of expression and opinion, and access to information on an equal basis with other sectors of the population, by whatever medium they choose. States Parties shall adopt measures to ensure the effective exercise of these rights by older persons.

Due to the importance of having access to information, OASSR considers it as a fundamental right.²¹ Hence, within the Inter-American system, access to information is a precondition for the exercise of the right to health, especially to provide informed consent and the right to be forgotten.

To guarantee it, states are obliged to observe the principle of maximum disclosure, which indicates that information produced by public authorities and institutions must be available to the public in a timely, complete, accessible, and reliable manner.²² The principle of maximum disclosure is a general principle that is extremely important to obtain informed consent. Actually, the ECLAC argues that national policies and programs should be designed in a manner in which:

... information on health-related issues is freely available on a non-discriminatory basis, accessible in view of the particular communication needs of the individual, and presented in an acceptable manner from cultural and other perspectives, so that the person granting the consent understands all the implications of the decision being made.²³

Treaty Series 999, Article 19 (December): 171; Organization of American States (OAS), *American Convention on Human Rights: Pact of San Jose, Costa Rica*, November 22, 1969, Article 13.

²¹ Inter-American Commission on Human Rights, Office of the Special Rapporteur for Freedom of Expression. *The Inter-American Legal Framework regarding the Right to Access to Information* (Washington D.C.: Organization of American States, 2011).

²² Catalina Botero, *Annual Report of the Inter-American Commission on Human Rights 2009: Report of the Special Rapporteur for Freedom of Expression* (Washington D.C.: Inter-American Commission of Human Rights, 2009), 304; Inter-American Commission of Human Rights, *Access to Information, Violence against Women, and the Administration of Justice in the Americas* (Washington D.C.: Organization of American States, 2015), para. 18, 25.

However, the right to access to information is not absolute.²⁴ States can impose restrictions to access certain data, and confidentiality is a legal exception to the observance of the principle of maximum disclosure on health-related cases. Actually, the IACHR argues, “Confidentiality is a duty of healthcare professionals who receive private information in a medical environment, and maintaining the confidentiality or privacy of information they obtain from their patients.”²⁵

Moreover, according to the International Code of Medical Ethics all physicians shall respect the right of their patients and “preserve absolute confidentiality on all he knows about his patient even after the patient has died.”²⁶ In consequence, for doctors it is a right and a duty that remains in time.²⁷ However, it is undeniable that other actors need to consult that information.

Health care personnel, including students, need to access information that can help them to provide better service to patients. The concerned person and her or his family shall also have access to it. States must have access to certain type of information to fulfill international obligations related to national statistics and implementation of the right to health. And society has the right to access health-related information, not only for public health but also for public policies. Because stakeholders need that data, health-related information is kept in several records and for different purposes. Doctors and hospitals keep personal medical history while public authorities keep information that can help them to attend to people’s needs. Both groups are interested in preserving the data, and nowadays, they are increasingly relying on digital archives. Yet, the problem is that the majority of patients are not consulted on this issue. Informed consent has not been linked to the decision that patients can make regarding the storage and use of their personal information. People have the right to determine what will be shared and what will

²³ ECLAC, *Challenges to the Autonomy*, 92.

²⁴ IACHR, *Access to Information*, para. 33.

²⁵ IACHR, *The Inter-American Legal Framework*, para. 76.

²⁶ World Medical Association, *WMA International Code of Medical Ethics*. October 2006, (accessed July 21, 2017), <https://www.wma.net/policies-post/wma-international-code-of-medical-ethics/>.

²⁷ Under international law, this obligation does not cease to exist after a determined period. Domestic regulations tend to follow this criterion (i.e. Australia, Spain, Venezuela); however, states have the sovereign right to regulate this obligation in a different manner.

remain confidential, to know how their personal data will be stored and managed, and if necessary how it can be corrected or deleted from records.

In the digital era it is particularly important to know if data will be kept in digital archives, if it will be available online, who can access it, and how the patient can use it. Without this minimum knowledge, it is impossible to exercise the right to be forgotten. However, before analyzing how older persons can exercise that right, it is necessary to review the character of the information because its management depends on its classification.

A. Health-related Information: Public or Private?

Article 10 of the Additional Protocol to the American Convention on Human Rights in the area of Economic, Social and Cultural Rights “Protocol of San Salvador” indicates that health is a public good. Hence, *mutatis mutandi* all health-related information that is under the control of the state is public.²⁸ In consequence, public authorities must make that data accessible to all people, and use it to demonstrate compliance of international obligations. However, this assumption is not absolute. Not all information can be treated as public.

The type of information that should be accessible for all is related to the content and scope of the right to health. States must disseminate data about diseases, health-care programs and treatments associated with one’s health, and their consequences for the affected person.²⁹ To fulfill this obligation, the IACHR developed several monitoring instruments. These tools seek to avoid duplication of efforts in collecting and processing data, and improve measures on progress.³⁰ The data that states should gather to complete them is varied; however, it must include

²⁸ Public information is “information that is in the care of, possession of, or being administered by the State; the information that the State produces, or the information that it is obliged to produce; the information that is under the control of those who administer public services and funds and pertains to those specific services or funds; and the information that the State collects and that it is obligated to collect in the performance of its functions” (Botero, 309).

²⁹ Article 19, *A Healthy Knowledge: Right to Information and the Right to Health* (London: Article 19, 2012), 6.

³⁰ Inter-American Commission on Human Rights, *Guidelines for Preparation of Progress Indicators in the Area of Economic, Social and Cultural Rights* (Washington D.C.: Organization of American States, 2008).

information related to age, sex, income, location (rural or urban), average of expenditure on health, diseases, disabilities, and medical procedures practiced (i.e. number of abortions).³¹ The problem is that this data is personal in nature. The immediate consequence of this situation is that even if patients would not like to share that personal data, they will have to provide it to serve public interests.³² Nonetheless, the state's obligation to respect privacy and to ensure confidentiality of the information given by the patient remains.

States must respect human rights and health care providers must observe domestic laws. Yet, if not all information can be fully protected, which type of data can actually remain confidential? To solve this conflict, scholars argue that the type of information that should be protected is the one:

- (1) that reveals the identity of the individual whose health care is the subject of the information (e.g., health data that refer to the name, social security number, or any other information about the person who is the subject of the data) or (2) that, in cases where there is a reasonable basis to believe, could be used (either alone or with other information that is known to be available to predictable recipients of such information) to reveal the identity of that individual.³³

Within this context, it seems that the underlying assumption is that health-related information is partially private. Health care providers must protect information that can make the patient identifiable.³⁴ Nevertheless, if public authorities need specific

³¹ Ibid.

³² For example, Article 25 of the Venezuelan Law on the Exercise of Medicine indicates that health care providers must provide the data requested by authorities (the law is available in Spanish at: <http://www.ginecowed.com/PDF/Ley-del-Ejercicio-de-la-Medicina.pdf>). Article 5 of the Costa Rican General Law on Health indicates that any person is obliged to provide information requested by national authorities and needed to develop national plans and policies on health-related issues (the law is available in Spanish at: <https://costarica.eregulations.org/media/1-5395.pdf>); similarly, Article 13 of the Chilean Law regarding the rights and duties of people in relation to actions related to their health care indicates that the National Institute on Public Health can request information contained in the medical history in the exercise of its faculties (the law is available in Spanish at: <https://www.leychile.cl/Navegar?idNorma=1039348#dato0>).

³³ Lawrence O. Gostin, James G. Hodge Jr., and Ronald O. Valdiserri, "Informational Privacy and the Public's Health: The Model State Public Health Privacy Act," *American Journal of Public Health* 91, no. 9 (2001): 1390.

data, doctors have to provide the information requested. The affected person is the missing factor in this equation. Patients' data is private; therefore, it is necessary to question if they have the right to indicate which information can be shared, or in other words, should this issue be included as an aspect of informed consent?

B. Informed Consent in the Digital Era

For the United Nations Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health informed consent is:

... not mere acceptance of a medical intervention, but a voluntary and sufficiently informed decision, protecting the right of the patient to be involved in medical decision-making, and assigning associated duties and obligations to health-care providers.³⁵

The Inter-American Commission of Human Rights (IACHR) defines it as “an ethical principle of respect for individual autonomy,”³⁶ and the ECLAC indicates that it is “a voluntary and sufficiently informed decision.”³⁷ Furthermore, the ECLAC recognizes that it implies the exercise of other human rights, as in “the right to self-determination, non-discrimination, freedom from non-consensual experimentation, security and dignity of the human person, recognition before the law, and freedom of thought and expression.”³⁸

All of these concepts have one issue in common: access to information. Nevertheless, to receive information without understanding it is like not receiving it at all. For that reason, the IACHR includes understanding as a key element of informed consent, and refers to the following factors as integral parts of the informed consent

³⁴ Ibid., 1389.

³⁵ United Nations General Assembly Resolution A/64/272, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, A/64/272 (10 August 2009), 5.

³⁶ IACHR, *The Inter-American Legal Framework*, 43.

³⁷ ECLAC, *Challenges to the Autonomy*, 91.

³⁸ Ibid.

process:

- I. To provide and obtain information about the nature of the procedure, treatment options, and reasonable alternatives, including the potential benefits and risks of proposed procedures. People must have access to information in a timely, complete, accessible, and reliable manner.³⁹
- II. To consider people's needs and abilities when providing information with the aim of ensuring that the person understands the information given.⁴⁰
- III. To ensure that the consent is given in a free and voluntary manner. Therefore, it cannot be obtained under coercion or influence of any kind, and when possible, in a written format.⁴¹

Autonomy and independence to make decisions are equally important to provide informed consent.⁴² However, one of the main challenges that states face in relationship to older persons is to guarantee their autonomy.⁴³ In fact, within the domestic legal frameworks, some of the protection measures that can be legally adopted can diminish their factual autonomy, and affect older person's capacities to make decisions.⁴⁴ Inter-American states, conscious about this problem, decided to include it in the IACPOP independence and autonomy as a human right. In particular, they recognized in Article 7 that:

the right of older persons to make decisions, to determine their life plans, to lead an autonomous and independent life in keeping with

³⁹ IACHR, *The Inter-American Legal Framework*, para. 45.

⁴⁰ *Ibid.*, para 57.

⁴¹ *Ibid.*, para. 61, 72.

⁴² UNGA Res. A/64/272, paras. 10, 13.

⁴³ "[A]utonomy refers to the ability to exercise freedom of choice and control over the decisions affecting one's life, including with the help of someone else if needed, independence means to live in the community without assistance or, at least, where the help provided does not subject older persons to the decisions of others" (ECLAC 2017, 88).

⁴⁴ ECLAC, *Challenges to the Autonomy*, 67.

their traditions and beliefs on an equal basis, and to be afforded access to mechanisms enabling them to exercise their rights.

In addition, in Article 30 of the same document, they also recognized “that older persons enjoy legal capacity on an equal basis with others in all aspects of life.” And in consequence, they also enjoy the right to access to justice in any type of procedure to which they could be party.⁴⁵

The exercise of these rights is what allows for the provision of informed consent. If an older person cannot make decisions in an autonomous and independent manner, the consent provided shall be considered null. However, the main problem of these arguments is that they limit access to health-related information to the available treatments options and consequences.⁴⁶ Discussions over the management of their personal data are usually not part of the conversation, and in the digital era this fact creates several challenges.

The increasing use of Internet-based platforms to compile and share information has several benefits for monitoring compliance of international obligations, fostering research, improving treatments, and so on. Yet they facilitate the identification of persons. If storage systems do not follow a strict security protocol, anyone with access to databases could obtain private data and use it to identify patients. The dangers of this situation are many. Pharmaceuticals, private health care providers, and other private entities could obtain data on diseases and treatments for commercial purposes. Private persons could use health-related information to discriminate against people, to impede them from obtaining jobs, to blackmail them, etc. In consequence, it is necessary that patients indicate that they understand that some information has to be shared with public authorities, and provide their consent to share the ones that can remain confidential. Otherwise, it would be impossible to affirm that people consented to the use of their data for any purpose.⁴⁷

⁴⁵ Organization of American States (OAS), *Inter-American Convention on Protecting the Human Rights of Older Person*, (Washington D.C., November 2017), Article 31.

⁴⁶ IACHR, *The Inter-American Legal Framework*, para. 43.

⁴⁷ Department of International Law, OAS. *Data Protection. Privacy and Habeas Data*, 2014, (accessed August 2, 2017), http://www.oas.org/dil/data_protection_privacy_habeas_data.htm.

The World Health Organization, noticing the increasing importance of Internet-based platforms for medical purposes, requested to ICANN the adoption of generic safeguards, and in particular, asked for the inclusion of mechanisms to control the use of personal data. It indicated that people should “be able to limit the sharing of their data with third parties (including, among other things, for research and marketing purposes) and to revise their decisions at any time.”⁴⁸ Some technology developers have followed the inclusion of generic safeguard criteria. In fact, scholars found that there are three forms in which websites and health applications are obtaining consent: (i) research participation as a condition of use of the site,⁴⁹ (ii) opt-in to research,⁵⁰ and (iii) opt-out of research.⁵¹ However, all of these forms assume that users comprehend what are they agreeing to, how the platform works, and who can access their data. As already discussed, this assumption is far from being true, and statistics corroborate it.

In the case of older persons, Anand Grover, Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, argued that they the elderly can barely understand health information, digital technologies, how information is treated, and the consequences of sharing private information.⁵² For that reason, it is essential to ensure that people can access information, understand it, and provide consent.

⁴⁸ World Health Organization, *The Health Internet*, May 15, 2014, (accessed July 31, 2017), <http://www.who.int/ehealth/programmes/governance/en/index3.html>.

⁴⁹ Condition of use occurs when the websites include in their term of use, service or privacy statements, “that they maintain the right to use the data they collect for research, among other uses. By virtue of using the site, the user agrees to research participation,” see Effy Vayena, Anna Mastroianni, and Jeffrey Kahn, “Caught in the Web: Informed Consent for Online Health Research,” *Science Translational Medicine* 5, no. 173 (February 2013): 173fs6.

⁵⁰ In opt-in researches users can agree to participate in a specific research project. For example, “Websites that use opt-in may include a statement with information about the project followed by a link that leads to the project or a requirement to click an ‘I agree’ button to allow research use of personal data” (Ibid.).

⁵¹ In opt-out approaches users “agree to research uses of their data unless they take action to exclude themselves from participation. Users thereby control their data, provided they are aware that the opt-out option exists” (Ibid.).

⁵² United Nations General Assembly Resolution A/HRC/18/37, *Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/HRC/18/37 (July 4, 2011), para. 62-63.

These issues were considered in the IACPOP. Article 11 of this instrument protects the right to provide informed consent and it establishes that states must "...ensure that the information provided is appropriate, clear and timely, available on a non-discriminatory basis in an accessible and easily understood form, and commensurate with the older person's cultural identity, level of education, and communication needs."

Moreover, article 26 of the IACPOP expressly obliges states to adopt the measures to ensure access "to information and communications, including information and communications technologies and system." It also promotes the development of programs to train stakeholders on the skills required to assist and support older persons in the process of accessing information, including access to ICT and the Internet at the lowest possible cost.⁵³

Today's societies depend on the availability of information, but that data cannot be obtained without people's consent. Informed consent processes must include this aspect because if people do not know who keeps information and how it is stored, they cannot exercise other human rights, especially the right to be forgotten.

IV. Right to be Forgotten

Before considering how this right is protected in the Inter-American system, it is necessary to bear in mind that "European legal developments in the so-called Right to Be Forgotten fit poorly with legal and human rights frameworks in Latin America."⁵⁴ In the Inter-American system, the exercise of the right to freedom of expression and the legal mechanisms protecting it have been developed to avoid abuses from authoritarian regimes, to fight corruption, and to guarantee that victims of mass violations of human rights can know the truth of what happened. Subsequently, in the Inter-American system the right to be forgotten is included as part of the right to freedom of expression.⁵⁵

⁵³ IACPOP, Article 26 (c-e).

⁵⁴ Daphne Keller, "Europe's 'Right to Be Forgotten' in Latin America," in *Towards an Internet Free of Censorship II Perspectives in Latin America*, ed. Agustina Del Campo (Buenos Aires: Universidad de Palermo. Facultad de Derecho CELE, 2017), 153.

⁵⁵ Luisa Parraguez Kobek and Erick Caldera, "Cyber Security and Habeas Data: The Latin American Response to Information Security and Data Protection," *Oasis* 24 (2016):118-119.

As already explained, to exercise it people must have access to information, and for that reason, principle 3 of the Inter-American Declaration of Principles on Freedom of Expression specifies that:

Every person has the right to access to information about himself or herself or his/her assets expeditiously and not onerously, whether it be contained in databases or public or private registries, and if necessary to update it, correct it and/or amend it.

Yet, to update, correct, amend and delete information, it is necessary to initiate the appropriate legal mechanism. States have the general obligation to implement all the measures needed to guarantee the protection of human rights, and in accordance to Article 25 of the ACHR:

Everyone has the right to simple and prompt recourse, or any other effective recourse, to a competent court or tribunal for protection against acts that violate his fundamental rights recognized by the constitution or laws of the state concerned or by this Convention, even though such violation may have been committed by persons acting in the course of their official duties.

To ensure that older persons can exercise their human rights, the IACPOP indicates that access to justice is a human right (Article 31), and effective judicial protection is a general principle that must be observed in any type of legal procedure (Article 3.n). Hence, unlike the European system, the exercise of the right to be forgotten is strongly linked to the due process of law protected under article 8 of the ACHR. Latin American judges are the only ones who can decide if the information should be updated, corrected, or deleted.

In the region, countries ensure the exercise of the right to be forgotten of older people through the use of the habeas data procedure. This mechanism grants to the affected person the right to control personal information, and to stop the abuse of personal data.⁵⁶ This mechanism is defined as:

the writ, or the formal written order and the legal notion by which a person may request to see any and all information that a company or government agency has about them. The latter presupposes a guarantee about the manipulation and use of the information, and citizens or clients must have access to this information in order to verify, update or modify their information.⁵⁷

Furthermore, the OASSR indicated that this mechanism is based on three premises:

- (1) the right of any individual to not have his privacy disturbed,
- (2) the right of any individual to access information about him or herself that is contained in public or private databases, and to modify, remove, or correct information if it is sensitive, false, biased, or discriminatory,
- (3) the right of any individual to use habeas data action as a mechanism for obtaining access to evidence required in judicial proceedings.⁵⁸

It is noticeable that the IACHR argues that the types of information that this right covers includes:

information in the State's custody, management, or possession; information the State produces, or information it is obliged to produce; information in the possession of those who manage public services or public funds; information the State receives, or is required to collect in the course of performing its duties; and information concerning one's own personal data (habeas data) or property held by those who administer private databases or registries and are legally required to provide it.⁵⁹

⁵⁶ Department of International Law, OAS. *Data Protection*.

⁵⁷ Parraguez Kobek and Caldera, 114.

⁵⁸ IACHR, *The Inter-American Legal Framework*, para. 63.

⁵⁹ *Ibid.*, para. 18.

Private and public entities gather and archive health-related information. As already noticed, there is an increasing tendency to storage it in digital platforms, which are also subject to revision. Therefore, to guarantee the exercise to be forgotten on health-related issues, state's authorities must ensure that individuals can:

- Establish the existence of a file containing information or data about their personal health, inquire about the reasons for its creation, determine the identity and address of the controller of the file and any parties who have access to the file;
- Access the file or data in an intelligible form without delay or expense;
- Obtain the rectification or the erasure of the file or data if they have been processed contrary to appropriate safeguards;

Have a remedy if the request for confirmation, communication, rectification or erasure is not complied with.⁶⁰

In consequence, the action should be firstly directed against those who control the archive, and not against those publishing the information.⁶¹ They are the ones who gather it, but more importantly, they are the ones who bear the obligation to inform the person about the existence of the archives, and to obtain patient's consent to use it and share it.

Moreover, in the digital era, *habeas data* should allow people to demand from search engines the de-listing or de-indexing of certain kind of information, or to demand to websites' hosts to erase information that has been published.⁶² This possibility is what favors the implementation of the decision adopted by the judge. Nevertheless, we cannot forget that the exercise of the right to be forgotten depends

⁶⁰ Article 19, *A Healthy Knowledge*, 38.

⁶¹ Article 19, "The 'Right to be Forgotten': Remembering Freedom of Expression," *Policy Brief*. London: Article 19, 2016, 19.

⁶² Nelson Remolina Angarita, "Right to Be Forgotten in Cyberspace? International Principles and Considerations about Latin American Regulations," in *Towards an Internet Free of Censorship II Perspectives in Latin America*, ed. Agustina Del Campo (Buenos Aires: Universidad de Palermo. Facultad de Derecho CELE, 2017), 179-180.

on the state's obligation to provide information.⁶³ The principle of maximum disclosure indicates that the general rule that states need to observe is access to information.⁶⁴ General information on health-related issues must be published because it "is essential for identifying major problems, formulating public policies, and assigning the necessary resources."⁶⁵ Statistics concerning health issues must include data on the causes, consequences and frequency of diseases.⁶⁶ Information has to be disaggregated by gender, income, age, race, religion, disabilities, and geographic location; therefore, the possibilities to successfully exercise this right are very limited, even more for older persons.

V. Conclusions

Only a few Latin Americans can exercise the right to be forgotten in the digital era, and the number dramatically changes when we reduce that group to older persons. The majority of them cannot access ICT, and those who can actually afford it, have limited access to education programs to learn how to use these technologies. Indeed, it is worrying that reports on the the most urgent issues that should be considered by Latin American countries do not consider access to the Internet, ICT, or education programs for older people.⁶⁷ Currently, everybody needs to understand these technologies to exercise their rights.

Nevertheless, understanding technology is not all. Older people also need to acknowledge the fact that health care providers are gathering and archiving personal data for different purposes. All over the world, practitioners collect health-related information, and the majority of the time, people do not know or agree to the use of their personal data. Usually, health care providers are not trained to provide this type of information in an accessible form, and many of them could even argue that is not

⁶³ Ibid., 194.

⁶⁴ IACHR, *The Inter-American Legal Framework*, para. 10.

⁶⁵ Ibid., 107.

⁶⁶ Ibid., 108.

⁶⁷ ECLAC, *Challenges to the Autonomy*, para. 60.

their responsibility. Nevertheless, they are the information controllers, and as such, they are obliged to explain to patients how data will be stored and used. Thus, it is necessary to evaluate if the systems designed to obtain informed consent on health cases are the most adequate, and if they guarantee the exercise of other human rights.

States need health-related information to fulfill international obligations and to respect other's rights; yet, we cannot forget that that information is private in nature. Confidentiality must be guaranteed. Information that can be used to identify the patient should not be available, but in case it is published, the affected person has the right to request its removal. However, the exercise of this right is limited by the rights of others, and by the observance of state's obligations. Therefore, not all information can be deleted, and in accordance with Inter-American standards, judges are the ones who have the power to determine what can be erased.

In accordance with Inter-American standards, older people can address their petitions against those controlling the information. On health-related information, the responsible people are health care providers; therefore, actions should be directed against them. Furthermore, in the digital era this means that Internet Service Providers and other types of intermediaries operating in Latin America cannot remove information to respond to private requests. They can only decide the mechanism to ensure that the information can be deleted from servers or de-listed from search engines, and to obey a judicial request.

In consequence, within the Inter-American system, the right to be forgotten can only proceed when a judge finds that there are reasonable arguments to protect one's right without impeding others from exercising their rights. This model guarantees that the state is concerned with the protection of all human rights. Due to the fact that the judiciary has an active role in determining which information can be erased and who the duty bearer is, the rights to due process, freedom of expression, and health can be properly protected. Moreover, with this determination the judge will also guarantee that the state can access the information needed to ensure the exercise of the right to health. Nevertheless, we cannot forget that a complete elimination of records is impossible. As explained, only those requests in which the affected person seeks to impede her or his identification will be successful.

Yet, at present and without the intention of being pessimistic, for some older

people the possibilities to exercise the right to be forgotten in the digital era are very limited, while for others it is simply impossible. To change this situation in Latin America, states need to close the gray digital divide and ensure that older person can access the judiciary to initiate the corresponding legal procedure. To improve international standards, it will be necessary that more states follow the Inter-American approach and create the appropriate domestic mechanisms. Consequently, judgments will clarify when the right to be forgotten can be exercised, and when it will proceed.

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