

Difficulty in Accessing Information about Institutional Review Board

La dificultad en el acceso a información sobre Comités de Ética en Investigación

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ABSTRACT

Health research is essential for advancing scientific knowledge and involves different stages. The first step is writing a research project, which must be evaluated by an Institutional Review Board (IRB). However, not all researchers have easy access to an IRB and need to look for contact information. The objective of this research is to describe the existing information for accessing an IRB. Data were collected by reviewing the website of the National Ministry of Health and the health ministries of Argentina's jurisdictions.

Key words: Ethics Committees; Research Ethics Committees; access to information

RESUMEN

La investigación en salud es esencial para el avance de los conocimientos científicos y conlleva distintas etapas. La primera es la escritura de un proyecto de investigación que deberá ser evaluado por un Comité de Ética en Investigación (CEI). Pero no todos los investigadores tienen fácil acceso a dichos CEI y necesitan buscar información de contacto. El objetivo de este trabajo es describir la información existente para acceder a los CEI. Para recolectar los datos, se visitaron el sitio web del Ministerio de Salud de la Nación y los de los Ministerios de Salud de las jurisdicciones argentinas.

Palabras claves: Comités de ética; Comités de ética en investigación; Acceso a la información.

INTRODUCTION

Health research is essential for advancing scientific knowledge, but it must adhere to certain safeguards that cannot be overlooked. Research involving patients with respiratory diseases is no exception. Researchers must meet essential requirements, such as ethical evaluation of their proposals,¹ as this is a prerequisite for publication in high-impact journals² and for applying for

grants from research agencies or national and international funding institutions. This is reflected in the health research map of Argentina, which has been developed by Fernando Althabe and collaborators.³

In Argentina, the Civil and Commercial Code mandates that ethical evaluations be conducted by accredited Institutional Review Boards (IRBs). This regulation requires the establishment of Central Ethics Committees (CECs) in all the juris-

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dictions of the country where research involving human subjects is conducted. While some jurisdictions, such as the province of Buenos Aires, have had CEC for years, others have never established them. To address this disparity, the National Ministry of Health has collaborated with Provincial Health Ministries to support the creation of CECs, as evidenced by the Ministerial Network for Health Research in Argentina (Red Ministerial de Áreas de Investigación en Salud para Argentina, REMINSA).⁴ Moreover, at the time of this research, a website maintained by the National Ministry of Health provides centralized information on existing CECs and their contact details, although it is not always updated.

One of the tasks of the CECs, in addition to accrediting IRBs, is to promote their creation in health institutions where research involving human subjects is conducted. They are also responsible for overseeing or auditing IRBs and ensuring the continuous training of their members.⁵

As previously mentioned, CECs are essential for IRBs, and IRBs, in turn, are crucial for researchers. However, the greatest challenge faced by Argentina's health research system is that not all healthcare institutions have an IRB.⁶ In such cases, researchers have to seek alternative solutions, such as requesting the delegation of the evaluation. Access to reliable and updated information is crucial for facilitating this process. It is worth noting that different types of IRBs exist in Argentina, depending on their institutional affiliation. While most are embedded within healthcare institutions,⁷ some operate within research centers and universities although most of the latter are not accredited.

This study emerged from accidental findings during research on the role of nursing staff in IRBs. These findings are considered accidental because one of the main challenges encountered was the difficulty in accessing information about these IRBs. Therefore, the objective of this work was to describe the existing information to access IRBs within Argentina's healthcare institutions.

METHODS

As previously mentioned, this article was developed based on the accidental findings of another investigation: difficulty in accessing information about IRBs. Despite this, once this challenge was identified, the information was systematically collected. The new research was structured as a sub-study within the central investigation.

Design: this is a descriptive, observational, quantitative, cross-sectional research study.

Data were collected between January and February 2024, with an update conducted in October 2024. The Research Directorate website of the National Ministry of Health was the first source consulted. This platform provides information about REMINSA and CECs in various jurisdictions, including their contact information (<https://www.argentina.gob.ar/salud/investiga/reminsa>). The website of the COVID-19 Research Observatory of the same Directorate was also visited (<https://www.argentina.gob.ar/salud/investigaciones/comites>).

As a complementary strategy, the websites of the Health Ministries of each jurisdiction were searched for information related to research areas, CECs, and lists of IRBs.

Data were recorded in an Excel spreadsheet using predefined variables.

Variables, values, and study procedures:

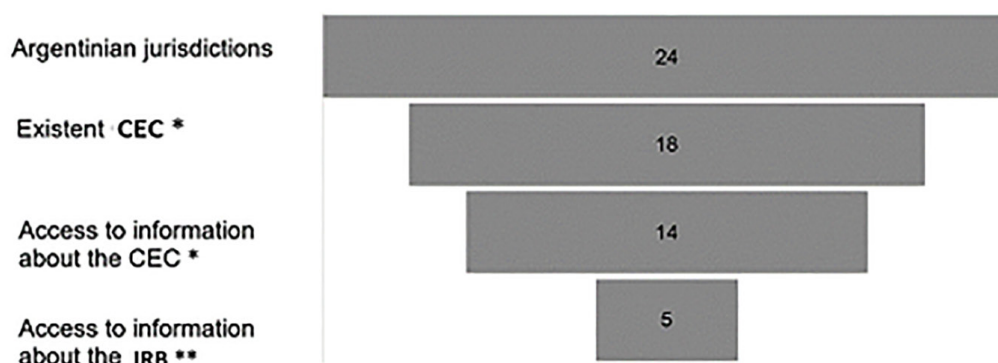
- Existence of CEC:
 - Values of the variable: found, not found
 - Procedure: verified on the National Ministry of Health website and the Health Ministry websites of each jurisdiction
- Availability of CEC Information
 - Values of the variable: available, not available
 - Procedure: verified on the National Ministry of Health website and the Health Ministry websites of each jurisdiction
- Availability of CEC contact information
 - Values of the variable: available, not available
 - Procedure: verified on the National Ministry of Health website and the Health Ministry websites of each jurisdiction
- Availability of information on IRBs accredited by the CEC's website
 - Values of the variable: available, not available
 - Procedure: verified on the CECs website
- Information on IRBs accredited on the CEC's website
 - Values of the variable: available, not available
 - Procedure: verified through the website of the CECs
- Quality of the information on the CECs website
 - Values of the variable: updated, not updated
 - Procedure: verified on the CECs website, considering the date of the last update (month and year)

Data analysis: Data were analyzed using an Excel spreadsheet (see Appendix 1). Absolute and relative frequencies were calculated.

RESULTS

Among the 24 jurisdictions, 18 (75%) have CEC (Graph 1). A key finding is that 20 (83%) jurisdictions have an official website for their Health Ministry. It is important to note that the absence of a website does not necessarily indicate lack of a CEC.

Regarding information of CECs, only 14 (58%) of the jurisdictions provide accessible information and contact details. The extent of published information varies across jurisdictions. Among the available data, the following elements can be identified: details on the composition of the CEC, international, national, and jurisdictional regula-



*CEC: Central Ethics Committees

**IRB: Institutional Review Boards

Graph 1. Central Ethics Committee and Research Ethics Committee of Argentina according to the availability and quality of information. 2024.

tions; activities; guidelines for project submissions; accreditation and re-accreditation guidelines for IRBs, etc.

Of the 18 CECs found, only five (28%) publish information about the IRBs accredited within their jurisdictions and provide contact details. However, two (40%) of these CECs do not have updated information.

DISCUSSION

The first point to highlight is that the information gathered in this study is dynamic. Each national and provincial administration adopts different public policies regarding health and health research. Therefore, the websites referenced here may change their web addresses (URL), be taken down, or have their content modified. Similarly, government bodies may undergo hierarchical changes, such as ministries being downgraded to secretariats or vice versa, which directly impact their budgets.⁵ These budgetary shifts could explain both the absence of websites and the lack of updated information.

Access to information is both a right and, in many cases, a necessity. The same applies to research involving human subjects. As discussed earlier, researchers require evaluation from IRBs, but this becomes a significant challenge when their institution lacks its own IRB.⁹ In such cases, researchers need to find an accredited IRB elsewhere. However, information on available IRB is often inaccessible in many jurisdictions, thus creat-

ing an obstacle to research development in some regions. This issue is not unique to Argentina.¹⁰

In addition, it is unclear whether all jurisdictions have a CEC. Without a CEC, IRB lack an accreditation authority, which further hinders their establishment. While Argentina's Civil and Commercial Code mandates the accreditation of IRB, this requirement also exists internationally. Other countries face similar challenges. For example, this was documented in Spain by Avilés.¹¹ In his article, he starts from the Spanish law that requires this accreditation, since it guarantees the independence, composition and review procedures of IRBs. The article shows the lack of clear accreditation mechanisms.¹¹ Despite these difficulties, several IRBs in other countries have documented the advantages of accreditation.¹²

The lack of CECs in certain jurisdictions creates an inequitable system that puts researchers at a disadvantage, as they cannot conduct any research without violating national and international regulations. This disadvantage highlights Argentina's centralized structure and lack of true federalism, particularly given that national regulations clearly state that each jurisdiction must have its own IRB, since evaluations must be carried out by IRBs from where the research will take place. It is important to emphasize that accreditation process improves IRBs operation by ensuring continuous training of their members, making it a fundamental requirement.¹²

The lack of accessible information regarding CECs complicates access to up-to-date local regula-

tion. While alternative sources exist, CECs have the advantage of centralizing relevant information for the IRBs and researchers. In other words, CECs websites are not only beneficial for researchers but also for IRBs.

However, the difficulties extend beyond accessibility. Even in jurisdictions where CECs websites provide information on IRBs, the data is often outdated, likely due to insufficient funding for website maintenance, as explained earlier. It is worth noting CECs members frequently balance multiple responsibilities in addition to their work for the CECs. Moreover, administrative personnel may lack the necessary training to manage website updates, or even if trained, the workload may prevent them from keeping the information up to date. While there are no studies on the functioning of CECs, it is possible to find papers that report on the difficulties of IRBs,^{7,13,14,15,16,17} and it is reasonable to expect that many of these challenges are shared by both entities.

This discussion highlights the need for increased investment in digital platforms that provide reliable information on the Health Ministries of the different jurisdictions, the establishment and maintenance of CECs, and personnel training to assist in information updates. Additionally, a centralized, complete, and regularly updated website should be created to consolidate jurisdictional data, which should be managed by the National Ministry of Health. The current lack of investment, among other reasons, may be due to a lack of awareness of the importance of these organizations or a general disinterest in fostering health research. It is worth remembering that Argentina was a pioneer in the creation of IRB in the region. In this regard, it would be valuable for the country to maintain its leadership in this area.

The authors of the article declare no conflicts of interest.

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APPENDIX 1. Information about the Ethics Committee according to the Argentinian jurisdiction

Jurisdiction	Has a CEC*	Has information about the CEC	Has contact details of the CEC	Has information about the IRB**	Has the contact of the IRB	Has updated information about the IRB
Buenos Aires	Yes	Yes	Yes	Yes	Yes	No
C.A.B.A	Yes	Yes	Yes	Yes	Yes	Yes
Catamarca	NF***	NF	NF	NF	NF	NA****
Chaco	Yes	NF	NF	NF	NF	NF
Chubut	NF	NF	NF	NF	NF	NA
Córdoba	Yes	Yes	Yes	Yes	Yes	No
Corrientes	NF	NF	NF	NF	NF	NA
Entre Ríos	NF	NF	NF	NF	NF	Yes
Formosa	NF	NF	NF	NF	NF	NA
Jujuy	yes	yes	NF	NF	NF	NA
La Pampa	Yes	Yes	Yes	Yes	Yes	Yes
La Rioja	NF	NF	NF	NF	NF	NA
Mendoza	Yes	Yes	Yes	Yes	Yes	Yes
Misiones	Yes	Yes	Yes	NF	NF	NA
Neuquén	Yes	Yes	Yes	NF	NF	NA
Río Negro	Yes	Yes	Yes	NF	NF	NA
Salta	Yes	Yes	Yes	NF	NF	NA
San Luis	Yes	NF	NF	NF	NF	NA
Santa Cruz	Yes	NF	NF	NF	NF	NA
Santa Fe	Yes	Yes	Yes	NF	NF	Yes
Santiago del Estero	Yes	NF	NF	NF	NF	NA
Tierra del Fuego, Antártida and islas del Atlántico Sur	Yes	Yes	Yes	NF	NF	NA
Tucumán	Yes	Yes	Yes	NF	NF	NA

*CEC= Central Ethics Committee

**IRB= Institutional Review Board

***NF= Not found

****NA= Not applicable