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RESEARCH ARTICLE

# Digital narratives on electronic informed consent in biomedical research in Latin America

## Narrativas digitales sobre consentimiento informado electrónico en investigaciones biomédicas en Latinoamérica

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## Abstract

Electronic informed consent (e-consent) represents the transformation resulting from technological changes in recent years, modifying traditional authorization processes in biomedical research. This article analyzes research participants' perceptions of the e-consent process through digital narratives posted on open platforms. An exploratory study was conducted using purposive sampling organized by platform type and study. Eighteen narratives related to clinical trials, observational studies, digital health, and biobanks were included, with six emerging categories: clarity and understanding of information, treatment received, expectations and motivations, data privacy, decision-making dynamics, and context of participation. The narratives reveal e-consent as a very lengthy text with difficult to understand terminology, decisions influenced by third parties, and a lack of transparency in the use and safeguarding of information. In conclusion, e-consent can expand access and facilitate remote participation processes, as well as addresses issues related to process oversight, transparency and privacy. It is recommended to incorporate multimodal strategies to ensure process transparency, including post-research feedback, in order to comply with data protection requeriments. It is proposed that Research Ethics Committees contribute to meeting these pre-research expectation.

**Keywords:** Bioethics; Biomedical research; Data protection; Right to privacy; Digitalization.

## Resumen

El consentimiento informado electrónico (e-consent) es la representación de la transformación resultante de los cambios tecnológicos en los últimos años, al modificar los procesos tradicionales de autorización en la investigación biomédica. Este artículo analiza la percepción sobre el proceso del e-consent de los participantes de investigación, mediante narrativas digitales expuestas en plataformas abiertas. Se realizó un estudio exploratorio con muestreo intencional organizado por tipo de plataforma y estudio. Se incluyeron 18 narrativas relacionadas con ensayos clínicos, estudios observacionales, salud digital y biobancos, con seis categorías emergentes: claridad y comprensión de la información, trato recibido, expectativas y motivaciones, privacidad de los datos, dinámicas de decisión y contexto de participación. Las narrativas evidencian al e-consent como un texto muy extenso y de difícil comprensión terminológica, así como decisiones condicionadas por terceros y poca transparencia en el uso y resguardo de la información. En conclusión, el e-consent puede ampliar el acceso y facilitar procesos remotos de participación, así como presentar problemas relacionados con el acompañamiento durante el proceso, la transparencia y la privacidad. Se recomienda incorporar estrategias multimodales y transparentar el proceso mediante retroalimentación posterior a la investigación para fortalecer la protección de los datos. Se propone que los Comités de Ética en Investigación aporten al cumplimiento de estas expectativas previas al desarrollo de la investigación.

**Palabras clave:** Bioética; Investigación biomédica; Protección de datos; Derecho a la privacidad; Digitalización.

## Introduction

The consentimiento informado (CI) [informed consent] in biomedical research constitutes one of the structural pillars of ethics in health research. The purpose of this document is to ensure respect for autonomy, safeguard dignity, and uphold the rights of individuals participating in scientific studies primarily in the health sector (Chaux, 2025). Its use is not limited to fulfilling a formal and regulatory obligation reviewed and validated by Comités de Ética en Investigación (CEI) [Research Ethics Committees], but also to verifying the guarantee of voluntary participation, based on free and informed decisions (National Research Committee, 2019).

Since its enshrinement in the 1947 Nuremberg Code, informed consent has traditionally been obtained through a face-to-face model, involving direct interaction between the research team and potential participants. This model relies on the preparation of written documents in which researchers outline the study's purpose, its characteristics, the methods to be used, how information will be safeguarded, and the associated risks and benefits. These aspects must be explained clearly and in detail, ensuring that participants or their guardians fully understand the content, so they can subsequently sign the document if they agree to participate in the research or intervention (Sahan et al., 2024).

However, with the advent of the digital era in the healthcare sector during the 2000s, the possibility of a transition from in-person to an electronic environment was raised. This allowed certain types or contexts of research to benefit from its use, for example, clinical trials or critical situations that prevented in-person interaction, as occurred during the COVID-19 pandemic. This opened up opportunities for multicenter research, in which geographical constraints and in-person interaction no longer posed a barrier to implementation.

In this context, electronic informed consent, or e-consent, became a technological alternative to improve access to research participants, the traceability of the process, and the understanding of the information (Sahan et al., 2024). This consent procedure, which utilizes remote digital communication, is implemented through digital platforms that can create a personalized user profile or simply provide an individual link guiding the user through pages and forms that facilitate their completion.

These types of tools can, therefore, incorporate multimedia resources, integrated comprehension assessments, modular navigation, interactive diagrams instead of text, and information customization, making participation more user-friendly for individuals interested in collaborating on biomedical research. Furthermore, this process helps reduce time and allows for a broader reach in recruiting participants (Gesualdo et al., 2021; Sahan et al., 2024; De Sutter et al., 2024; Mazzochi et al., 2023).

The operational contribution of e-consent is fundamental, especially in the context of multicenter studies and in scenarios where there are limitations to in-person participation, as well as in research requiring remote follow-up. In this regard, expanding population access constitutes a significant advantage by incorporating participant support resources into the data collection design. Similarly, the assessment and reduction of geographical barriers can enable researchers to access data from under-explored areas (Catalán et al., 2025).

These benefits depend on the usability of the tools and the technological design of the algorithms, which must ensure that participants fully understand the instructions and provide clear information in their responses. Similarly, the voluntary nature of contributions must be clearly stated in the attached consent form, thereby significantly reducing risks or doubts regarding the collected information and strengthening participants' trust in the process (Cusí, 2023; Lajonchere et al., 2021). Doubts regarding certain aspects of the e-consent form could be resolved through communication with

chatbots or the study coordinator via short interactive audio and video messages.

E-consent is not without complexities, due to questions regarding the authenticity of participants' autonomy, especially in deferred interactions. Likewise, the veracity and clarity of participants' responses, the formulation of timely and truthful questions, as well as aspects related to confidentiality, safeguarding, and the subsequent use of information are compromised (Wu et al., 2025; De Sutter et al., 2020).

Pietrzykowski and Smilowska (2021) describe difficulties in its application in biomedical research, due to a lack of understanding of concepts such as sample selection and the rationale for participation, the presence of potential risks or alternative treatments, and limitations on participation in the event of withdrawal or continued participation in the study. In this regard, certain participants find the scenarios unrealistic, especially when dealing with complex pharmacological or medical procedures, so their responses will depend on the accuracy of the information provided by the researchers, as well as their mood at the time of responding (Ecarnot et al., 2017). These limitations extend to participants with mental illnesses or disabilities, which cannot be verified by the researchers.

In this scenario, it is necessary to critically review the use of e-consent in light of the ethical conflicts circulating online. Among these conflicts is participants' uncertainty due to the lack of answers to potential questions about their participation should they agree to it. This also includes concerns regarding vulnerability and potential violations resulting from information leaks. Likewise, institutional transparency and that of the electronic support team—which is part of the data collection process itself—are considered.

The digital narratives of individuals who spontaneously enter virtual spaces constitute an important tool for gaining insight into the research subject's perspective and analyzing how they perceive and understand e-consent at the time of their participation. These expressions, found in open spaces for dialogue among non-medical users and free from personal or institutional pressure, allow for the analysis of opinions regarding this electronic tool, how it is accessed, the complexity or ease of completing it, and users' expectations regarding their participation in research.

Based on the above, the objective of the study is to analyze the digital narratives available on open digital platforms. These include public forums, patient community blogs, microblogging spaces, video comments, and public testimonial sites related to participation in health studies. The analysis focuses on the electronic informed consent process in biomedical research.

## Materials and Methods

An exploratory study with a phenomenological approach was conducted through an analysis of the subjective experiences reflected in the digital narratives of participants in biomedical research regarding the use of e-consent. The unit of analysis consisted of narrative excerpts from users or family members/caregivers describing their experiences during the process of providing consent for participation in biomedical studies.

The digital narratives were obtained from publicly accessible digital platforms, including open forums and blogs from thematic and patient communities in the health sector. Public social media platforms, such as X (formerly Twitter), Reddit, YouTube, and Facebook, as well as websites featuring public testimonials about participation in health-related studies, were also included. These narratives were available in Spanish and English and primarily originated from Latin America. The written posts and audiovisual recordings consisted of original first-person narratives or narratives provided by caregivers describing experiences with e-consent. They included texts of at least 30 words or their audiovisual equivalents and had been published between January 1, 2020, and August 31,

2025.

Promotional or journalistic content was excluded. General opinion posts without first-hand user experiences were also excluded, as were posts from closed groups or those containing private content. Additionally, duplicate posts and records containing sensitive information (involving minors or individuals with legal or employment-related issues) were excluded.

The information search was conducted on social media platforms through the progressive combination of keywords and natural-language phrases adapted to each platform's search functionality. Unlike searches conducted in bibliographic databases, rigid Boolean operators were not applied. Instead, manual search strategies using equivalent terms in Spanish and English were employed, using terms such as "consentimiento informado electrónico", "formulario de consentimiento", "ensayo clínico", "me pidieron firmar", "mi experiencia fue", "participé en un estudio", "clinical trial", "informed consent", "e-consent" y "they asked me to sign". For platforms with search limitations, two or three terms were combined in a simple manner, together with associated comments, date filters, and related topics.

Sampling was purposive and theoretically informed, organized according to platform type and the type of biomedical study referenced, until thematic saturation was achieved across the different group.

Initially, 1,146 records were identified on publicly accessible platforms. An additional 534 records were retrieved through an Application Programming Interface (API).

Subsequently, duplicate or repeated records (n = 613) were removed from the total dataset (n = 1,680), together with records that did not meet the inclusion criteria (n = 614), records corresponding to general opinions unrelated to the topic (n = 219), and promotional content (n = 108).

Of the 126 eligible records, those originating from closed groups (n = 41), narratives unrelated to e-consent (n = 27), records containing sensitive user information (n = 18), and duplicate records identified during the final screening stage (n = 22) were excluded. Finally, 18 records were included in the analysis.

The distribution of narratives by platform type was as follows: open forums, Reddit, and patient communities (n = 5); microblogging platforms, such as X (formerly Twitter) (n = 4); YouTube videos and comments (n = 4); blogs and long-form testimonials (n = 3); and open social media platforms, such as Facebook (n = 2). Regarding the type of biomedical study, the narratives included clinical trials (n = 6), observational studies (n = 4), digital health studies (n = 5), and biobanks or studies involving biological samples (n = 3).

Coding was performed independently by two researchers, who participated in both the selection of the narratives and the initial coding process. Inter-coder agreement was assessed using Cohen's kappa coefficient, yielding a value of 0.81, which indicates substantial agreement regarding the selection and coding of the eligible narratives. Any discrepancies were resolved through discussion and consensus among the members of the research team.

The phenomenological analysis involved a thorough process of reading the narratives, identifying primary and secondary coding units, grouping them into categories that emerged from the qualitative analysis, and establishing relationships among these categories. The criteria of density (the level of connections between concepts) and groundedness (the frequency with which concepts appeared in the narratives) were applied. The analysis was primarily interpretive and descriptive and was not intended to support statistical inference.

In accordance with research ethics standards, all participant narratives were anonymized while retaining information on the country of origin and the year in which each statement was made. Some distinctive quotations were paraphrased to prevent participant re-identification. Likewise, quotations from minors were identified and removed through investigator triangulation (Enworo, 2023).

## Results

Narratives from participants in biomedical research conducted in Latin America since 2020 were collected. Open coding was applied to identify expressions that were repeated or recurrent in narratives related to the use of e-consent, resulting in the emergence of codes and categories associated with specific experiences (Table 1):

### Table 1

*Emerging codes from narratives on e-consent according to research participants*

| Emerging codes | Frequency | Rootedness | Narratives |
|---|---|---|---|
| 1. Clarity and understanding | 10 | 4 | • "They explained everything in detail"<br>• "The document was very long / difficult"<br>• "I didn't understand the part about the placebo"<br>• "I didn't ask because I was embarrassed" |
| 2. Treatment received | 7 | 4 | • "I felt heard"<br>• "There was no follow-up after signing"<br>• "The team was very friendly<br>• "They didn't tell me the results" |
| 3. Expectations and motivations | 11 | 5 | • "I wanted to help science"<br>• "I hoped to improve my health"<br>• "Participating gave me hope"<br>• "I knew it could be a placebo" |
| 4. Privacy and data handling | 3 | 2 | • "I don't know what they'll do with my samples"<br>• "Who will see my data?"<br>• "They never mentioned biobanks" |
| 5. Decision- making process | 11 | 3 | • "I read it with my husband/ daughter"<br>• "The doctor told me to sign"<br>• "I felt pressure because of the illness"<br>• "I decided to do it because there was no other option" |

| Emerging codes | Frequency | Rootedness | Narratives |
|---|---|---|---|
| 6. Context | 11 | 2 | • “It was the pandemic, and we all wanted to help”<br>• “I signed up because there were no vaccines in my country”<br>• “Chronic illness-Í ve already tried everything else” |
| 7. Subjective outcome | 11 | 5 | • “I’m proud to be participating”<br>• “I was left with doubts afterward”<br>• “I don’t know if it helped, but I’m confident it was useful”<br>• “There was a lack of transparency” |

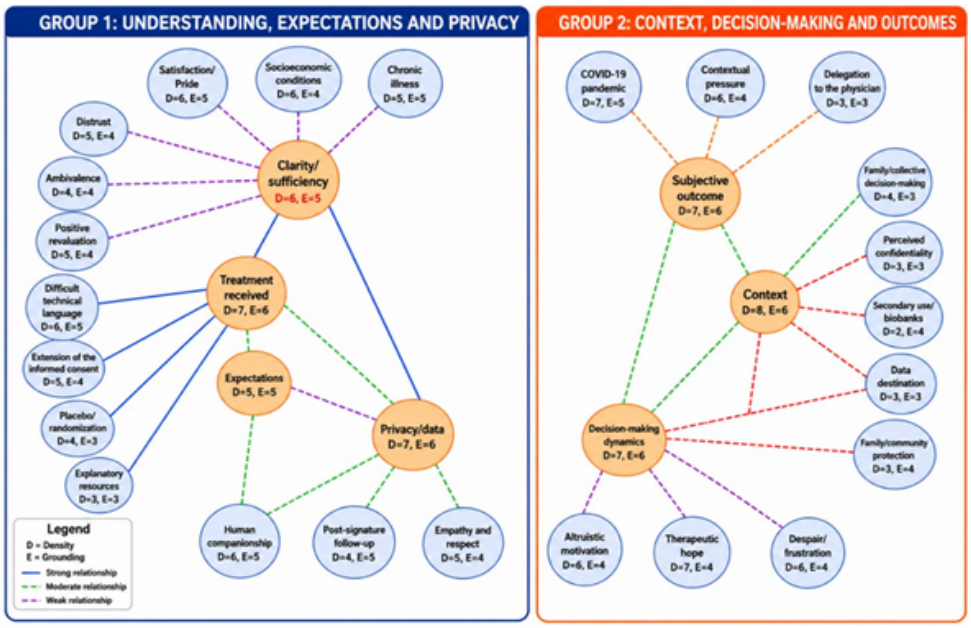
*Note.* Density: semantic Depth or number of connections and relationships with other codes. Embedding: empirical breadth or number of citations linked to the code

These emerging codes and categories were compared with international regulatory standards, such as the Declaration of Helsinki (World Medical Association, 2024), which requires clarity, voluntariness, and sufficient information. Similarly, the 2017 Pautas del Consejo de Organizaciones Internacionales de las Ciencias Médicas (Council for International Organizations of Medical Sciences [CIOMS]), which emphasize data confidentiality and privacy, and e-consent (2021), which highlight relational interaction, cultural adaptation, and dynamic participation. These documents supported the categories of data privacy, decision dynamics, and context (e.g., COVID-19 studies or clinical trials).

The most extensive categories are the clarity and sufficiency of information, user expectations, the decision-making dynamics used at the time of public disclosure, and the expected outcome expressed in the e-consent. Meanwhile, the most critical subcategories are the description of placebo use and randomization, how post-signing follow-up will be managed, the pressure associated with completing the form due to tight deadlines, and the lack of clarity and transparency regarding the use of the requested information (Figure 1).

## Figure 1

*Hierarchical tree of the relationship between emerging codes and subcategories of participants narratives*




*Note.* Data: Orange, main category (axial code); blue, subcategory. Blue lines: explanatory relationship; green, relationship with the source; purple, evaluative relationship; orange line: conditioning relationship; red line: normative relationship. D = density; E = embeddedness.

Similarly, it can be observed that the gap present in all cases is data privacy, due to the lack of sufficient testimonies on the subject.

On the other hand, comparing the findings with normative sources reveals disparities in their implementation, generally related to the pandemic, trust relationships with researchers, and communication gaps in the information presented in the e-consent (Table2).

## Table 2

*Ethical conflicts identified by ethical principle*

| Ethical principle (Helsinki Declaration, CIOMS Guidelines) | Regulatory expectation | Experiences reported in narratives (18 records) | Conflict identified |
|---|---|---|---|
| Autonomy | The decision must be free, informed, individual, and without coercion. | Decisions shared with family members ("I read with my husband, we decided together", Argentina, 2022); and influence from doctors ("I signed because the doctor told me it was best", Venezuela, 2023). | Autonomy is understood as relational, not strictly individual, and may be influenced by authority figures or family dynamics. |

| Ethical principle (Helsinki Declaration, CIOMS Guidelines) | Regulatory expectation | Experiences reported in narratives (18 records) | Conflict identified |
|---|---|---|---|
| Comprehension | The information must be clear, sufficient and understandable to any participant. | Complex technical language ("I didn t really understand the part about the placebo", Argentina, 2023); long and difficult forms ("It was too long, I got tired of reading", Chile, 2021). | Actual understanding is limited: the participant signs based on trust rather than full understanding. |
| Voluntary participation | Participation must be completely voluntary without external or internal pressure. | The narratives reveal constraints: pandemic ("It was the only way to get vaccinated", Cuba, 2021); limited access to treatments ("It was only way I could continue with my medication", Bolivia, 2022). | Voluntarieness is affected by structural factors (pandemic, health inequalities, and lack of alternatives). |
| Respect for dignity | Respectful treatment the right to withdraw, and the return of results must be guaranteed. | Some appreciate a friendly approach ("They gave me their number for questions, which put me at ease", Uruguay, 2022); Others complain about a lack of follow-up ("We never knew how the study was going", Mexico, 2021). | Respect for dignity is linked to human support, but is violated when there is no post-research feedback. |
| Data protection and confidentiality | Participants must be informed about the use of data, secondary use, and anonymization. | Frequently asked questions about biobanks and the fate of samples ("They didn t tell me what happened to my blood", Colombia, 2023; Ecuador, 2022). | Transparency regarding data and biobanks is insufficient; participants feel insecure about the protection of their information. |

## Discussion

The analyzed narratives show that some users perceive e-consent as a lengthy and complex document, in which technical terminology is not always understood (for example, the use of placebos or sample randomization), a finding consistent with that reported by O'Sullivan et al. (2021) and Thanh et al. (2015).

On the other hand, in many cases, the signing of the e-consent relies more on the trust users have in the research team than on the content they read, which calls into question the autonomous and voluntary decision, an indispensable requirement established by the CIOMS guidelines, which is also related to direct interaction with the individual (Chau et al., 2025; Skelton et al., 2020), demonstrating the empathy necessary with the participant to positively influence their collaboration (Corneli et al., 2024; Mondragón-Barrios, 2009).

Regarding expectations and motivation for participating in the study, several narratives

were observed related to therapeutic hope, altruism, and family or community protection, which reveal a clear tension between participants' expectations and the actual outcome of the study, a phenomenon that Appelbaum et al. (2012) defined as therapeutic misconception (Abernethy et al., 2021).

On the other hand, the decision to participate in a biomedical study is considered a shared one; this way a frequent in the accounts found: "I read it with my husband and we decided together". Although another participant stated: "I signed because the doctor told me it was the best thing to do". Regarding the use of data and the handling of biological samples, it was found that some narratives reflect uncertainty about the fate of the information, storage and safeguarding conditions, the confidentiality of the information, secondary use for other purposes, and inclusion in biobanks, which aligns with both McGrath et al. (2025) and Remes and Fink (2023), who suggest that the information documents provided to participants do not always contain sufficient detail regarding the subsequent handling of their personal information and samples. In this context of e-consent, this limitation may be exacerbated in cases where researchers use brief, automated, or standardized formats.

The information presented during the e-consent process also evokes a subjective sense of hope in patients: "participating gave me hope; I'm better today and grateful," or a sense of despair: "they never reported the results; I was left with a bad taste in my mouth". Therefore, post-research feedback is a mandatory and fundamental requirement that ensures transparency in research toward users, as part of participatory ethics and the individual right to information regarding research progress and results (George et al., 2023).

Finally, the study allows us to identify a series of needs regarding the use of e-consent: a) to improve understanding of the forms, which must be culturally adapted, with their comprehensibility validated beforehand through pilot studies; b) to promote dynamic consent as a continuous process not limited to the act of signing the acceptance form, in order to avoid perpetuating doubts and mistrust; c) ensure post-signature consent through timely and clear communication of results, procedures, and actions, for which an effective means of communication with researchers must be established; d) ensure data transparency and anonymization, as well as the destruction of information, clearly stating where and how it will be stored, who will have access to it, and the retention period; e) recognize collective dynamics, including family members or support staff when requested by the participant; and f) contextualize voluntariness by acknowledging special situations such as public health crises, inequalities in access to health care, and ethnic and cultural inequalities.

The study's limitations stemmed from the scarcity of publicly available narratives, which introduced a visibility bias. Closed groups were not accessed out of respect for user privacy, thereby limiting the number of experiential accounts. However, the thematic saturation and richness of the content allowed for a meaningful and interpretive overview of the narratives studied.

As this is a qualitative study, the findings cannot be generalized to the entire population participating in biomedical research in Latin America, and the value of the results lies in the identification and interpretation of the perceptions and experiences expressed in open digital spaces.

## Conclusions

It is concluded that the digital narratives analyzed regarding e-consent, while expanding the possibility of increasing sample sizes in biomedical research, present significant ethical limitations related to understanding the document, voluntariness support, and

data protection.

In Latin America, the implementation of e-consent must take into account structural inequalities, such as digital literacy and connectivity, as well as unequal access to technology, linguistic differences, ethnic diversity, and sociocultural conditions, which may affect participants' understanding and effective participation. Although these dimensions were not evaluated in the study, they are presented as contextual factors to be taken into account when interpreting the narratives.

In this regard, research ethics committees must pay attention to the structure, content, and follow-up of electronic consent in order to safeguard participants' dignity and autonomy and ensure the security and accuracy of the information generated by the study.

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