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Ethics in Information Science Research: principles and legal procedures for submitting research projects to institutional ethics commitees

Ética em pesquisa em Ciência da Informação: princípios e procedimentos legais para submissão de projetos de pesquisa em comitês de ética institucionais

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Abstract

Introduction: The aim of this article is to present principles and procedures in order to run researches in Information Science in observance of research ethics Brazilian legislation. **Method:** Narrative review on current regulations of social sciences research protocols by the Health Ministry and reflections from the researcher as an institutional ethics committee former member. **Results:** A summary of necessary operational aspects for research approval on ethics committees is presented, including tips on elaborating documents of informed consent [use of understandable language to the participant, avoiding technical terms, writing as invitation letter, presentation of risks and benefits in a clear way to preserve enlightening and autonomous decision by the participant in being part of the study] and Plataforma Brasil use [online Brazilian system owned by Health Ministry to submit the research protocol]. Furthermore, some aspects that deserve attention to researching in the area are raised, in observance of Access Information Law and General Data Protection Law. **Conclusions:** Care with the participants must guide the researcher, and the research evaluation and approval by ethics committees should facilitate review on issues related to participants protection by qualified peers of scientific community.

Keywords: Ethics; Research; Information Science; Ethics Committee; Informed Consent.

Resumo

Introdução:*O objetivo deste artigo é apresentar princípios e procedimentos para realização de pesquisas em Ciência da Informação que atendam a ética em pesquisa, conforme a legislação brasileira.* ***Método:*** *escrita de revisão narrativa das normas vigentes do Ministério da Saúde para submissão de protocolos de pesquisa na área de Ciências Sociais e Humanas, acrescidas de reflexões da autora advindas de sua experiência como ex-membro de comitê de ética institucional.* ***Resultados:*** *são apresentados, de forma sumária, aspectos operacionais necessários para aprovação de pesquisas da área em comitês de ética, incluindo cuidados com elaboração de documentos de registros de consentimento livre e esclarecido (emprego de linguagem compreensível ao participante, evitando-se termos técnicos, redação em forma de carta-convite, com apresentação de riscos e benefícios de maneira clara, para preservar o esclarecimento e decisão autônoma da pessoa em participar da pesquisa) e uso da Plataforma Brasil (sistema que permite o cadastro unificado de todas as pesquisas com seres humanos no Brasil, do Ministério da Saúde). Além disso, são levantados alguns aspectos que merecem atenção para pesquisa com dados na área, em observância à Lei de Acesso à Informação e à Lei Geral de Proteção de Dados.* ***Conclusão:*** *o cuidado com o participante da pesquisa deve guiar o pesquisador, e que a avaliação e aprovação de pesquisa em comitês de ética propiciam a revisão de questões relativas à proteção dos participantes por pares qualificados na comunidade científica.*

Palavras-chave: *Ética; Pesquisa; Ciência da Informação; Comitê de Ética; Registro de consentimento.*

INTRODUCTION

This article aims to provide researchers in the field of Information Science, especially those who are new to the discipline, with the necessary steps for submitting research papers to institutional ethics committees, which are legal bodies responsible for evaluating and approving research involving human subjects in Brazil.

First and foremost, it is assumed that conducting research with human subjects in Brazil adheres to the legal frameworks established by the Ministry of Health and is overseen by the National Health Council (CNS), a collegiate body within the Ministry of Health (MS). The CNS established the CEP System (Research Ethics Committee) / CONEP (National Commission for Research Ethics) through CNS Resolution 196/96, which was later replaced by CNS 466/2012 (Resolução n. 466, de 12 de dezembro, 2012). Currently, this system is responsible for evaluating, approving, and monitoring research involving human subjects in Brazil according to ethical principles, as well as serving in advisory and educational capacities.

While it is widely accepted that approval by independent ethics committees is a prerequisite for any study in the health field, the importance of these committees is not always recognized in the social sciences, humanities, and engineering. This may be due to underestimating the risks associated with non-clinical research, a lack of tradition

in ethical evaluation by peers, or disagreements with health-related peer reviews due to differences in theoretical and methodological orientations across different knowledge areas. Nevertheless, according to Brazilian legislation, any research involving human subjects should be submitted for approval to independent ethics committees, which, by their very composition, are not limited to health research. My experience in an institutional ethics committee at a university allowed me to closely observe a substantial volume of protocol submissions for evaluation, including those from both health and humanities fields, and the committee's composition is necessarily multidisciplinary.

Given the rationale for having research reviewed by institutional committees, what are the ethical principles that guide research protocols in compliance with Brazilian legislation? What procedures should be followed for the submission of research protocols to institutional committees?

METHOD

To address the question posed above - what are the principles and procedures for submitting research protocols in the field of Information Science in compliance with Brazilian research ethics regulations? - the following section presents a narrative review of the ethical principles and procedures in the domain of Human and Social Sciences. This choice is driven by the fact that Information Science research largely falls within this domain. The preference for a narrative review over a systematic one is due to the limited presence of discussions on research ethics within the scientific literature of the Information Science field, rendering a systematic review impractical. In a search for articles in BRAPC[1] using the keywords "ethics AND research" in October 2021, 146 articles were retrieved, but only 12 of them aligned with the approach of principles and procedures for research ethics as proposed here. Among these twelve, only two pertained to the specific principles and ethical procedures for Information Science research - Kremer (1982) and Araujo and Francisco (2016). The other eight articles focused on bioethics, with two addressing the use of medical records in research, and the remaining two discussing the peculiarities of research ethics in the social sciences, including ethical dilemmas encountered in social research. Both Kremer (1982) and Araujo and Francisco (2016) provided narrative reviews of the topic and offered subjective opinions on the application of ethical principles that require updating, which aligns precisely with the intent of this article.

Another reason for opting for a narrative review is to be able to incorporate reflections on the application of ethical research standards from my own experiences serving on the Ethics Committee of a Brazilian university. Over the course of five years, I held positions as a substitute member, a full member, a sub-coordinator, and a coordinator. By including these experiences when presenting the submission procedures, I am able to provide insights that can be especially valuable to novice researchers. Nevertheless, by incorporating the author's experience in an institutional ethics committee, the article takes on the form of an experiential account, aimed at constructing innovative theoretical and practical knowledge within a contextual framework. Such an approach is considered one of the avenues for "creating a scientific narrative, particularly in fields of research that encompass subjective processes and productions, as is the case with psychology and applied human sciences, among others" (Daltro & de Faria, 2019, p. 224).

Furthermore, this article also includes a review of the current regulations governing research involving human subjects in the field of human and social sciences in Brazil as outlined by the Ministry of Health. It covers the specific resolutions CNS 510/2016 (Resolução n. 510, de 7 de abril, 2016) and CNS 466/2012 (Resolução n. 466, de 12 de dezembro, 2012), which must be taken into account when submitting research projects. Additionally, it touches upon CNS 304/2000, concerning research involving indigenous populations. The article also provides guidance on the use of information sources in accordance with the Access to Information Law (Lei n. 12.527, de 18 de novembro, 2011) and considerations regarding the use of personal data under the General Data Protection Law (Lei n. 13.709, de 14 de agosto, 2018).

RESULTS

The outcomes of this study are presented in a structured text focusing on two key aspects: ethical principles in research involving human subjects and ethical research procedures.

Ethical Principles in Research Involving Human Subjects

An approach to discussing research ethics is clarified through the contrast between ethics and morality. Guareschi (2008) provides a definition of morality as social customs considered rules for establishing social order. In contrast, ethics originates from "ethos," signifying human dwelling, and pertains to the construction of values and principles guiding human actions, which may involve a critical evaluation of morality.

[1]BRAPCI – Database of Information Science Journals, accessible at www.brapci.inf.br.

Ethics is inherently linked to justice, and one can only be ethical in relation to others, not in isolation or individually (Guareschi, 2008). "I am just when I establish fair relationships with others, i.e., when I respect the rights of others. Justice, therefore, is related to respecting the rights of individuals" (Guareschi, 2008, p. 25).

Given this definition of ethics, in contrast to morality, research ethics should not be viewed as mere adherence to rules for conducting scientific work. Guareschi (2008) outlines two fundamental ways to consider ethics: as a natural inclination of human beings toward good, and as a contractual concept necessitating the existence of contractual limits on human action established by positive law.

Ethics in research, particularly, is primarily established in its contractual dimension, setting boundaries for the relationships between research subjects and researchers to ensure the well-being of the researcher-researched relationship, with special attention to the protection of the more vulnerable party in the relationship, the researched subjects, thus ensuring that research is conducted justly.

In addition to the need for a fair relationship with the researched subjects, it is also crucial that researchers commit to the knowledge to be generated and its applications, as understood by Zanella (2008). This is one of the important principles of ethics – non-triviality – evaluated through the analysis of the technical and scientific merit of the research protocols submitted, based on substantiated opinions from peer members of the scientific community, as assessed by institutional ethics committees. The ethical principles governing the regulatory framework for research involving human subjects in Brazil, as set by the National Health Council, resolutions CNS 466/2012 and CNS 510/2016, share a common reference to the Universal Declaration of Human Rights from 1948 and the Inter-American Declaration of Human Rights and Duties from 1948 (Brazil, 2012; 2016). Dignity, freedom, and autonomy are affirmed in these declarations (Resolução n. 510, de 7 de abril, 2016), which, according to Tosi (2004), are guided by a liberal conception and an individualistic ethic, where the individual is seen as someone whose freedom is limited by the freedom of others under the law. The ethical principles that must be observed in research (Koerich, Machado, & Costa, 2005), shared across these resolutions and stemming from bioethics, include: 1) Beneficence: the duty to promote good and to conduct research only if the potential benefits (both individual and collective) outweigh the risks, which must be carefully assessed. 2) Non-maleficence: research should not cause harm, and the researcher should evaluate and avoid foreseeable harm. 3) Autonomy: self-determination, self-governance, and individual freedom must be respected, implying that participants have the choice to join or decline participation in the research, with the violation of autonomy being acceptable only in cases where the public good outweighs individual rights. 4) Justice: "the coherent and adequate distribution of social benefits and duties" (Koerich et al., 2005, p. 109), which includes not subjecting participants to poorly designed research.

Before initiating the work, it is essential to assume that it should bring benefits to the participant and/or the community (principle of beneficence), a crucial aspect that needs to be investigated. Conducting research is not permissible if its risks outweigh its benefits. The researcher must anticipate and mitigate the risks, which may involve healthcare assistance, medical monitoring, psychological referral, among other actions. The research approach must take into consideration the consent of the participant, enabling them to be informed about the research's risks and benefits and to decide on their participation. This aligns with the principles of self-determination, self-governance, autonomy, and freedom. In Brazil, payment for research participation is not allowed, as it risks limiting the participant's autonomy (Chapter 2, Article 10 of Resolution CNS 466/2012).

Continuing research that indicates unfavorable results during its course is also discouraged (principle of non-maleficence). Resolution CNS 466/2012 defines that research may have the potential to cause "harm to the physical, psychological, moral, intellectual, social, cultural, or spiritual dimensions of the human being" (Article 2, Section XXV). This potential harm must be considered during the research's execution, in any of its stages or subsequently, with attention to avoiding stigmatization of the participant. Resolution CNS 510/2016 recognizes both material and immaterial harm resulting from research, along with all the harm mentioned in CNS 466/2012. Researchers are liable for compensating for any harm, as stipulated in both resolutions. Research can be halted whenever disproportionate harm to the participants is observed, even under the oversight of the Ethics Committee, and in the field of social and human sciences, the study's interruption can be agreed upon by both parties, as per Article 19 of CNS 510/2016.

Additional precautions are essential when involving individuals in vulnerable conditions or those incapable of making decisions for themselves (minors, incapacitated individuals). Resolutions CNS 466/2012 and CNS 510/2016 require that minors or incapacitated individuals provide their assent, to the extent of their capabilities since they lack the autonomy to decide on their participation. In such cases, parents or legal guardians must provide consent for their participation in the study.

Resolution CNS 466/2012 mandates anonymity, confidentiality, and the secrecy of participants, all of which must be consistently upheld. Resolution CNS 510/2016, on the other hand, requires confidentiality and secrecy of participants' personal information while also guaranteeing privacy, allowing the participant to decide whether their identity will be disclosed. The discussion surrounding the revelation of the participant's identity raises several considerations. In social research, especially in action research, providing visibility to the individuals,

communities, and groups involved can be considered a research benefit. However, in research involving individuals in vulnerable and socially risky situations, the disclosure of identity may even lead to the risk of stigmatization.

Regarding privacy, attention must also be given to the use of research participants' images, which necessitates explicit authorization for usage by adult participants and, in the case of minors or incapacitated individuals, by their legal guardians through an Image Usage Authorization Form.

Other aspects relating to the preservation of the participant's autonomy must be observed, such as institutional participation. Participants in research are often recruited within institutions/organizations, and investigations may occur within or about these institutions/organizations. In such cases, it is always necessary to obtain consent for conducting the study within the institution/organization to which the participant is affiliated.

Conducting research involving the observation of groups of people (e.g., research involving classroom observations or medical procedure observations) that entail taking field notes requires institutional approval for observation, and all those observed should be informed about the research if they are not direct subjects of the investigation (e.g., informing students that teachers are subjects of observation in the classroom). They should give their consent for observation if they are direct subjects of the research. Conducting observation without consent (covert research) is allowed only in exceptional circumstances, as stipulated in Resolution CNS 510/2016 (Article 2, Section XV), and, if necessary, obtaining post-informed consent from the participant is recommended whenever possible.

Other important considerations regarding autonomy and freedom of participation pertain to the involvement of individuals from communities where there exists authority from leaders or collectives over the individual, as in the case of "traditional, indigenous, or religious communities," as per Article 13 of CNS 510/2016 (Resolução n. 510, de 7 de abril, 2016). For such cases, apart from individual consent, authorization from the leadership is required to conduct the research. However, specific legislation applies to research in indigenous communities – CNS 304/2000 – which mandates the need for approval from recognized indigenous authorities (respective indigenous organizations or local councils; and, if applicable, the district health council of the involved region), in addition to individual consent. It also requires a dual evaluation of the protocol (by the CEP and CONEP, as it is a special thematic area according to CNS 466/2012), with special care to avoid the exploitation of the technological knowledge of the communities (such as for patent creation) and their phylogenetic heritage, traditions, and compliance with restrictions on research involving indigenous people in isolation (Resolução n. 304, de 9 de agosto, 2000).

While there are formal issues related to the participation of institutions and communities, it is always a challenge for ethics committees to deal with research designs that are fluid and negotiable with communities. This is because the researcher-participant-community-institution relationships are not always foreseeable to be included in consent records and institutional approval terms. The contractual logic outlined in both CNS 466/2012 and CNS 510/2016 can also lead to participation constraints. Institutions or individuals may hesitate to sign research contracts, such as the Terms of Free and Informed Consent, or they may not directly benefit from the results. Research in which the researcher collects data from populations often serves the researcher's purposes, not those of the community, meaning that research subjects are instrumentalized by the researcher, which would not constitute a fair relationship. The relationship can slip into the concept of a domination relationship, in which the researcher exercises power over the dominated and silences them or distorts their speech, which is not ethical. Fair relationships and effective contributions to social reality are envisaged in the preamble of CNS 510/2016, stating that scientific production must bring benefits to the community. This gives rise to some of the important ethical principles for the evaluation of research in social and human sciences: recognition of the freedom and autonomy of participants and researchers, rejection of authoritarianism in research relationships and prejudices (respecting diversity and differences), respect for the values of the participants, and the return of results to participants (individual and/or collective), as stated in Article 3 of CNS 510/2016 (Resolução n. 510, de 7 de abril, 2016).

Regarding the dialogical nature of research in social and human sciences, which requires closer engagement of researchers with the researched reality and the establishment of trust-based relationships, CNS 510/2016 stipulates that the preliminary phases of research (the investigation of field research possibilities through direct field contacts), excluding pilot research and exploratory studies, are not subject to evaluation by the CEP-CONEP system (Resolução n. 510, de 7 de abril, 2016).

Ethical Research Procedures

In Brazil, scientific research involving human subjects must receive approval from at least one Research Ethics Committee (CEP) that is part of the CEP-CONEP system. This approval is granted through a protocol submitted on the Plataforma Brasil (http://plataformabrasil.saude.gov.br/login.jsf), a web-based platform administered by the Ministry of Health. It allows for the registration and evaluation of research projects by all members of the CEP-CONEP system. A visual representation of this system is depicted in the figure below:

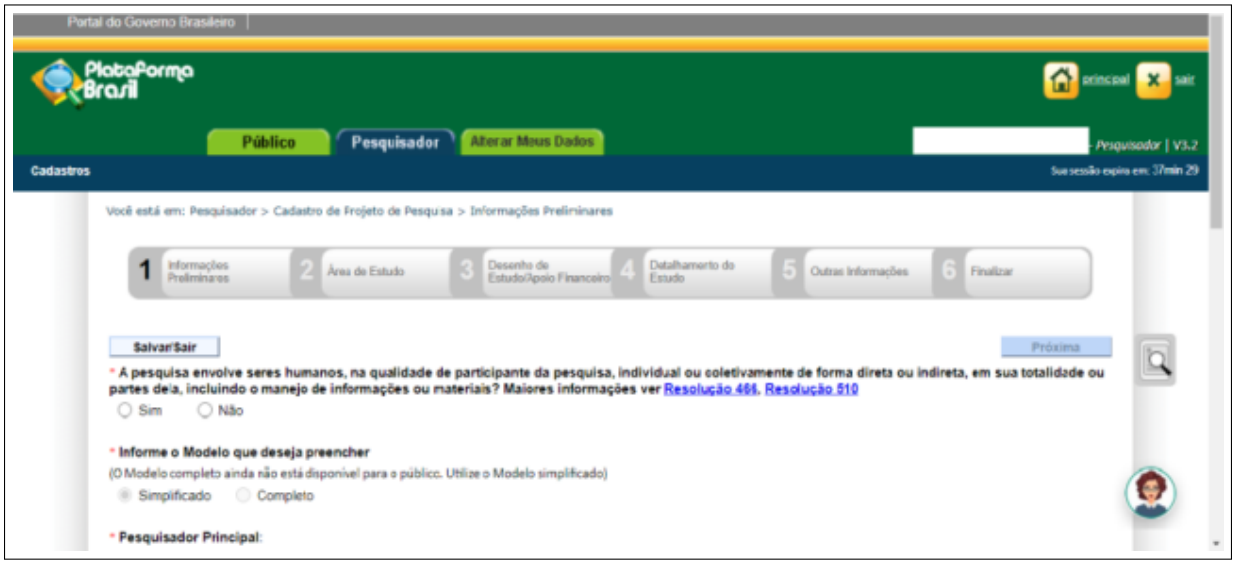

Figure 1. Plataforma Brasil's Initial Research Protocol Submission Screen
Source: Author's screenshot.

The execution of the six steps of submission is self-explanatory for almost all fields, but there are some important guidelines to highlight:

a) Step 3 [Study Design/Financial Support] requires selecting whether the research is observational or intervention/experiment and defining the study design. In the field of social and human sciences, the study design may refer to the nature of the study, such as quantitative, qualitative, mixed-methods, action research, for example, defining the research framework;

b) In Step 3, specific research funding should be registered if applicable. Scholarships, such as CAPES or CNPq scholarships, should not be included since they are not exclusive to the research;

c) In Step 4, filling out the research hypothesis is not mandatory for research in the field of social and human sciences, as per Circular Letter 110 (Ministério da Saúde, 2017);

d) Risks must be filled out and pertain to the risks associated with participation in the study, including physical, moral, psychological, social, financial, and other applicable risks;

e) Benefits refer to those arising from participation in the study, not the benefits of the research to the field of knowledge;

f) In the field of social and human sciences in Brazil, the sample size should be entered as 0 if it is not possible to determine the exact number, with inclusion criteria specified in the relevant fields, as per Circular Letter MS 110 (Ministério da Saúde, 2017);

g) A study is considered multicenter when it involves more than one partner institution in all phases of the study (participating institution), whereas a co-participating institution is one that participates in one of the study's phases, such as data collection;

h) The execution schedule should include data collection steps after CEP approval, considering the minimum regulatory period of 40 days for issuing substantiated opinions, as per CNS Operational Standard 001/2013 (Norma operacional 001/2013, 2013);

i) A financial budget should be completed, even for self-funded research.

Certain special conditions for the exemption from the research protocol submission process in the CEP-CONEP system are provided in Resolution CNS 510/2016, in its first article:

a) Opinion research with unidentified participants;

b) Research using publicly available data assured by the LAI;

c) Research in databases with non-identified personal data (aggregated data);

d) Literature review research;

e) Research arising from professional practice that does not identify the participant;

f) Research conducted solely for teaching purposes in undergraduate, technical, or specialization courses.

One of the main instruments for conducting research ethically is the process of obtaining informed consent from adult research participants or a legal guardian for minors, allowing them to participate. First, it is necessary to inform the study participant about its objectives, purposes, risks, and benefits. At a later stage, it becomes necessary to establish an agreement between the participant and the researcher through the signing of an Informed Consent Form (ICF), as provided in CNS 466/2012, or a Record of Informed Consent (RIC), as provided in CNS 510/2016.

Both ICF and RIC are instruments that seek to align the research with ethical principles by: 1) Informing the participant about the research objectives so that they can exercise their right to accept or refuse participation (respect for autonomy, respect for dignity); 2) Explaining the risks and benefits of the research to the participant, including necessary assistance for risk mitigation (beneficence, non-maleficence, justice); 3) Allowing the participant to withdraw from the study at any time (respect for autonomy, freedom); 4) Guaranteeing reimbursement of expenses and compensation for damages resulting from the research (justice); 5) Providing contact information for the researchers and the ethics committee (participant protection, justice).

The record of agreements between participants for research participation must be understandable in the participant's language, avoiding the use of complex technical terms common in research. A common mistake made by novice researchers is to present the research objectives and its problem as they are written in the research project to the participant. By doing so, they make it more difficult for participants to understand and participate, compromising the exercise of autonomy and freedom to choose their inclusion in the study.

Regarding the format, the records should be in the form of an invitation letter rather than self-declaration, and they can be in writing (as in the case of the ICF, provided in CNS 466/2012) or in audio, audiovisual, or other formats, as provided in CNS 510/2016.

Another important aspect is to ensure that consent is obtained for each data collection instrument used in the research. For example, if a research project involves questionnaires and interviews, separate ICFs or RICs can be used for administering the questionnaire and conducting the interview, as the risks may differ for each of them.

If a single consent record is adopted for more than one data collection method, the associated risks for each data collection method must be made clear, and the participant should choose whether they will participate in all data collection stages or not. Additionally, in cases where the research involves multiple participant groups (e.g., research with teachers and school coordinators), a separate consent record should be created for each participant profile if the risks and data collection methods vary between the groups. Table 1 provides a summary of the elements and characteristics that should be included in informed consent forms and records according to Resolutions CNS 466/2012 and CNS 510/2016.

Characteristics of Informed Consent Records.	Document Drafting.
Do not use institutional logos or emblems.	Avoid institutional logos or emblems.
Presented in the form of an invitation letter.	You are invited to take part in a research study [...].
Clarify the research objectives and procedures in language understandable to the participant, including ways to record their participation.	[...] with the aim of [clearly stated objective]. To participate, we ask that you [complete a questionnaire/consent to an interview/describe the data collection tool], which will take approximately [...] minutes. The data will be [audio-recorded.../video-recorded... and then transcribed...].
Explanation of potential discomforts, risks, benefits of participation, and methods for mitigating risks.	When you [complete the questionnaire/consent to the interview/participate...], you may [experience discomfort/ encounter unpleasant memories... describe risks in the participant's own words]. If... occurs, the researcher will [halt the interview... describe how to mitigate the risk]. You also have the option to [withdraw your participation...].
Assurance of the right to exit or withdraw from the study at any time without consequences.	You have the option to withdraw from the study at any time, without any repercussions, simply by communicating your decision to the researcher using the provided contact details.
Ensuring confidentiality and data privacy.	The data collected during the research [information provided in the interview/questionnaire... describe the data] will be kept confidential and will only be accessible to the research team. Such data will be retained for a period of 5 years after the conclusion of the study, which is expected to end on [specify the probable study end date].
Choice of anonymity or identification.	Your name and identity may be disclosed when disseminating research results, based on your preference [...]. Alternatively, your participation in this study will remain anonymous, and your identity will not be revealed. Pseudonyms will be used when referencing your statements [...].
Guarantee of receiving a copy of the document.	You will receive an original copy of this document [...].
Guarantee of expense reimbursement and free participation. Guarantee of compensation.	You will not receive any monetary compensation for participating in the study [or... you will receive reimbursement for travel expenses to the research location... include expense reimbursement if applicable]. In the event of any harm resulting from your participation in the study, you will be entitled to compensation.
Contact information for the researchers and the ethics committee that approved the study.	If you have any questions about the research, you can contact the responsible researchers. If you have any concerns about the research's ethical conduct, you can reach out to the ethics committee... [Researcher contact information... Institutional ethics committee contact information. Contact information for CONEP, if applicable].

Table 1. Components of Informed Consent Records.
Source: Compiled by the author, drawing from CNS 466/2012 and CNS 510/2016 resolutions, as well as her experience in the institutional ethics committee.

To respect the principles of autonomy and freedom, special attention must be dedicated to research involving minors or individuals lacking capacity. When conducting research with these subjects, the following steps should be taken:

1) Consent from the legal guardians (e.g., parents) through the collection of consent from the legally responsible adult.

2) Assent from minors or individuals lacking capacity to participate in the research, respecting their level of understanding, using an Informed Assent Form (IAF) or a Record of Informed Assent (RIA). The latter may not necessarily need to be in written form; it can be obtained through other means such as audio, audiovisual

materials, for example. These documents may incorporate visuals, simplified language, or even a comic book-style format to enhance participant comprehension.

Another critical consideration pertains to institutional involvement. It's not uncommon for research to be conducted within or about organizations, whether they are public, private, or of another nature. In every case, institutional consent must be obtained for the research to proceed. This is done using a specific document such as an Institutional Consent Document (ICD). This document should clarify the research objectives and procedures, including an agreement regarding the organization not being identified in reports and articles resulting from the research.

When conducting research within corporate documents, it's essential to specify the documents being accessed in the ICD (Institutional Consent Document). It's also advisable to use a Data Utilization Commitment Document (DUCD) for confidential data (e.g., medical records). For instance, if a person is researching the interactions of children and teachers within a school, the following should be obtained:

- Consent from the school to conduct the research.
- Consent from parents or guardians of minors.
- Assent from the children to participate.
- Consent from the teachers to participate in the study.

It's essential to note that research involving not only individuals but also records related to those individuals, such as data and biological materials, requires participant consent for data usage. For example, if there is a need to access patient medical records in hospitals, participants must agree to their data being used in research through the signing of an ICED (Informed Consent Document). In cases where it's not possible to obtain consent directly from participants for medical record access, a request for an exemption from ICED may be justified with the ethics committee. A DUCD (Data Utilization Commitment Document) for data use should be used in this case.

Data collection and use that doesn't allow participant identification, with recruitment conditions ensuring anonymity and preventing accidental identification, doesn't require submission to the CEP-CONEP system. This applies to opinion research surveys without participant identification, whether conducted online through self-administered questionnaires or in-person (e.g., paper surveys placed in collection boxes).

In cases of research that exclusively involve information covered by the Lei de Acesso à Informação (LAI), there is no need to submit the research to the CEP-CONEP system, as per Article 1, sole paragraph, item II of CNS 510/2016. The scope of the law covers information about activities of public bodies at the federal, state, and municipal levels, including the executive, legislative, and judicial branches, as well as non-profit entities that receive public funding (Lei n. 12.527, de 18 de novembro, 2011). However, there are exceptions:

1) Access to information classified as "ultrasecret," "secret," or "reserved."

2) Access to nonexistent information (Article 15, Decree n. 7,724, 2012) may have its disclosure or access authorized by legal provision or express consent from the data subject.

3) Requests that are unreasonable or disproportionate; generic; or require additional processing, as per Article 13 of Decree 7,724/2012;

4) access to personal information, as per Article 31 of the LAI (Lei n. 12.527, de 18 de novembro, 2011).

Article 31 of the LAI considers that personal information – information relating to the "intimacy, private life, honor, and image of individuals, as well as their freedoms and individual rights" – must be respected and will have restricted access to public entities authorized by law and to individuals to whom it refers, for a period of 100 years from its production date. For example, requesting a government agency to provide individuals' addresses violates the LAI.

Regarding scientific research, Articles 59, 60, and 61 of the aforementioned decree (Decreto n. 7.724, de 16 de maio, 2012) stipulate the need to demonstrate the relevance and public interest in accessing personal data, unlike other LAI information, which doesn't require justification for its acquisition. Recognition of the scientific relevance or high historical interest of the study must be substantiated, as stated in Article 59 of the law, which requires technical reports from scientific entities (universities, institutes) justifying data usage, supporting decisions to open documents, including permanent records held in archival institutions, such as the National Archives.

The design of various research projects may involve the handling of personal data, requiring special care. This consideration is based not only on CNS 510/2016 but also on the General Data Protection Lei n. 13.709, de 14 de agosto of August 14, 2018 (LGPD) and Lei n. 13.853, de 8 de julho of July 8, 2019, which establishes the National Data Protection Authority (ANPD). Personal data, as defined by this law, includes "information related to an identified or identifiable person" (Article 5, Section I) (Lei n. 13.709, de 14 de agosto, 2018), except

for data about deceased individuals, which are not covered by the law. The LGPD applies to the use of personal data by legal entities, whether public or private, and also by private individuals, with exceptions for scientific research, as long as Articles 7 and 11 of the LGPD are observed, which require consent for the use of personal data in such cases. In other words, the handling of personal data, especially sensitive data (data related to racial/ethnic origin, religious beliefs, political opinions, union membership, health and sexual life data, genetic data) (Article 5, Section II, LGPD, Lei n. 13.709, 2018), can only occur under the law with unequivocal consent regarding the purpose of data usage and its processing methods, or for research purposes, preferably anonymized according to Article 11, LGPD (Lei n. 13.709, de 14 de agosto, 2018).

Exemption from requiring consent is provided when there are "data made manifestly public by the data subject, while respecting the rights of the data subject and the principles outlined in this Law" (Article 7, Lei n. 13.709, de 14 de agosto, 2018). This applies to research involving identifiable data about individuals (physical or legal) on social media networks. Even without direct contact with individuals, for instance, when analyzing content from open profiles on platforms like Facebook or Instagram, it is possible to identify participants. According to the LGPD, permission is not required for usage, as privacy – an individual's control over what they choose to disclose about themselves – is already adequately satisfied. However, caution must be exercised regarding the risk of using images, statements, and data, especially sensitive data, for purposes not foreseen by the data owner. The use of data, even if publicly shared by the data owner, particularly sensitive data, should not permit the identification of the participant.

Another aspect to consider is the use of images of individuals captured on internet social media, for example. Ideally, the researcher should create their own images for the study. In such cases, authorization to use images must be obtained through an image usage authorization agreement, which should be granted free of charge and exclusively for research dissemination through any means. This is especially important when considering images that could expose sensitive data of the participants, as briefly mentioned. If the researcher is not responsible for capturing the image, they should acquire the rights to the image from the owner (which can be licensed, transferred, or granted) and respect the rights of the image's author. A summary of the documents required for research and exemption from processing is provided in Table 2.

Nature of Research	*Documents for Participants*
Research Exempt from CEP-CONEP Processing	
Research involving data collection without the possibility of participant identification and tracking (opinion surveys).	Information equivalent to the Informed Consent Record provided to adult participants.
Research using secondary data with unidentified participants (e.g., using PNAD data).	None.
Research stemming from the researcher's professional practice, with no identification of any participants.	None. If there is identification, you need to obtain individual consent and assent records, image usage authorization terms as applicable, and the protocol must go through CEP. Post-informed consent terms with participants, if applicable.
Literature review or review of open documents and open data research.	None.
Research processed through the CEP-CONEP system (Use of Plataforma Brasil).	
Any research.	Plataforma Brasil Cover Sheet.
Research using secondary data with identified participants (e.g., using medical record data, using schoolwork data, using private documents).	ICR (for adult participants). ICR (completed by legal guardians for the participation of minors or incapacitated individuals). ACR (minors or incapacitated individuals). Terms of Commitment for Data Usage (in case individual consent is unfeasible; CEP approval is required for ICR exemption).
Research using secondary data of identified and publicly available participants (e.g., using data available on social networks).	If they identify participants and deal with sensitive issues: ICR (for adult participants). ICR (filled out by legal guardians for the participation of minors or incapacitated individuals). ACR (minors or incapacitated individuals). Image Release and/or Usage Terms (when applicable).
Individual research involving contact and participant identification, using any data collection instrument.	ICR (for adult participants). ICR (completed by legal guardians for the participation of minors or incapacitated individuals). ACR (minors or incapacitated individuals). Image Usage Authorization, if applicable.
Research conducted in or about institutions.	Institutional Assent Form.
	Informed Consent Records for each individual participant: ICR (for adult participants). ICR (legal guardians, for the participation of minors or incapacitated individuals). ACR (minors or incapacitated individuals).
	Information sheet about the research for participants not directly involved in observations, if applicable.
	Post-informed consent form (if applicable).
	Data Usage Commitment Form (DUCF) for the use of privately accessed data.
	Image Usage Authorization Form, if applicable.
Research involving individual and collective participation (e.g., indigenous peoples, traditional communities).	Approval from tribal leadership (tribal communities). Approval from the district council (if applicable).
	Individual consent and/or assent for each participant as applicable (ICR for adults, ACR for minors or incapacitated individuals, and ICR for legal guardians).
	Image Usage Authorization Form (if applicable).

Table 2. Summary of Procedures and Documents for Research. [a]
Source: Author's compilation.

[a]RCLE as an acronym for Record of Free and Informed Consent (which may take the form of Informed Consent Form - ICF) and RALE as an acronym for Record of Free and Informed Assent (which may take the form of Informed Assent Form - IAF).

While the list of documents presented in Table 2 may appear comprehensive and has been discussed in the relevant sections of this text, researchers in the field of Information Science must exercise great care when dealing with research participants, whether through direct or indirect interactions. This care is essential for building a strong researcher-participant relationship and ensuring the ethical conduct of the research.

FINAL REMARKS

Contemplating how to conduct research involving human subjects, whether through direct or indirect engagement, requires researchers in the field of Information Science to take various precautions. For most research endeavors in this domain, it is necessary to submit the research protocol to the Plataforma Brasil for evaluation by the CEP-CONEP systems. This process necessitates meticulous document preparation to secure informed consent from research participants, documented in consent and assent records, and obtaining any applicable institutional approvals. The committee's assessment provides a more profound understanding of the research data collection instruments concerning their legal compliance. This not only contributes to the researcher's institutional credibility but also safeguards and protects the research participants.

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NOTAS DA OBRA E CONFORMIDADE COM A CIÊNCIA ABERTA

CONTRIBUIÇÃO DE AUTORIA

Papéis e contribuições	Eliane Cristina de Freias Rocha
Concepção do manuscrito	X
Escrita do manuscrito	X
Metodologia	X
Curadoria dos dados	X
Discussão dos resultados	X
Análise dos dados	X

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EQUIPE EDITORIAL