ética em pesquisa

• COMISSÃO NACIONAL DE ÉTICA EM PESQUISA •

Are you a PARTICIPANT ?

PESQUISA

these guidelines are for you

• RESEARCH PARTICIPANTS' **RIGHTS BOOKLET** •

RIGHTS PRIMER OF RESEARCH PARTICIPANTS

presentation

Hello, we are happy that you have access to this material!

This booklet provides important information about the protection of people who are participating in research (Research Participants), that is, who are being researched. If you have been invited to participate in a survey but have not yet made a choice, this material can also help you decide whether or not to accept the invitation.

Here, you will be able to better understand how research with human beings takes place in Brazil, find out which competent bodies work to regulate, standardize, educate and provide security and autonomy for people who, in some way, are participating, have already participated or intend to participate of a search.

Don't worry! If you have any doubts about any subject, you can speak to us. We prepare some important contacts and a glossary at the end of this booklet.

We understand that when we are about to participate in some activity that we are not aware of, in this In the event of a survey, we may feel apprehensive. It is common for some questions to arise:

· How will this research take place?
· What are the risks?
· Is it reliable?
· Where to look for help?

It was questions like these that inspired the creation of the booklet. When all information is clearly communicated in advance, as well as the means of seeking help, feelings of insecurity are alleviated.

The Research Participant Rights Booklet was developed especially to support you who have already submitted or are analyzing the possibilities of participating in research and want to know everything about your rights and guarantees.

HOW WE MADE THIS BOOKLET

This material is based on **CNS Resolution nº 466/12 and CNS Resolution nº 510/16,** the main guidelines on research ethics in Brazil. The content is a selection of excerpts from resolutions, manuals and regulations of the CEP/Conep System and was interpreted in a didactic way to facilitate reading and understanding of the information.

RIGHTS PRIMER OF RESEARCH PARTICIPANTS

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RIGHTS PRIMER
OF RESEARCH PARTICIPANTS

important

**Know that all information,
documents and contacts can be consulted on the website:**
www.conselho.saude.gov.br/eticaempesquisa.php

the CEP/CONEP SYSTEM

The CEP/Conep System has the function of protecting research participants, through the ethical evaluation of any and all research that involves the direct or indirect participation of human beings in Brazil. The system has two main characters:

1. Research Ethics Committee – CEP: CEPs are interdisciplinary and independent collegiate bodies, of public relevance, of a consultative, deliberative and educational nature, created to defend the interests of research participants in their integrity and dignity and to contribute to the development of research within ethical standards. According to CNS Resolution No. 370/07, the CEP can also be:

> (...) at state, regional, intermunicipal and municipal levels, in public administration bodies, at the discretion of Conep Operational Standard No. 001/13, when they are not Teaching and/or Research Institutions.

The gateway to all research projects involving human beings in Brazil is the Research Ethics Committee. The complexity of the procedures proposed in the research project is what defines whether you go (or not) to Conep.

2. National Research Ethics Commission – Conep: commission of the National Health Council – CNS created by CNS Resolution nº 196/96 (revoked in 2012 by CNS Resolution nº 466). Conep is a collegiate body, of a consultative, deliberative, normative, educational and independent nature, and is responsible for standardizing, regulating, deliberating and promoting educational actions related to the ethical aspects of research with human beings in Brazil.

Conep's educational actions aim to clarify and inform all interested parties in the CEP/Conep System, such as: researchers, members of ethics committees, Conep members, research institutions, research sponsors and, mainly, research participants.

Linked to the Ministry of Health and the National Health Council, the CEP/Conep System is responsible for ethically evaluating research projects from all academic and scientific segments, such as: exact sciences, human, social and biological sciences.

who

Ethical assessment has the function of protecting and guaranteeing the rights of those who are subjected to an search. These people are Research Participants.

In this way, the CEP/Conep System has the main purpose of defending the rights and interests of research participants, maintaining their integrity and dignity, and contributing to the development of research in Brazil.

RIGHTS PRIMER OF RESEARCH PARTICIPANTS

The Brazil Platform

The CEP/Conep System uses a virtual platform for recording and processing documents referring to research projects involving human beings: **it's Plataforma Brasil!**

With **CNS Resolution nº 466/12, CNS Resolution nº 510/16** and **Conep Operational Standard 001/13,** the platform is the official tool for submitting research projects. You can access the platform via link:

www.plataformabrasil.saude.gov.br

Plataforma Brasil was created with the aim of **improving and intermediating the processing of research projects involving human beings** between researchers, Ethics Committees and Conep. The procedures take place **entirely online,** eliminating the need to physically send documents. The tool has database protection features and also allows **everyone to have access to public data** from all approved research.

If you have any questions about how Plataforma Brasil works or need help with any topic **related to the research in which you or a family member was invited to participate,** please contact us contact:

know more about

The CEP/Conep System has educational channels so that you can follow all information about **protection actions for research participants.** Access:

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nas principais redes sociais.

consent/assent form free and enlightened

registration of consent or assent

The TCLE is the document that details the rights, procedures, risks and benefits associated with the choice to participate in a research. It is formulated and presented by the researcher. The decision to sign and agree to participate in the research is yours (as a research participant or as a legal representative). Consent is registered by signing the TCLE.

Research involving children under 18 years of age must have **a consent form and also a TALE,** Free and Informed Assent Form. The TALE must have accessible language for minors or those legally incapable, as indicated in items II.24 and II.25 of CNS Resolution No. 466/2012.

In Human and Social Sciences (CHS) research, the Record of Consent or Assent can be made on paper, in the TCLE or TALE, or in other formats, such as audio, film, electronic and digital media, for example.

The form of registration chosen by the researcher takes into account individual, social, linguistic, economic and cultural characteristics of the research participant and due to the methodology applied in the study. For further clarification, see CNS Resolution No. 510/2016, Chapter I, article 2, item XXII.

TCLE and TALE biomedical science research

When you are invited to participate in a research, firstly, **the responsible researcher has the duty to provide you with all the information** about the procedures that will be carried out and to prove that the project has undergone ethical analysis and was **duly approved by a Research Ethics Committee and /or by the National Research Ethics Commission.**

All information must be registered in the **TCLE - Free and Informed Consent Form:** document that, in addition to explaining the details of the research (justification, objectives, procedures, discomforts, risks, benefits, groups researched, etc.), must also **inform and ensure the rights of participants.** The ICF must be easy to understand.

When the researcher is writing the ICF, he or she must put himself in the shoes of a research participant. Item **IV.5.b of CNS Resolution No. 466/12** advises that the ICF must be adapted by the responsible researcher, always using clear and accessible language for research participants, taking special care to ensure that it is easy to read and understand.

Remember that the ICF must be in invitation format. DO NOT ACCEPT a TCLE in form of statement, as it may reduce your autonomy to decide whether to accept (or not) participate in the research.

Also DO NOT ACCEPT a TCLE with a different title. According to CNS Resolution No. 466/12, the document it should only be titled: **“Free and Informed Consent Form”.**

TCLE and TALE

humanities and social sciences research

In accordance with CNS Resolution No. 510/16, the TCLE can be prepared in any **medium, format or media, such as paper, audio, filming, electronic and digital media,** which records the granting of consent or free and informed assent, the form of registration being chosen based on the individual, social, linguistic, economic and cultural characteristics of the research participant and due to the methodological approaches applied.

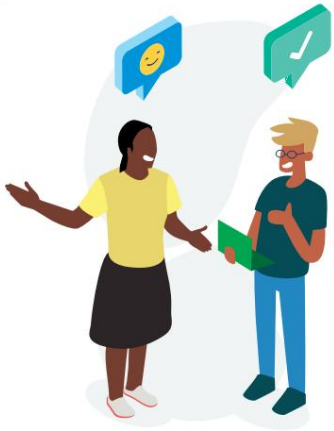
CNS Resolution No. 510/2016 (Chapter 1, article 2, item XXII).

rights of research participants

The rights listed below guarantee the maintenance of your integrity and dignity as a research participant. In addition to existing regulations, **the responsible researcher has the duty** to reflect all these rights in the project and guarantee them before, during and after the research.

In accordance with **CNS Resolutions nº 466/12, nº 510/16, nº 563/17, nº 580/18, nº 340/04, nº 304/00, nº 441/11, Operational Standard nº 001/13 and manual Frequent Pending Issues in Protocols Research,** we highlight the following **rights regarding the protection of research participants:**

1) Receive study information clearly;
2) Have the opportunity to clarify your doubts;
3) Have the time necessary to make an autonomous decision;
4) Have the freedom to refuse to participate in the study;
5) Have the freedom to withdraw your consent at any stage of the research;
6) Have the freedom to withdraw consent to the use and storage of biological material;
7) Receive assistance (full and immediate) for damages, free of charge;
8) Request compensation for damages;
9) Receive reimbursement for expenses (including companion expenses);
10) Have access to the results of exams carried out during the study;
11) Request the removal of your genetic data from banks where they are stored;
12) Have free post-study access to the research product (when applicable);
13) Have free access to the chosen contraceptive method (when applicable);
14) Receive free genetic counseling (when applicable);
15) Ensure the confidentiality of your data;
16) Have your privacy assured;
17) Receive a copy of the TCLE/TALE (signed and initialed by the research participant and the researcher).



to receive information from clear form

The responsible researcher has the duty to provide you with information (orally and recorded in the TCLE) clearly, highlighting the receipt of full and immediate assistance, free of charge, for as long as necessary, in case of damage resulting from the research. You must also ensure reimbursement for all expenses (if any) that you and your companion will incur when participating in the research.

In the case of **research with underage or incapacitated participants,** the researcher has the duty to ensure (orally and recorded in the TCLE) that the legal guardian and the participant will receive full and immediate assistance, free of charge and for as long as necessary. .

In the case of **research with pregnant women,** the researcher has the duty to ensure (orally and recorded in the TCLE) that the mother and child, during and after pregnancy, will receive full and immediate assistance, free of charge and for as long as possible. necessary.

The responsible researcher has the duty to provide information (orally and recorded in the TCLE) about the **right to compensation in case of damages resulting from the study.** And in the case of drug studies, individuals will continue to receive the research product free of charge from the sponsor.

Know more:

· The ICF must present, in a clear and objective way, the potential benefits of the research to you, participant, without overvaluing them;

· If the study does not anticipate any direct benefit, this information must be included in the ICF in a explicit;

· The potential risks associated with the research must be recorded in the ICF, without underestimating them;

· The TCLE must explain the measures and precautions that will be adopted to avoid or reduce risks associated with the research.

opportunity to clarify your doubts

The responsible researcher has the duty to provide you with information (orally and recorded in the TCLE) **about the means of contact,** as you (or your legal guardian) may need guidance, clarification of doubts, or even request assistance, for example , for an adverse reaction to the investigational drug.

Contacts must be easily accessible and available 24 hours a day, 7 days a week. **According to CNS Resolution No. 466/12, item IV.5.d:** (...) the TCLE must include "the address and telephone or other contact details of those responsible for the research, the local zip code and Conep, when relevant".

Such information is relevant so that you (or your legal guardian) can contact the Research Ethics Committee - CEP or the National Research Ethics Committee - Conep **to clarify any doubts, complaints or reports.**

respect for your decision autonomy

It's your decision! Therefore, the researcher responsible for the study must make you comfortable for as long as possible. is necessary. You must make the decision about whether or not to participate in the research, freely.

Freedom to accept or refuse your participation in the study;

Freedom to withdraw your consent at any stage of the research;

Freedom to withdraw consent to the use and storage of biological material.

Receive assistance for damages for free

CNS Resolution No. 466/12 defines the **damage associated (or resulting) from research as:** "immediate or subsequent harm, direct or indirect, to the individual or community, resulting from the research" (item II.6). Still in item V.6, the aforementioned Resolution defines that **the researcher, the sponsor and the institutions involved in the research have the duty to provide immediate assistance,** in accordance with item II.3, as well as being responsible for **providing comprehensive assistance** to participants of the research with regard to complications and damages resulting from the research.

The researcher ~~must~~ NOT:

- Omit information about assistance;
- Omitting assistance, regardless of proof of the damage caused;
- Limit the types of assistance to the research participant;
- Limit the time of assistance to the research participant;
- Omit information about free assistance.

The researcher must ensure (via TCLE) in a clear and affirmative way, that you will receive full and immediate assistance, free of charge (by the sponsor), for as long as necessary, in case of damage resulting from the research.

Request compensation for damages

CNS Resolution No. 466 of 2012 (item IV.3) deÿnes that “research participants who suffer any type of harm resulting from their participation in the research, whether or not provided for in the Free and Informed Consent Form, **have right to compensation** from the researcher, the sponsor and the institutions involved in the research” (item V.7). **It is worth emphasizing that the issue of compensation is not the prerogative of CNS Resolution No. 466/12,** being originally provided for in the Civil Code (Law No. 10,406 of 2002), especially in articles 927 to 954, Chapters I (Obligation to Indemnify) and II (Obligation to Indemnify), Title IX (Civil Liability).

The researcher must NOT:

- Omit information about compensation;
- Link the compensation to the contracted insurance.

Receive reimbursement of expenses

CNS Resolution No. 466 of 2012, item II.21, defines reimbursement as material compensation, exclusively for **expenses of the participant and their companions,** when necessary, for transportation and food. Furthermore, item IV.3.g advises that **the researcher has the duty to register in the TCLE the guarantee of reimbursement** and how the expenses will be covered.

Expenses can also be covered in advance, as defined by item II.18 of Resolution No. 466 of 2012: “material compensation, exclusively for transportation and food expenses for the **participant and their companions,** when necessary, prior to their participation in research.”

The researcher must NOT:

- Omit information about reimbursement;
- Limit reimbursement items and amounts;
- Failing to offer compensation to the companion(s).

rights

The researcher must ensure (via TCLE) in a clear and affirmative way that the research participant will receive full and immediate assistance, free of charge (by the sponsor), for as long as necessary, in case of damage resulting from the research.

Have access to results of the exams carried out during the study

The researcher has the duty to grant the patient's doctor or the patient himself access to the results of exams and treatments, whenever requested or indicated. If there is no substantiated justification or greater reason, the researcher should not limit research participants' **access** to the results of their exams that were carried out during the study.

The ICF should not restrict your access as a research participant to the results of exams carried out during the study, unless there is a methodological justification for doing so.

Request withdrawal of genetic data

CNS Resolution No. 340 of 2004, in item III.7, determines: "Every individual can have access to their genetic data, as well as having the right to remove them from banks where they are stored, at any time".
The Researcher must ensure that the research participant has complete freedom to withdraw their consent to genetic data at any time during the research and that this decision will not result in any type of penalty.

free post-study access when necessary

CNS Resolution No. 466 of 2012, item III.3.d, states that research must "ensure all participants at the end of the study, by the sponsor, **free and indefinite access to the best methods prophylactic, diagnostic and therapeutic treatments** that have been demonstrated to be effective". It also adds in **item d1** that "access will also be guaranteed in the interval between the end of individual participation and the end of the study, and, in this case, this guarantee may be given through an extension study, according to a duly justified analysis." each from the participant's attending physician."

free access to contraceptive methods when necessary

When the contraceptive method (example: oral contraceptive, condom, intrauterine device, etc.) chosen by you, the research participant, involves expenses, **it will be up to the researcher and the sponsor to provide the method free of charge,** for as long as necessary.

CNS Resolution No. 466 of 2012 (item III.2.o) advises that research must "ensure research participants the **conditions for monitoring, treatment, comprehensive assistance and guidance, as appropriate, as long as necessary, including in research tracking".**

free access to genetic counseling when necessary

Studies involving human genetics have certain characteristics that must be observed, especially when there is the possibility of generating information capable of causing psychological harm, stigmatization and discrimination of individuals, family members or groups (clinical genetics, population genetics and behavioral genetics studies) .

It is important and necessary that you, as a participant in this type of research, are informed about who will carry out your genetic counseling (or, at least, the institution or location where it will take place). Furthermore, **it is necessary to ensure that this clinical counseling and monitoring is offered free of charge by the sponsor.**

The researcher must not omit information about access to the genetic counseling and clinical monitoring.

your data and your privacy must be ensured

According to CNS Resolution No. 466 of 2012, item III.2.i, in the research the person responsible must (...) "provide procedures that ensure conÿdentiality and privacy, image protection and non-stigmatization of research participants, ensuring that information is not used to the detriment of individuals and/or the group, including in terms of self-esteem, prestige and/or economic-financial aspects".

The Researcher must NOT:

· Neglecting the data that will be passed on to the sponsor or third parties;
· Provide broad access to data;
· Omitting that medical records can be consulted;
· Omit the mechanisms adopted for data anonymization.

research participant

rights

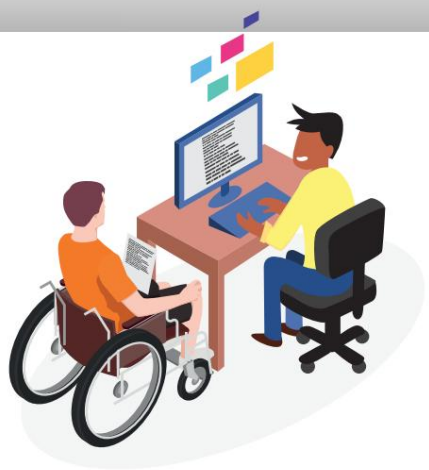
Your data is confidential and will be forwarded to the sponsor or third parties only after due anonymization, i.e. as long as you cannot be identified.

The researchers, monitors and auditors of the sponsor may have access to your data personal, and must assure you of the commitment professional with absolute confidentiality of information.

Your medical record may be consulted by researchers and also by monitors and auditors of the sponsor. Therefore, this information must be expressly registered in the TCLE.

You have the right to know what the mechanism will be like used to ensure confidentiality and the anonymization of your data.

to have access to one way full tcle



CNS Resolution No. 466 of 2012, item IV.5.d, advises that the ICF must be prepared in two "COPS" and initialed on all its pages (by the research participant and the researcher). These requirements aim to ensure that you can receive a duly signed and initialed copy of the TCLE.

The researcher ~~must~~ NOT:

- Omit information about your right to have a copy of the TCLE;
- Use the word "COPY" on your copy of the TCLE;
- Omit initials and/or signature on all pages of the TCLE.

The ICF must clearly and affirmatively ensure that you, as a research participant, will receive a copy (and not a copy) of the document signed by the researcher and initialed on all pages.

know more about

Potenciais penalidades aplicáveis às instituições que não se atentam às normas sobre ética em pesquisa vigentes no País:

- Cada modalidade de pesquisa deve cumprir as exigências setoriais e regulamentações específicas ao caso concreto, além to **preserve the conduta ética aceitável** (inciso XII.1, Resolução CNS nº 466/2012);
- **Potenciais danos associados ou decorrentes das pesquisas com seres humanos são de responsabilidade do pesquisador, seja ele pessoa física ou jurídica**, que executa ou proporciona, direta ou indiretamente, o fomento e promoção à pesquisa, cabendo reparação pelo dano causado (incisos II.6, II.7, II.15, II.22, e XI, Resolução CNS nº 466/2012);
- Pesquisas envolvendo seres humanos em qualquer área do conhecimento deverão **observar todos os critérios elencados na Resolução CNS nº 466/2012;**
- **Estudos que não foram submetidos à análise ética no Sistema CEP/Conep** podem não ser aceitos por agências de fomento à pesquisa, além de o corpo editorial das revistas científicas, visto que estes devem exigir documentação comprobatória de aprovação do projeto de pesquisa em âmbito ético (inciso XII.2, Resolução CNS nº 466/2012).

Cabe salientar que o Sistema CEP/Conep, criado em 1996, possui a atribuição regimental para apreciar protocolos de pesquisa com seres humanos e de debater seus aspectos éticos, de forma a evitar abusos e proteger os participantes das pesquisas, contribuindo, assim, para o desenvolvimento seguro das investigações científicas, considerando sempre a relevância social da pesquisa, o que garante a igual consideração dos interesses envolvidos, não perdendo o sentido de sua destinação sócio-humanitária.

Enfatize-se que o pesquisador **é aquele responsável** pela coordenação da pesquisa e corresponsável pela integridade e pelo bem-estar dos participantes da pesquisa de forma solidária (inciso II.16, Resolução CNS nº 466 de 2012). Portanto, o pesquisador responsável, o patrocinador e as instituições e/ou organizações envolvidas nas diferentes fases da pesquisa devem proporcionar, além da assistência imediata prevista nos termos do inciso II.3 da Resolução CNS nº 466 de 2012, **a assistência integral aos participantes da pesquisa** em todas as fases da prática investigativa (inciso V.6, Resolução CNS nº 466 de 2012).

Se, malgrado todos estes cuidados, **os participantes da pesquisa vierem a sofrer qualquer tipo de dano resultante de sua participação na pesquisa**, previsto ou não no Termo de Consentimento Livre e Esclarecido, **terão direito à indenização, em face do pesquisador, do patrocinador e das instituições envolvidas nas diferentes fases da pesquisa (inciso V.7, Resolução CNS nº 466 de 2012).** Assim, as instituições se submetem às responsabilizações administrativa, cível ou penal, isolada ou cumulativamente, quando na condução de pesquisas com seres humanos, que possuem riscos potenciais à vida humana, saúde e integridade psíquica e física.

Como se denota acima, considerando que **a Resolução CNS nº 466/2012 é norma que disciplina matéria de competência específica e que, portanto, não possui, o condão de estipular penalidades não há** that if **falar deste instituto no âmbito do Sistema CEP/Conep, mas sim da análise ética na condução de pesquisas envolvendo seres humanos**, prezando pelo maior benefício e menor risco aos participantes da pesquisa.

Salienta-se, ainda, que como parte dos procedimentos administrativos, o Sistema CEP/Conep ao receber denúncias ou perceber situações de infrações éticas, sobretudo as que impliquem em riscos aos participantes de pesquisa, os fatos deverão ser comunicados às instâncias competentes para averiguação e, quando couber, **ao Ministério Público (Norma Operacional CNS nº 001 de 2013, 2.1.k).**

important contacts

Conep telephone
(61) 3315-5877

Speak Easy with Conep

Conep email
conep@saude.gov.br

Opening hours from Monday to Friday from 8am to 7pm

Matters related to **Research Ethics Committees.**	**conep.cep@saude.gov.br**
Matters related to **training for the CEP/Conep System.**	**conep.treina.insp@saude.gov.br**
Matters related to **complaints about lack of ethical conduct in the CEP/Conep System.**	**conep.denuncia@saude.gov.br**
Subjects related to **biobanks and/or biorepositories.**	**conep.biobancos@saude.gov.br**
Subjects related to the **Humanities and Social Sciences Institute.**	**conep.instancia@saude.gov.br**

rights

the representation of research participants in the CEP and CONEP

Did you know that research participants have constant representation on the Research Ethics Committees - CEP and the National Research Ethics Committee - Conep?

Research Participant Representatives are people capable of expressing the views and interests of individuals and/or groups participating in research. They must necessarily belong to the target population and their nomination to be a member of the CEP must be made by the corresponding Municipal Council.

Research Participant Representatives have active participation in Ethics Committees. They're part of a collegial body, they give their opinion at meetings and can even be responsible for reporting research protocols.

The number of Research Participant Representatives in CEPs is deÿned as follows:

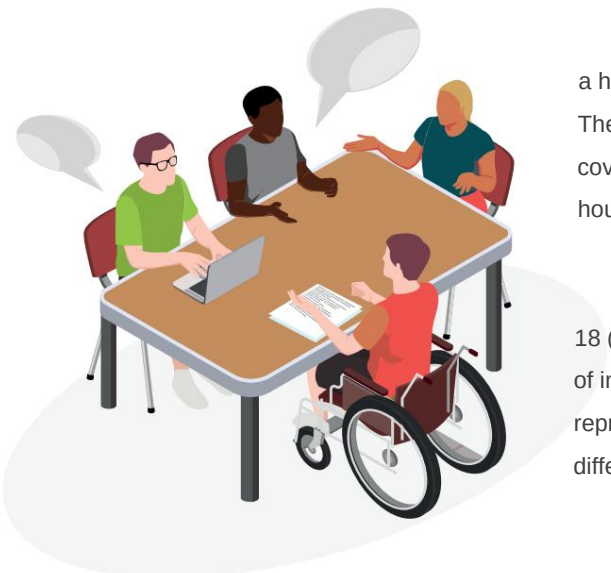
Ÿ The CEP will be composed of at least seven members. Among them, at least one representative of the Research Participants, respecting proportionality by number of members. At least 50% of members must demonstrate research experience.

To better define the role of the Research Participant Representative at CEP and Conep, the following terms should be considered:

I – Social control: process in which the population participates, through representatives, in the definition, execution and monitoring of public policies;

II – Entity indicating the Representative of Research Participants: it is the organization or movement, preferably a social control council (example: health, education, environment, etc.), legally constituted or not, with a history of activity in at least one of the segments social control (health, education, environment, among others), responsible for appointing the Representative of Research Participants to the CEP/Conep System;

III – Representative of Research Participants: member of the CEP/Conep System and member of social control (social and citizen participation), which represents the interests of research participants.



The Research Participant Representative - RPP must have a history of participation in social and/or community movements. The RPP's history of participation is not limited to the health area, covering all social segments, such as education, environment, housing, among others.

The Research Participant Representative must be at least 18 (eighteen) years old and be able to express the views and interests of individuals and/or groups of research participants, in order to represent, within the CEP System /Conep, the collective interests of different audiences.

The role of RPP in the CEP

Ÿ Regularly attend meetings, training and events organized by the CEP/Conep System;

Ÿ Promote, together with other members of the CEP/Conep System, specific issues related to interests and rights of research participants;

Ÿ Report research protocols.

It is the RPP's obligation to maintain confidentiality of any and all information obtained in the exercise of its activity as a member of the CEP/Conep System.

The CEP must provide a Permanent Training Plan for its members, including content targeted and accessible to the RPP. The CEP has the duty to encourage the protagonism of RPPs, respecting their individual characteristics.

Ÿ Involve and include the RPP in the CEP's regular ethical analysis and debate activities;

Ÿ Ensure the registration and linking of the RPP profile to the CEP on Plataforma Brasil;

Ÿ Integrate RPP into member training.

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Contact us and find out how you can contribute to **representation of research participants** in CEP or Conep:

conep@saude.gov.br

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OF RESEARCH PARTICIPANTS

to finish

The Representative of Research Participants is essential to authenticate the existence of a Research Ethics Committee. A CEP that has difficulty having a Research Participant Representative member also has difficulty acting to protect these participants. participants.

It is essential that the Research Participant is the protagonist of the CEP/ Conep System.

José Araújo Lima Filho

Em memória do saudoso Membro da Conep
Representante dos Participantes de Pesquisa
*07/08/1957.
†03/09/2019.

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RIGHTS PRIMER OF RESEARCH PARTICIPANTS

glossary

- **Research sponsors:** these are the entities or institutions that act as research sponsors. Example: pharmaceutical industries, research support foundations, etc.; **Entitle:** act of putting a title or name on something;
- **Prophylactic methods:** part of medicine that establishes preventive measures to preserve the health of the population;
- **Anonymization:** act of proposing anonymity, making anonymity. Non-disclosure of information or names; **Listed:** enumerated, listed, specified, related, catalogued;
- **Despite:** despite, nevertheless, in spite of, regardless of, although, even though, despite, although;
- **RPP:** Representative of Research Participants.

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conep coordination:

Conep Coordination:

- Coordinator/CNS*: Jorge Venancio.
- Deputy Coordinator/CNS*: Denise Torreão.
- Deputy Coordinator/MS*: Patrícia Boaventura.
- Deputy Coordinator: Claudio Stefanoff.
  (representative of the full Conep)

Conep Executive Secretariat:

- Executive Secretary/MS*: Cristiane Fulgêncio.
- Deputy Executive Secretary/CNS*: Carlos Lanna.

*MS: Ministry of Health.
*CNS: National Health Council.

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• COMISSÃO NACIONAL DE ÉTICA EM PESQUISA •

• RESEARCH PARTICIPANTS' **RIGHTS BOOKLET** •

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