

Participant Bill of Rights

A blueprint for research participants
and the insights & analytics industry



November 2024



WHO WE ARE

Insights Association

The Insights Association protects and creates demand for the evolving insights and analytics industry by promoting the indisputable role of insights in driving business impact. All revenue is invested in quality standards, legal and business advocacy, education, certification, and direct support to enable our members to thrive.

Influential and informative, IA members are transformative actors in software, data analytics, data collection, and market, social, and healthcare research. They span companies large and small, including Nielsen, Dynata, Ipsos, SAGO, Cint, YouGov, and Material+, the insights departments of such major brands as Bayer, Capital One, Hulu, Eli Lilly, Nestlé Purina, MetLife, McDonalds, and The Travelers Companies; and countless individual practitioners.

Council for Data Integrity

Led by Insights Association member industry leaders and experts, the Council for Data Integrity (CDI) follows the continual evolution of sample and data integrity definitions, quality standards, evaluation processes, and industry education. Founded in 2021, the CDI develops educational content, best practices, and guidelines for the insights and analytics industry.

InsightsAssociation.org

Global Data Quality initiative

The Global Data Quality initiative is a cross-association collaboration between the Insights Association (IA), Association for Qualitative Research (AQR), The Canadian Research Insights Council (CRIC), ESOMAR, the Insights Association, the QRCA, MRS (Market Research Society), The Research Society (TRS), SampleCon, and the Association of Market Research Austria (VMÖ) that addresses ongoing and emerging risks to data quality in the market and social research, consumer insights, and analytics industry.

GlobalDataQuality.org



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INTRODUCTION

Our profession relies on people. Yes, we who work in or with the industry are essential people. So too are the people who take part in our studies. We rely on the lived experiences, behaviors, and beliefs they share with us to inform the development of insights and solutions. What happens when research participants don't have a good study experience? The trust they place in us to care for their stories falls. They may abandon the study or not participate in another again.

Abandonment and refusal can be just as detrimental to data quality as participant fraud. We believe that restoring trust in our profession requires letting participants know what they *should* expect from their research experience and that we value and respect their person and story to uphold it.

CALL TO ACTION

On the following page, we present a list of fundamental rights or rules of engagement that participants should expect, at a minimum, when participating in a research study. Whether you are a corporate researcher, a traditional market research agency, a sample provider, a digital analytics, a quantitative or qualitative house or an insights consultancy, we all have a part to play if we want to build back the trust in exchange for more quality data stories, more participants completing studies and more participants returning to be in another study in good faith. Let's continue to work together on letting participants know they should expect a good experience and that we will actually deliver on it. Join us by embracing and adopting the Participant Bill of Rights.

— *The Council for Data Integrity*

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16 RIGHTS PEOPLE SHOULD KNOW & THE INDUSTRY SHOULD COMMIT TO PROVIDING

1. I have the right to know the research study's general purpose, what I will do, how often, and for how long.
2. I have the right to communication that is easy to read and understand.
3. I have the right to know how to contact the company that invited me to the research study.
4. I have the right to be free from harassment or intimidation to join or continue in a research study.
5. I have the right to know how I can leave a study at any time.
6. I have the right to request that my personal information be removed from the database of the company that invited me to the study and to not be contacted again.
7. I have the right to be treated with dignity and respect before, during, and after the research study.
8. I have the right to be in a study that is free from discrimination. This includes race, ethnicity, sexual orientation, gender identity, disability, age, national origin, religion, or status as a protected veteran.
9. I have the right to know if reasonable accommodations are available for persons with disabilities.
10. I have the right to know if I will receive an incentive for my time, in what form, its value, how, and when I will receive it.
11. I have the right to not be sold anything or asked for money as part of a research study.
12. I have the right to be told about any risks that might happen as a result of participating in research.
13. I have the right to confidentially share my experience in the research study with the company that invited me to the research study.
14. I have the right to request and receive the privacy policy of the company that invited me to the study.
15. I have the right to know if a data breach exposed my personal information. This is governed by the state law where the company that invited me to the study is based.
16. I have the right to ask for and receive a printed or electronic copy of these rights.

WHY A BILL OF RIGHTS?

The Context:

People are the lifeblood of the insights and analytics industry.

Data quality, defined as the measure of the condition of data based on factors such as accuracy, completeness, consistency, reliability¹, and how up-to-date it is, is a known problem for the insights and analytics community. While much focus is placed on data fraud², peoples' willingness to participate in research is also a measure of data quality. People who have a positive experience while participating in research are more likely to be engaged in the survey and provide high-quality data. They are also more likely to want to participate in future research³. However, many factors can drive away or cause negative, non-fraudulent behavior by the very people we depend on to surface insights. This brings us back to data quality. Length of study, for example, may lead to survey abandonment or a lack of care or detail when answering questions in an online qualitative board or quantitative survey.

Distrust and mistrust in research studies and researchers themselves can have the same end effect – or, prevent participants from starting or returning.

The Challenge:

There continues to be widespread distrust in research.

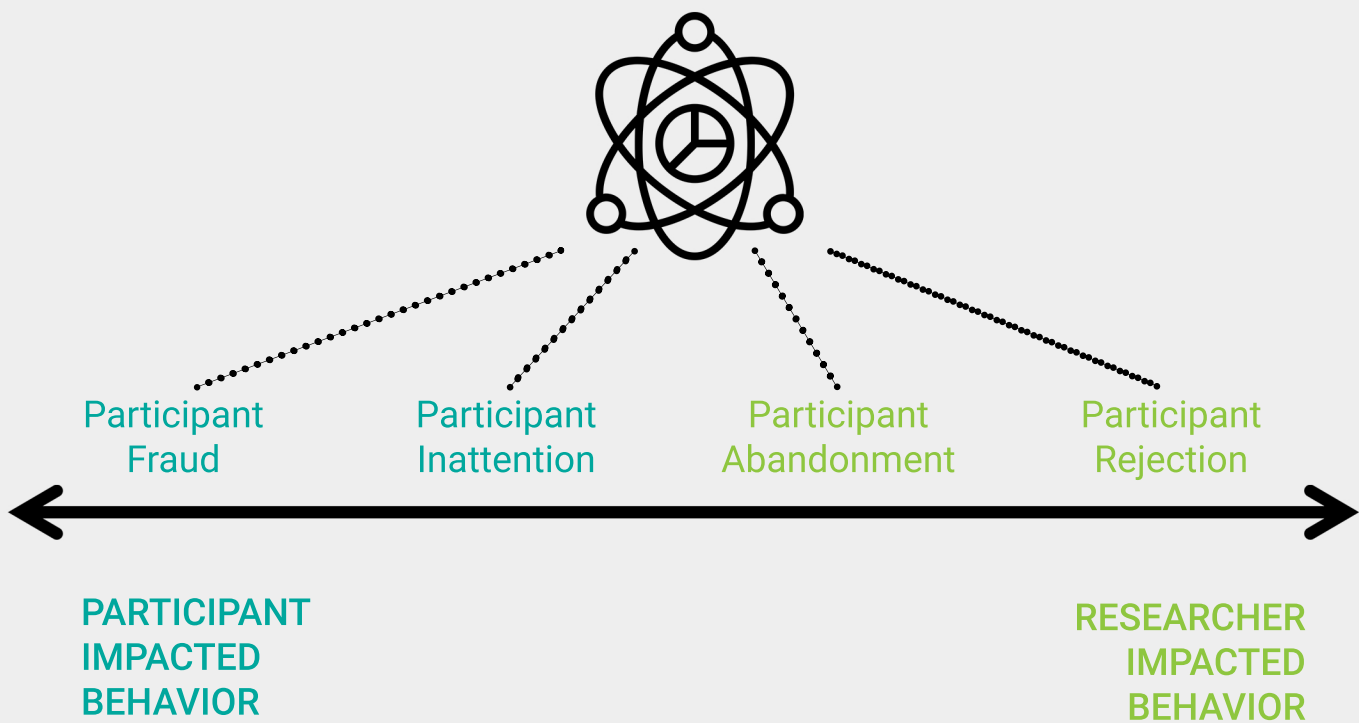
Distrust and mistrust of research among U.S. adults prevails for four key reasons⁴:

- Data privacy. Distrust in how the insights and analytics profession handles and stores their personal data.
- Fair Trade Value. Do not see how market research benefits them.
- Respectful of time. The belief is that studies are too long.
- Technology use. Skepticism of the use of AI for interviews and the collection and analysis of their data.

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Data Quality & Behavior Continuum

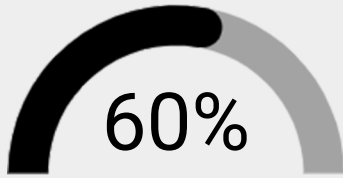


Poor experience contributes to participant distrust and reduced data quality



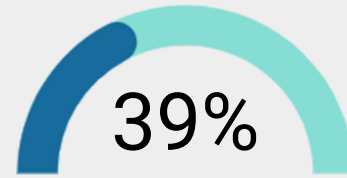
Overall Company Trust⁵

Banks/Financial Institutions



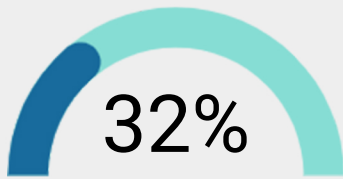
Net Trust Index: +47

Market Research



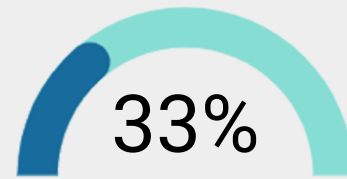
Net Trust Index: +24

Data Analytics



Net Trust Index: +14

Election & Opinion Polling



Net Trust Index: 0

Perceptions & Beliefs⁶

Data privacy. Trust market research companies to protect and appropriately use personal data

19%

Fair trade value. Believe market research benefits themselves versus businesses: (68%)

56%

Respectful of time. Feel that surveys are too long

42%

Technology use. Trust the use of AI by market research companies to collect and analyze my data

13%

Net Trust Index = % Trust – % Do Not Trust



The Solution:

Restoring trust will require an industry-wide commitment to a universal set of guidelines. These guidelines will empower participants with a bar on how they will – and should – be treated. For the insights and analytics industry and profession, a blueprint will detail what the optimum duty of care looks like and act as a platform for self-regulation.

The Participant Bill of Rights is designed to protect the participant experience in the ever-evolving world of market research in the United States. The purpose of the Bill of Rights is three-fold:

- To outline critical rights and protections for participants.
- To continue to push the industry's perspective on participant well-being to the forefront of a new business model that centers on the participant experience.

- To protect the industry's participant pool, and subsequently its insights, from erosion due to poor participant experience and growing fraud.

This blueprint is an expansion of the duty of care section in Insights Association's Code of Standards which emphasizes the duty of care to research participants and the protection of personal data provided by research participants to ensure participants' continued trust in our profession and to comply with laws, regulations, and the ethical standards described in this Code to encourage their continued cooperation.

THE PARTICIPANT BILL OF RIGHTS & EXPLANATIONS

Notes about the Participant Bill of Rights

The Participant Bill of Rights outlines research participants' basic rights before, during, and after a study and are intended to be made available to participants.

They have been developed to be logistically applicable across the research journey and methodologies and not harm the insights and analytics function or industry, though we acknowledge there may be exceptions. The rights do not encompass protections for category-specific rights such as children or pharmaceutical research. They apply to research conducted in the U.S. only and local law may take priority.

Lastly, the rights are written with ease of understanding and accessibility in mind; written between a 6th and 7th-grade reading level, and available in Spanish (see Appendix).

Notes on the Terminology Used in the Participant Bill of Rights

Participant versus Respondent. What to name those people who participate in our research is an ongoing water cooler topic in the insights and analytics community. While our insights and research might not be public-facing, using a term that reminds us, as researchers, to humanize and recognize that there isn't an average person is important.

- "Participant" reads as more human-centric and reflects the relationship we as researchers want: one where a person willingly and actively participates in our studies versus simply responding. We suggest this use across methodologies.
- "Person" or "people" is the most human-centric but may not work in all situations.
- "User" reads similarly to "respondent".

Research subject. In our Code of Standards, we call participants "research subjects", a term that is used and accepted when writing law. It is also used in the academic space and medical studies.

Company that invited me to the study. In any given project, multiple companies may be involved in its execution. While we recommend that all companies in the research journey adopt the Participant Bill of Rights, research participants are likely to only interact with one: the "company that invited them to the study." We use this phrase to refer to this point of contact for interactions such as receiving details about the project and how to withdraw from a study.

The Rights

Some rights are followed by a note for clarification purposes.

- 1. I have the right to know the research study's general purpose, what I will do, how often, and for how long.**
“General purpose” does not mean complete study details should be shared with participants. Rather, it means that some degree of detail is shared before, during, or after a study. This gives participants the autonomy to decide whether they will join a study or understand how their contributions were used, for example.
- 2. I have the right to communication that is easy to read and understand.**
According to the National Literacy Institute, 21% of adults in the US are illiterate in 2022 and 54% of adults have literacy below the 6th-grade level. It is generally recommended that content be written or spoken between a 6th and 8th-grade level for general audiences.
- 3. I have the right to know how to contact the company that invited me to the research study.**
- 4. I have the right to be free from harassment or intimidation to join or continue in a research study.**
- 5. I have the right to know how I can leave a study at any time.**
- 6. I have the right to request that my personal information be removed from the database of the company that invited me to the study and to not be contacted again.**
Removal of personal and contact information includes AI systems and the use of information in long-term training data sets.
- 7. I have the right to be treated with dignity and respect before, during, and after the research study.**
- 8. I have the right to be in a study that is free from discrimination. This includes race, ethnicity, sexual orientation, gender identity, disability, age, national origin, religion, or status as a protected veteran.**
For studies where sensitive information needs to be asked or the quota for a specific audience is full, for example, be transparent about the why.
- 9. I have the right to know if reasonable accommodations are available for persons with disabilities.**
- 10. I have the right to know if I will receive an incentive for my time, in what form, its value, how, and when I will receive it.**

The Rights (Con't)

11. I have the right to not be sold anything or asked for money as part of a research study.
12. I have the right to be told about any risks that might happen as a result of participating in research.
13. I have the right to confidentially share my experience in the research study with the company that invited me to the research study.
14. I have the right to request and receive the privacy policy of the company that invited me to the study.
15. I have the right to know if a data breach exposed my personal information. This is governed by the state law where the company that invited me to the study is based.
16. I have the right to ask for and receive a printed or electronic copy of these rights.

Additional Considerations

Following is a shortlist of rights that cannot be universally applied to all studies and companies. These repeatedly surfaced as important to increasing trust with research participants – if and when they can be applied – during the workshops and online qualitative board we conducted.

1. **Reward research participants for every interaction where they contribute information; for example, a qualifying screener for a qualitative study. Related, where possible, reward participants fairly for their time spent, not cents on the dollar.**
Participants are human and they want to be paid for their time, even if the activity is only a few minutes long. Just like a salary, the dollar amount goes a long way towards motivation -- and it respects their time.
2. **Where possible, minimize the number of times a person has to answer already known questions in a database or study; rather, offer them the opportunity to update it.**
An analogy is filling out the same forms every time you visit a doctor you've seen before. How frustrating do you find that?
3. **Keep screeners, questionnaires, and study guides as short as possible.**
Requiring someone to answer questions for a long period of time is a huge ask and task. Hundreds of things vie for attention daily, such as social media, family and errands. Long surveys or daily online qualitative logs are simply not practical unless there is significant remuneration for that time.
4. **Offer the opportunity to skip questions that are too sensitive or offensive.**
This can go a long way towards trust and willingness to go above and beyond.
5. **Share some degree of how the information people share is being used or how it compares to others who participated in the same study post-study or along the way.**
People are curious. Doing this can increase the feelings of fair trade value on top of the incentive, drive engagement and responsiveness during a study or future one.



PLACEMENT OF THE BILL OF RIGHTS

Ensuring people see the Bill of Rights is crucial to addressing the lack of trust.

We recommend that the Participant Bill of Rights be used to set operational practices, as a guide when building a study, and as a teaching or training tool for any colleagues that design studies, manage, or engage with participants. Sit down with your team and/or research partners and put yourself in the participants' shoes. Map all the points where a participant might interact with your/their company. Then identify the key places where it would be prime moment for participants to know their rights and how best to share it with them. Placements will likely vary by company, part of the research journey, your ability to influence where and how a partner informs participants; but the key is to start having these discussions and acting. Here are some thought starters:

Before a study

- Make reading the Bill a requirement as they are screened and, once recruited, include it in the study invitation emails.
- Incorporate the Bill into the NDA, agreement, or waiver.
- For panels, make the Bill part of onboarding and on an annual basis.

On an ongoing basis

- Add it to the webpages where potential and current research participants visit.
- For panels, have participants agree to the Bill on an annual basis.

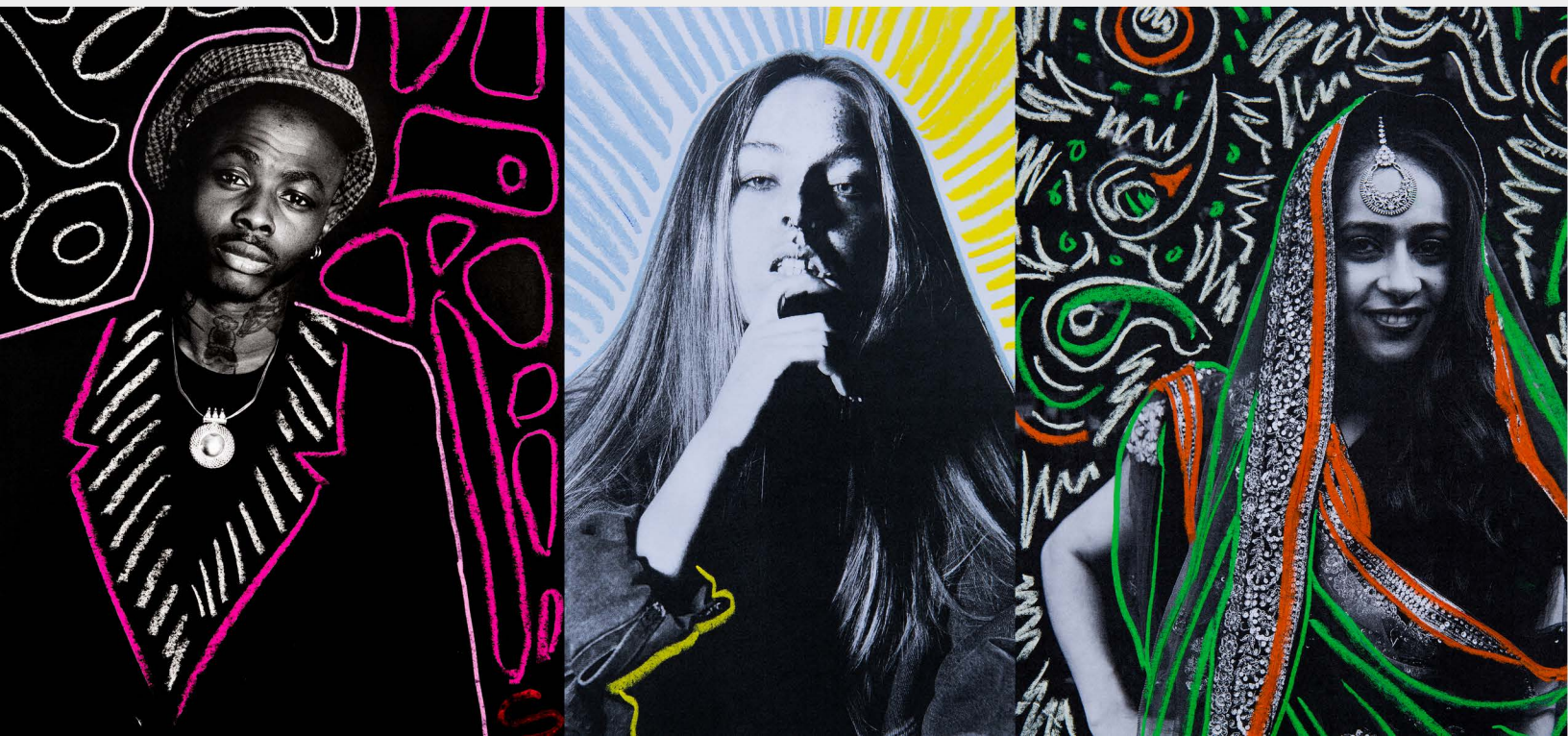
Partnerships

- Ask all research partners to ensure participants are presented with the Bill of Rights.

APPENDIX

Endnotes

1. *Global Data Quality Glossary*, Global Data Quality, <https://www.globaldataquality.org/glossary>.
2. Ibid.
3. *Client's Guide to Data Quality in Online Research*. Canadian Research Insights Council, 2024, <https://www.canadianresearchinsightscouncil.ca/wp-content/uploads/2024/05/CRIC-Clients-Guide-to-Data-Quality-in-Online-Research.pdf>.
4. *Global Trust Survey 2024: A Report on the Level of Trust in Market Research: U.S.*, Global Research Business Network (GRBN), 2024, <https://grbn.org/Building-Public-Trust>. The primary objective of the research is to understand the level of trust the general public has in the market research industry across the globe, both overall and specifically when it comes to the handling of personal data. The secondary objective is to understand more broadly how trust in different types of organizations and bodies compares across the globe. The sample was designed to be representative of the population, aged 18+, split 50%/50% into two cells, with each cell balanced by quotas. The total sample size for the U.S. was 1,006.
5. Ibid.
6. Ibid.



PARTICIPANT BILL OF RIGHTS (CLEAN, ENGLISH)

YOUR RIGHTS AS A MARKET RESEARCH PARTICIPANT

Participation in a market research study is voluntary. You may decline to participate for any reason.

This document outlines your rights and protections when asked to participate in a research study. We are committed to upholding these rights and protections as we value the participation of people like yourself and the information shared in research studies. It is your responsibility to read these rights and contact us with questions or concerns.

What is a market research study?

In a research study, companies listen to and try to understand people's opinions and behaviors. This information guides decisions made by companies, nonprofits, and governments.

As a participant in a market research study, you have the following rights:

1. I have the right to know the research study's general purpose, what I will do, how often, and for how long.
2. I have the right to communication that is easy to read and understand.
3. I have the right to know how to contact the company that invited me to the research study.
4. I have the right to be free from harassment or intimidation to join or continue in a research study.
5. I have the right to know how I can leave a study at any time.
6. I have the right to request that my personal information be removed from the database of the company that invited me to the study and to not be contacted again.
7. I have the right to be treated with dignity and respect before, during, and after the research study.
8. I have the right to be in a study that is free from discrimination. This includes race, ethnicity, sexual orientation, gender identity, disability, age, national origin, religion, or status as a protected veteran.
9. I have the right to know if reasonable accommodations are available for persons with disabilities.
10. I have the right to know if I will receive an incentive for my time, in what form, its value, how, and when I will receive it.
11. I have the right to not be sold anything or asked for money as part of a research study.
12. I have the right to be told about any risks that might happen as a result of participating in research.
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PARTICIPANT BILL OF RIGHTS (CLEAN, SPANISH)

SUS DERECHOS COMO PARTICIPANTE EN ESTUDIOS DE INVESTIGACIÓN

La participación en un estudio de investigación de mercado es voluntaria. Usted puede negarse a participar por cualquier motivo.

Este documento describe sus derechos y protecciones cuando se le solicita participar en un estudio de investigación. Nos comprometemos a defender estos derechos y protecciones porque valoramos la participación de personas como usted y la información compartida en los estudios de investigación. Es su responsabilidad leer estos derechos y comunicarse con nosotros si tiene preguntas o inquietudes.

¿Qué es un estudio de investigación de mercados?

In a research study, companies listen to and try to understand people's opinions and behaviors. This information guides decisions made by companies, nonprofits, and governments.

Como participante en un estudio de investigación de mercado, usted tiene los siguientes derechos:

1. Tengo derecho a saber el propósito general del estudio de investigación, qué haré, con qué frecuencia y durante cuánto tiempo.
2. Tengo derecho a una comunicación que sea fácil de leer y comprender.
3. Tengo derecho a saber cómo contactar a la empresa que me invitó al estudio de investigación.
4. Tengo derecho a estar libre de acoso o intimidación para participar o continuar en un estudio de investigación.
5. Tengo derecho a saber cómo puedo abandonar un estudio en cualquier momento.
6. Tengo derecho a solicitar que mis datos personales sean eliminados de la base de datos de la empresa que me invitó al estudio y que no me contacten nuevamente.
7. Tengo derecho a ser tratado con dignidad y respeto antes, durante y después del estudio de investigación.
8. Tengo derecho a participar en un estudio que esté libre de discriminación. Esto incluye raza, etnia, orientación sexual, identidad de género, discapacidad, edad, origen nacional, religión o condición de veterano protegido.
9. Tengo derecho a saber si hay adaptaciones razonables disponibles para personas con discapacidades.
10. Tengo derecho a saber si recibiré un incentivo por mi tiempo, en qué forma, su valor, cómo y cuándo lo recibiré.
11. Tengo derecho a que no me vendan nada ni me pidan dinero como parte de un estudio de investigación.
12. Tengo derecho a que me informen sobre cualquier riesgo que pueda surgir como resultado de participar en una investigación.
13. Tengo derecho a que me informen sobre cualquier riesgo que pueda surgir como resultado de participar en una investigación.
14. Tengo derecho a solicitar y recibir la política de privacidad de la empresa que me invitó al estudio.
15. Tengo derecho a saber si una violación de datos expuso mi información personal. Esto se rige por la ley del estado donde tiene su sede la empresa que me invitó al estudio.
16. Tengo derecho a solicitar y recibir una copia impresa o electrónica de estos derechos