



CONSENT GUIDELINES FOR EQUITY IN RESEARCH

COMMUNITY COALITION
FOR EQUITY IN RESEARCH

THE HARVARD CLINICAL
AND TRANSLATIONAL
SCIENCE CENTER



THE COMMUNITY COALITION FOR EQUITY IN RESEARCH creates tools and materials to help address common issues identified during the study review process. These guidelines were created by members of the community coalition. Outlined in this guide are best practices for accessible consent in research.

WHY DOES THIS MATTER? Researchers must equitably design and conduct the consent process. Doing so offers respect and recognition to a community, which may help get more people interested in the research. In this way, community members can better understand the research and the ways they can be involved. Partnership in the consent process creates opportunities for success and promotes equal collaboration between researchers and community members. This becomes the start to building trust and communication with the community, which provides the opportunity for researchers to understand authentic experiences from a rich diversity of community members.



“Equitable consent in research is important because when we work with all community members, we get the best information possible.”

Marie Jacques Toussaint,
Coalition Member

INCLUDE THE FOLLOWING CONSIDERATIONS IN THE CONSENT PROCESS



Think of **consent as a continual process**, rather than one step to check off. As the study progresses, make sure to check in with participants about how they are feeling and if they want to continue.



Ensure that potential **participants have enough time to consider and fully understand** activities, risks, and benefits before deciding to participate.



Talk through the consent form with participants. Encourage questions and open discussion from participants during the consent process and throughout the study.

ADD THE FOLLOWING PRACTICES TO INCREASE UNDERSTANDING OF THE CONSENT PROCESS



Allocate enough time during initial consent; participant should not feel rushed and have time for dialogue.



Use plain language in the consent form & talk through confidentiality and data privacy with the participant. Here are some [tools for incorporating plain language](#).



Come prepared with answers to frequently asked questions. Some examples include questions about the time commitment, compensation, and how their data will be used.



Translate consent and related documents in the languages spoken by the participants you want to reach. [Use our guide](#) to local translation and interpretation services in Boston.



Consider cultural practices; it may be necessary to receive consent from the individual *and* others in their community group.



Explain risks and benefits that may occur from participating in the study. Respect participants time when planning study activities.

OTHER RESOURCES:

[Embedding Health Literacy in Clinical Trials to Improve Recruitment and Retention - Health Literacy in Clinical Research - NCBI Bookshelf](#): Describes experiences and emotions of the process of participating in research. It is good reading material for building a tool or designing a workshop on health literacy and recruitment/consent in research. The material focuses on diversity, inclusion, and belonging, and how to navigate discussions on these topics.

[Principles of Health Literacy in Clinical Research - Health Literacy in Clinical Research](#): A clearly designed, easy to navigate website dedicated to health literacy in research. It gives clear guidance on how to incorporate health literacy principles into the [recruitment](#) and [consent](#) process and provides examples.

[Tips and Tricks for Successful Research Recruitment \(Toolkit\)](#): Outlines how communication should be presented, and offers communication ideas in different mediums (e.g., TV, radio, community partnerships).

REVIEW YOUR STUDY WITH US:

The Community Coalition for Equity in Research serves as a free resource for high-quality community input on research proposals and protocols, as well as a trusted communication channel between researchers and community stakeholders.

Please email community@catalyst.harvard.edu if you are interested in having your research study reviewed by our coalition members.