

Securing Consent for Data Sharing & Reuse

The informed consent process is a central component of the ethical conduct of research with human subjects overseen by an Institutional Review Board (IRB). Crafting compliant consent forms with permissive language broadens the shareability and usability of research data. Incorporating considerations for data sharing and potential reuse into the informed consent process is crucial to preempt future complications and adverse outcomes, all while meeting funders' and publishers' increasing data sharing requirements.

WHAT IS AN INFORMED CONSENT?



- The process through which researchers seek permission from human participants to conduct research.
- The consent form should outline how the research team will manage, use, and share the collected data.
- Researchers must adhere to the terms expressed in these forms.

THINGS TO INCLUDE



- Any identifying information that will be retained and who will have access to it.
- Clear and reasonable efforts to protect participants' confidentiality and privacy.
- Conditions and methods for granting others access to the data.
- Data de-identification method(s) that will be employed.
- Participants' withdrawal rights and options.
- Data sharing and publication method(s).
- Provisions for potential future data reuse.

THINGS TO AVOID



- Ambiguous language or unrealistic promises (e.g., fully anonymous, strictly confidential, all data).
- Inconsistent or vague statements about the data and security measures.
- An expiration date for the research project or the consent form.
- Promises that only the research team will access data.

DATA SHARING & REUSE CONSENT APPROACHES

Permissive

It allows the public to share deidentified or controlled access to identifiable data. The project team or external parties can use the data repeatedly, expanding opportunities for research beyond the initial study.

Somewhat Permissive

Enables the reuse and public sharing of deidentified data, while prohibiting the reuse of identifiable data by both the original research team and any other parties in the future.

Non-Permissive

Data access is restricted to the research team. Data use is limited to the project, with identifiable data expected to be destroyed by a set date.

WHICH APPROACH SHOULD YOU CHOOSE?

Because obtaining re-consent from research participants can be impractical and sometimes impossible, we encourage you to choose the most permissive consent approach possible.



Contact Us



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