SRAENE
Sexual Risk Avoidance Education
National Evaluation

September 2023

Tip Sheet

OPRE Report No. #2023-225

Obtaining Institutional Review Board Approval for Data Collection

When organizations plan to collect data from or about people, they are strongly encouraged to have an institutional review board (IRB) review their data collection plans and materials. IRBs help ensure the rights and safety of individuals are protected when data are collected from or about them. IRBs ensure no serious risks are involved, such as physical or emotional harm, and data collectors don't disclose personally identifiable information, such as names or phone numbers, to anyone outside the trained data collection team. The accompanying video introduced the steps organizations should take when applying for IRB approval. Read more about these steps below and see Table 1 for definitions of key terms.

Identify an IRB to work with. IRBs often operate within organizations such as government agencies, universities, school systems, or hospitals. If your program is affiliated with any of these organizations, you will likely use your organization's IRB. If not, you can identify a private IRB that is registered with the federal government. When selecting an IRB, ask about its experience reviewing data collection plans that are similar to yours, how long the review will take, and the cost.

Determine submission requirements and type of review. Contact your IRB to determine the materials required for your submission and the type of review required for your data collection. Be prepared to submit documents describing all aspects of your data collection. These will likely include the purpose of your data collection, intended respondents, consent and assent forms, participant recruitment materials, and data collection materials. See Table 1 for definitions of the different review types.

Submit required documents. After you submit your application, the IRB might ask follow-up questions, request changes to your documents, or request additional documents.

Respond to questions from the IRB. After your plans are approved, the IRB will provide submission requirements for ongoing reviews and instructions on when you must alert the IRB of issues or updates.

Table 1. Key terms

Key term	Definition
Institutional review board (IRB)	A group that oversees data collection about people and ensures data collection follows ethical procedures. All IRBs must be registered with the Office for Human Research Protection in the U.S. Department of Health and Human Services.
Exempt review	Applies to data collection with the least amount of risk, such as conducting an anonymous survey. Select IRB staff determine your data collection is exempt from review, and you are unlikely to have responsibilities for reporting to the IRB.
Expedited review	Applies to data collection with minimal risk, such as collecting non-sensitive information along with some personally identifiable information. Select IRB staff review plans and materials; you must notify the IRB of any changes; and you may need annual approval to continue data collection.
Full review	Applies to data collection with more than minimal risk to respondents, such as asking sensitive questions, and data collection involving youth younger than 18 or other vulnerable populations. The full IRB committee reviews plans and materials; you must notify the IRB of any changes; and you need annual approval to continue data collection.

For more on finding an IRB to work with:

This web page provides a search function to find an IRB registered with the federal government (use the advance search option to find a local IRB): https://ohrp.cit.nih.gov/search/irbsearch.aspx?styp=bsc

For more on the purpose of IRBs and how to work with them:

This resource provides answers to frequently asked questions about working with IRBs: https://sraene.com/sites/default/files/pdfs/Frequently_asked_questions_about_working_with_IRBs.pdf

This tip sheet provides guidance about contacting IRBs: https://opa.hhs.gov/sites/default/files/2020-07/opa-tip-sheet-irb.pdf

This webinar provides guidance about working with IRBs for performance measures data collection: https://vimeo.com/764342817?embedded=true&source=video_title&owner=105974908

This resource provides an example of an IRB application: https://www.sraepas.com/wp-content/uploads/2021/11/Handout-12-Example-IRB-Application.pdf

This video describes the role of IRBs and how IRBs protect people who participate in data collection: https://www.youtube.com/watch?v=U8fme1boEbE

This resource includes a series of decision charts related to the type of data collection an IRB must review: https://www.hhs.gov/ohrp/regulations-and-policy/decision-charts-2018/index.html#c1

For more on IRB requirements for data collections involving youth:

This resource provides answers to frequently asked questions about collecting data from or about youth: https://www.hhs.gov/ohrp/regulations-and-policy/guidance/faq/children-research/index.html

About this series

This video series, and the accompanying tip sheets on understanding and collecting high-quality data, were created as part of the Sexual Risk Avoidance Education National Evaluation (SRAENE). The series covers a range of data-related topics to help grantees understand the importance of high-quality data and provide guidance on how they can collect them in their program. Although some of the resources are drawn from topic areas that are not related to SRAE, the content on data is still relevant.

FYSB does not recommend any particular survey platform or data system that may be referenced in tip sheets.

For more information or questions, contact the SRAENE team at SRAETA@mathematica-mpr.com.

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