

## **Tip Sheet**

OPRE Report No. #2022-276

# Consent, Assent, and Pre-Testing to Prepare for Collecting Survey Data

Organizations often want to collect information about their programs to determine whether programs are achieving their goals. Surveys can be great for this because they are an easy way to gather a variety of information from a large number of participants. When preparing to collect survey data, it is important to ensure your organization uses surveys ethically and collects information from as many respondents as possible, so the results accurately reflect the experiences of all program participants. The accompanying video introduced steps to prepare for survey data collection and suggested strategies to ensure your organization collects the necessary data from the intended respondents in an ethical way. Read more about these steps below, and see Table 1 for definitions of key terms and Table 2 for descriptions of possible methods to collect parent and guardian consent.



**Draft consent forms** for parents or guardians and youth older than 18 and submit to an Institutional Review Board (IRB) for approval. An IRB will need to approve the modes for collecting consent and ensure the language on the forms is accurate and appropriate, as well as approve all other data collection materials. The modes you select for the consenting process might depend on what contact information is available, such as email addresses, mailing addresses, or phone numbers. Because IRBs might have their own procedures, check with your IRB for required templates and recommended language to include in the consent forms.



**Collect parent or guardian consent** for youth younger than 18. Consent is collected before you administer the survey and is an important part of preparation. To achieve a higher response rate and maximize the number of youth who can complete your survey, consider using multiple methods to collect parent or guardian consent (see Table 2).



**Prepare to collect assent** from youth younger than 18. Even if their parents or guardians have consented, assent allows the youth to choose if they want to participate in the survey. Similar to preparing consent materials, an IRB must approve the mode and form for collecting assent and ensure language is accurate and appropriate.



Pre-test the survey questions on a population similar to your population of interest to ensure the survey questions are clear and measure what they are supposed to measure. If consent and assent are required, use the same procedures described earlier. Make sure to include language about the survey in the consent and assent forms, such as estimated time to complete and an overview of content. After pre-testing, revise the survey based on what you learned.

#### Table 1. Key terms

Term	Definition
Institutional Review Board (IRB)	A group that oversees research on human subjects and ensures the research 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.
Parent/guardian consent (for youth 18+)	Ensures parents or guardians and youth 18 and older are fully aware of all aspects of the study before agreeing to participate or allowing their child to participate. For youth younger than 18, parents or guardians can choose whether their youth can or cannot participate in a survey. Youth 18 and older may be able to consent for themselves.
Youth assent	Provides youth younger than 18 with the choice of participating or not participating in the study, even if their parents have given consent.
Pre-test	Administering the survey to a small group of eligible respondents who are similar to the population of interest before collecting actual data. This process helps organizations identify whether any of the questions or instructions are confusing or require changes based on respondents' feedback.

Table 2. Methods to collect parent or guardian consent

Method	Description
Distribute hard-copy forms by mail	Mail parents or guardians a hard-copy consent form and request they send the completed form back. Be sure to include an addressed return envelope and include postage, if possible. Allowing parents to sign the mailed consent form, take a photo of it, and send the photo via email may also be an option but must be approved by the IRB. Youth may also return the signed copy of the mailed consent form to their school or organization. Additionally, if using passive consent, youth only need to return the consent form if their parent or guardian does not allow them to participate in the research.
Distribute hard-copy forms in person	Provide youth with a hard-copy consent form for their parents or guardians to complete. Request the youth bring back the completed form.
Distribute forms via email	Email parents or guardians the consent form. Request they either email back a copy of the completed form or provide you with a hard copy of the completed form. Be sure to include instructions on how to complete and return the form electronically.
Web form	Create an online consent form on a web-based platform and send the link to parents or guardians via email.
Verbal consent	Obtain consent over the phone, via video call, or in person.

### For more on the institutional review board (IRB):

This web page is a resource for grantees to find an IRB and check if it is certified: <a href="https://ohrp.cit.nih.gov/search/irbsearch.aspx?styp=bsc">https://ohrp.cit.nih.gov/search/irbsearch.aspx?styp=bsc</a>

This video describes what IRBs are and how they protect people who participate in research: <a href="https://www.youtube.com/">https://www.youtube.com/</a>
<a href="https://www.youtube.com/">watch?app=desktop&v=U8fmelboEbE</a>

This web page provides guidance for working with IRBs: <a href="https://sraene.com/resource/Frequently%20">https://sraene.com/resource/Frequently%20</a> asked%20questions%20about%20working%20 with%20IRBs

This web page provides tips on IRBs: <a href="https://opa.hhs.gov/sites/default/files/2021-05/irb-tip-sheet-2020\_0.pdf">https://opa.hhs.gov/sites/default/files/2021-05/irb-tip-sheet-2020\_0.pdf</a>

This web page provides multiple webinars on preparing for data collection. Two webinars that are particularly helpful for the IRB are "Human Subjects and Privacy Protections for SRAE Performance Measures Data – January 11, 2021" and "Sexual Risk Avoidance Education (SRAE) Guidance for Obtaining Partnership Buy-In and Approval for Performance Measures – November 1, 2021.": https://www.sraepas.com/webinars/

This web page provides graphic charts to help you decide if an activity is research involving human subjects and must be reviewed by an IRB: <a href="https://www.hhs.gov/ohrp/regulations-and-policy/decision-charts-2018/index.html">https://www.hhs.gov/ohrp/regulations-and-policy/decision-charts-2018/index.html</a>

This web page provides reasons for exemptions from IRB review: <a href="https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/common-rule-subpart-a-46104/index.html">https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/common-rule-subpart-a-46104/index.html</a>

### For more on obtaining parent or guardian consent:

This web page provides guidance on the consenting process and IRBs: <a href="https://www.aapor.org/Standards-Ethics/Institutional-Review-Boards/Full-AAPOR-IRB-Statement.aspx">https://www.aapor.org/Standards-Ethics/Institutional-Review-Boards/Full-AAPOR-IRB-Statement.aspx</a>

This web page provides webinars on performance measures. Specifically, the webinar "Human Subjects Research and Privacy Protections for SRAE Performance Measures Data – January 11, 2021" and the materials that accompany it are helpful for obtaining consent: https://www.sraepas.com/webinars/

#### For more on survey pre-testing:

This PDF provides information on the pre-test process: https://ctsi.ucla.edu/patients-community/files/view/docs/Howto\_pretest\_survey\_questionnaire.pdf

This web page provides step-by-step instructions for survey pre-testing: <a href="https://www.thecompassforsbc.">https://www.thecompassforsbc.</a> org/how-to-guides/how-conduct-pretest

#### **About this series**

This video series, and the accompanying tip sheets on understanding and collecting high-quality data, were created as part of the <u>Sexual Risk Avoidance Education National Evaluation (SRAENE)</u>. 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 <a href="mailto:SRAETA@mathematica-mpr.com">SRAETA@mathematica-mpr.com</a>.

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