

Study Title: Agenda Gap:

Youth-led policy advocacy to promote adolescent mental health and advance health equity across socioecological domains

Know Your Rights with Research

As a study participant it is important that you understand the full details of participating in a research study. The better you and the researcher understand each other and the details of the study, the more likely it is that you might have a positive research experience. Here are some things you should know before you participate in a research study.

You are allowed at any time to:

- ☐ **Refuse a question.** Whether it's an interview question or one in a background questionnaire.
- ☐ **Withdraw from the study.** With most studies you can stop participating at any time during the study and all of your information will be withdrawn as well. Make sure you check with the researcher, because some studies have a limited withdrawal period.
- ☐ **Speak with the researcher at any point during the study.** Make sure you are able to speak with them before, during, and after the study, if you wish.
- ☐ **Ask the researcher questions about anything in the study that you don't understand or you are unsure of.**

Has the researcher told you:

- ☐ **The benefits and risks of the study?** If not, ask.
- ☐ **The purpose of the study?** If you don't understand it, ask questions.
- ☐ **The study procedures and methods?** (For example, how the study will be conducted, the length of time it will take to complete the study.) If you think they left something out, ask them questions.
- ☐ **Where and how your information is going to be used?** Make sure this is clear to you.
- ☐ **That your participation is entirely voluntary?** You do not have to participate if you don't want to.
- ☐ **That you have time to decide whether or not you want to participate?** Make sure you have the time to think about participating.
- ☐ **The details of the incentive/honorarium?** (For example, how and when you will receive it.) Be sure you know beforehand when and how you will be recognized for your participation.
- ☐ **That you have the right to remain anonymous?** If they don't give you the option of using a fake name or ID number, tell them you want to. Make sure that when you receive your honorarium your identity is still kept confidential.
- ☐ **Who they work for and who is conducting the actual study?** It's important to know if the person distributing the study is the actual researcher conducting the study.
- ☐ **Where you can contact them if you have further questions?** If not, ask them for their contact information.

Research Vocabulary

Here are some common words that are often used by researchers that might help you better understand how a research study is being conducted.

Analyze: to examine something carefully and in detail so you can identify causes, key factors, or possible results of an event, behaviour, issue, or experience.

Anonymity: the personal identity of a research participant is not known to the researchers.

Confidentiality: researchers do not share any of the information provided during the study with anyone, except those working on the research project who need to know. Researchers also don't share the identities of people they may have met, seen or spoken with, with anyone outside of the project.

Ethics: the principles that describe how a research project should be conducted. Universities, health authorities, and school districts typically have a strict set of guidelines that a researcher must follow to make sure research is done in ways that do not harm participants. Universities also have ethics boards that review a researcher's project and must approve it before the researcher can begin their study.

Findings: information (or data) that is discovered because of research.

Focus Group: a small group of people specially chosen to represent a wider population who are asked to talk about and share their opinions about a particular subject.

Honorarium: money or a gift in kind (for example, gift certificate) given to research participants as a way to compensate them for sharing their time, knowledge, and opinions with the researchers.

Informed Consent: when a person agrees to participate in a study after having been told about and understood the risks and benefits of participating.

Interview: a meeting where a researcher asks questions in order to find out a study participant's views or experiences. Sometimes, interviews are audio or video recorded. Other times, only written notes are taken. The researcher should tell you about how the interview will be conducted before you agree to participate.

Pseudonym: a false name used by a participant instead of their real name to keep their identity a secret.

Research:

Academic: research done for educational purposes that is completed by schools, universities, colleges, health authorities, or government agencies.

Market Research: the work of collecting information about what people buy and why.

Study Methods: the way that the study is being done. Common study methods include surveys, interviews and focus groups.

Survey: using questionnaires to investigate the opinions or behaviour of a particular group of people.

Transcript: a written word-for-word copy of what was said during an interview.

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