

Your Rights in Research

An Information Sheet for People Taking Part in Forced Migration Research

Taking part in a research project gives you a chance to make your voice heard, but it can also be inconvenient, cost you time or money, and/or make you feel physically or emotionally uncomfortable. This information sheet explains key terms and outlines your rights.



Voluntary, informed consent

This means that only you can decide whether or not you want to take part in a research project. Let's break this down:

- ◇ **Voluntary** means that you can decide of your own free will—with no penalties for refusing to participate and no major benefits (like large amounts of money) for agreeing to take part.
 - You cannot be refused goods or services for refusing to participate.
 - Even if a person, government official, or organization recommends that you take part in the research, you do not have to. You are still entitled to the same services and resources even if you don't participate.

- ◇ **Informed** means that you have the right to know what the research is about, what you are asked to do, and what are the potential benefits and risks to participating.
 - You should ask how long the research will take and what exactly is required of you.
 - You have the right to know how the research will be shared and how you can access the research results.
 - You have the right to this information in a language you understand. You can ask for interpretation or translation if you need it.
 - The researcher must provide you with contact information that you can use if you have questions or concerns. This contact information can also be used if you want to withdraw from the study at a later time.
 - You have the right to ask questions at any time.

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◇ **Consent** means that you explicitly agree to participate.

- No one can consent on your behalf (except for minors or adults with limited cognitive abilities; see below for information on assent in these cases).
- Usually, you will be asked to sign a form to officially show that you have consented to taking part in the research. You have the right to discuss the form with relatives, friends, settlement workers, community members, or any other person before you decide whether or not to sign it. The researcher should provide you with a copy of the form you signed.
- If you prefer, you can ask to give oral consent instead. This is not always possible, depending on the requirements of the researcher's Research Ethics Board (REB)¹.
- You can withdraw from the research at any time—you are not obliged to finish a research study. If you decide to withdraw, you have the right to ask that none of your information is used.
- You can also refuse to answer any particular question or take part in any specific aspect of the research.

◇ **Assent** means that a person under the age of majority or with limited cognitive abilities agrees to participate. In these cases, a parent or guardian must also give permission in order for the research to proceed. In other words, it requires both consent and assent.

¹A Research Ethics Board (REB) is a committee at the researcher's institution, which is responsible for reviewing research projects to ensure that the researcher upholds the ethical principles explained in this document. The REB should work to promote your rights in research.



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Your right to privacy and confidentiality

This Means that a researcher cannot identify you or your answers in the research without your express permission. Some things to think about:

◇ Privacy is the right to be free from intrusion or interference and the right to control information about yourself.

- You have the right to ask that research be conducted in a place that is private and safe, where others are unlikely to recognize you and know that you participated in the study.
- You have the right to choose whether or not you want to be identified in the research findings. In some cases, the researcher may not be able to use your real name, even if you explicitly ask, because it could identify others in the study who chose not to be identified.
- You have the right to know how the information from the study will be used.
- Researchers should clearly explain how you will be able to learn about the findings of the study.

◇ Confidentiality is the protection of personal information.

- The researcher must have a way to secure the information collected so that other people don't have access to it.
- You have the right to know how long your information will be stored and who will have access to it.
- The researcher is not allowed to give or sell this information to a third party.
- In some cases, the researcher may have an ethical obligation to disclose information about self-harm or harm to others. The consent form should clearly indicate such limits to confidentiality. If in doubt, ask! You also have the right to insist on the anonymization (see below) of all information that is collected about you.

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- In some cases, the researcher may have a legal obligation to report criminal activity to police. The consent form should clearly indicate such limits to confidentiality. If in doubt, ask! You also have the right to insist on the anonymization of all information that is collected about you.
- When responding to online surveys, you should be aware that any information stored in servers in some countries, like the United States, can be accessed by the government. You have the right to ask how the researcher will guarantee confidentiality and privacy in such circumstances.

◇ **Anonymity means there is no identifying information, so that specific research findings cannot be traced back to any individual.**

- This is one solution to the limits to confidentiality discussed above: by ensuring that the way information is collected means that no one—not even the researcher—knows who is connected to that information.
- If your immigration status is not yet regularized, you should ask how researchers will guarantee that your information is anonymized. Otherwise, the research findings may put you at risk.



The researcher's obligation to do no harm

This Means that your well-being, dignity, and safety is always being considered.

- If at any point you feel uncomfortable during a research process, you have the right to tell the researcher.
- If the researcher continues to make you feel uncomfortable, you should tell someone you trust (a friend, a family member, a settlement worker, a community member) and you should contact the researcher's REB. This contact information should appear on the consent form. Or you can search for the information on the Internet. All universities and hospitals have an REB or similar committee.
- You have the right to be treated with respect and in a manner that honours your cultural, religious, and ethnic history.