

Research Ethics Q&A

1. Who is Cairo 52 Legal Research Institute and why are they collecting my data?

Cairo 52 Legal Research Institute is an independent policy and legal research institute established in 2020. It operates as a non-profit association under registration number 80627894 with the Estonian Business Registry. The Institute's objective is to advance the fundamental human rights of sexual and gender minorities, including LGBTQ+ individuals, women, sex workers, and people living with HIV (PLHIV), in the Middle East and North Africa (MENA) region.

The institute's Research Unit conducts data collection and empirical research to inform our advocacy efforts and policy recommendations. We utilize various research methods, such as surveys, interviews, and case studies, to gather valuable insights into the social, legal, and political landscape of the region.

For each research project, participants will receive a fact sheet providing key information about the research's unique objective, principal investigator, and expected outputs.

2. What is informed consent and why is it important?

Informed consent is the process of notifying potential research participants about essential aspects of a research study and their involvement in it. The informed consent process plays a vital role in the ethical conduct of research with human subjects. Typically, it involves providing a written consent document containing the necessary information (i.e., elements of informed consent) and delivering this information to prospective participants. In cases where signing documents proves difficult, oral consent can also be obtained.

Informed consent represents a fundamental principle of research ethics. Its intention is to ensure that human participants enter research voluntarily and fully informed about their participation. Participants must provide consent before engaging in the research.

Before requesting participants to provide their data, whether through surveys or interviews, informed consent in oral or written format will be required.

3. Raw Data vs Published Data?

Raw Data refers to the unprocessed information directly gathered by researchers and research assistants of the institute. It may contain sensitive details that could potentially identify individuals. Raw data is strictly accessible to the researchers and research assistants directly involved in conducting the interviews and cannot be accessed by external parties.

Published or analyzed data, on the other hand, refers to the processed information that has undergone analysis by the aforementioned individuals. It has undergone anonymization measures to guarantee the non-disclosure of participants' identities in final publications.

4. How does the institute handle data to ensure my safety and confidentiality?

As an organization registered in Estonia, we adhere to the General Data Protection Regulation (GDPR) of the European Union (EU), which is one of the strictest and safest laws governing data handling worldwide. The GDPR provides guidelines and establishes our legal responsibility for any unauthorized use of your data, for which you have not explicitly provided informed consent. To learn more about the GDPR, please visit:

<https://www.typeform.com/help/a/what-is-gdpr-360029580771/>

Additionally, we ensure anonymity and confidentiality throughout our surveys by not collecting any data that identifies you, such as emails, names, phone numbers, or addresses. Our surveys are hosted on [Typeform](#), which is a highly secure platform that encrypts your data and implements multiple measures to prevent unauthorized access or transfer.

For interviews, we recommend using [Jitsi Meet](#), a secure open-source communication platform that encrypts all audio and video traffic on the network using DTLS-SRTP. We use recordings solely for transcription purposes. Once the transcription is complete, all recordings are deleted and not used for any public purposes. They are only accessible to individuals responsible for the transcription process. Transcripts are then anonymized, removing any personal information to ensure your safety and security.

All collected data is securely stored on personal devices and encrypted using [VeraCrypt](#), a widely recognized program for file encryption. Data sharing among our research staff is done through secure communication means via our web hosting services at [Hetzner](#), which is based in Germany and complies with the GDPR. Communication through its email services is automatically encrypted.

5. How will we use your data?

As previously mentioned, the data collected is utilized to conduct thorough analysis of the human rights situation within the communities under study. This analysis serves as the basis for generating advocacy-oriented materials, including publications, articles, research papers, and shadow reports for the United Nations human rights mechanisms. These publications can be accessed on our website, published in scholarly journals by our staff members, or included in the UN Database as Shadow reports. It is important to note that only analyzed, anonymized, and confidential data is utilized for these publications.

Raw data will never be disclosed to individuals outside of the immediate research team at the Institute. Raw data, such as audio recordings or notes containing identifiable information of the participants, will be deleted once the analyzed anonymized data has been generated. Post-research, only analyzed anonymized data will be retained in our storage.

Here are some examples of data usage for your review:

- [Understanding the Needs and Challenges of Transgender Individuals - Accessing Gender-affirming Healthcare in Egypt: A Mixed Methods Study \(Publication of the Institute\)](#)
- [Access Denied: A Qualitative Study on Transgender Health Policy in Egypt \(Publication by Staff in an Academic Journal\)](#)
- [Joint Stakeholder Submission to the Universal Periodic Review on Transgender and Intersex Health and Non-discrimination at the UN Human Rights Council \(UN Submission\)](#)

6. Can I revoke my consent?

Yes, you have the right to withdraw from the study at any stage without facing any consequences. However, some studies may have a specific deadline for withdrawing consent, which will be outlined in the research fact sheet.

7. Am I entitled to any compensation for participating in the research?

No, currently we do not provide compensation to participants in our data collection process. However, this may change in the future depending on the budget allocated to each research project. This information will be provided in the research fact sheet.

8. What can I do if I believe that my data has been misused by the researchers?

If you suspect that the researchers or research assistant have misused your data, or if you found the information given to you to be inaccurate or insufficient for making an informed decision about your consent, please contact us by email at research@cairo52.com. We will promptly conduct a thorough investigation and may request your attendance to provide oral testimony. This is to ensure an accurate assessment of the situation and determine appropriate disciplinary actions to be taken.