

# COLECTIV APP PRIVACY NOTICE

IMPORTANT, PLEASE READ CAREFULLY:

THIS APP IS DESIGNED TO ENABLE MULTIPLE INSTITUTIONS TO CONDUCT ELECTRONIC CONSENT AND DATA COLLECTION FOR CLINICAL RESEARCH STUDIES. THE APP IS NOT FOR TREATMENT PURPOSES AND IS IN NO WAY INTENDED TO TAKE THE PLACE OF TALKING TO YOUR DOCTOR. IF YOU HAVE A MEDICAL QUESTION OR CONCERN, PLEASE SPEAK TO YOUR DOCTOR. IF YOU THINK YOU MAY HAVE A MEDICAL EMERGENCY, CALL 911 OR GO TO THE NEAREST EMERGENCY FACILITY.

Duke University, its affiliates or subsidiaries (“Duke”, “we”, “our”, or “us”) recognize that parties may be concerned about the collection, use and disclosure of your personal information obtained via the Colectiv Application (the “App”). We respect your privacy and are committed to providing a transparent notice of our privacy practices.

This privacy notice describes Colectiv App privacy and data ownership and use as it pertains to both institutions and individual users who may be using the application.

## 1. Institutions:

When you register with the App as an Institution or an Institutional Study Staff Member, you and your institution are agreeing to conduct a research study and collect data from individual users via an application (Colectiv) operated and governed by Duke University in the United States. Please note that these terms do **not** apply to information collected, received, or accessed outside of the App unless that information is stored in the app.

- a. **Research Regulations.** You agree to abide by all local, state, and Federal research regulations and Good Clinical Practice (GCP) guidelines.
- b. **Legal Agreements.** If you are a non-Duke Institution, you agree to enter into and to conduct your study under the terms and conditions of a Data Use Agreement (DUA) with Duke University. All non-Duke studies require a DUA for use of the system because Duke hosts the study data, even if the DUA does not allow Duke the use of the data for research or other purposes.
- c. **How We Use Your Study’s Data.** Duke will only use your study’s data in a manner as agreed to in the DUA. Duke will host your study and all of your study data on secure servers. Only staff who conduct system maintenance will have access to your study space or your study data in your study space.

- d. Disclosure of Your Study's Data.** Any data that you agree to share to Duke will be sent, upon your manual "pushing" of data across an API, to a separate secure electronic storage location at Duke for research or other purposes as described in the DUA. Data provided will be accessed, shared, and used only in accordance with the DUA between your institution and Duke.
- e. Accounts.** By creating an account on the App, you agree to (a) provide accurate, current and complete information, (b) maintain the security of your account credentials, (c) immediately notify us if you discover or otherwise suspect any security breaches related to the App or your account. By creating an account on the App, you agree to receive communications from the Colectiv system (e.g., via email, push notifications, or SMS messaging) about Your Study or the system function.
- f. Security.** We have implemented reasonable measures designed to secure your personal information and the personal information of your study participants from accidental loss and from unauthorized access, use, alteration, and disclosure. The safety and security of your information and your study's information also depends on you. Where we have given you (or where you have chosen) a password for access to the App, you are responsible for keeping this password confidential. We ask you not to share your password with anyone.
- g. Protecting Children's Privacy.** The App is intended to be used by individuals age 18 and older. We do not knowingly collect personal data from persons under 18 years of age. If we become aware that we have collected personal data from a child under 18 years of age, we will promptly remove such information. If You believe we have collected information from your child, please notify us through "Question and Comments" below. This does not pertain to information collected about a person under 18 that is collected from a parent or guardian or other adult with the parent or guardian's permission.

## **2. Individuals:**

When you register as a user of the App, you are agreeing to participate in a research study conducted and governed by an institution which may or may not be Duke University. Please note that these terms do **not** apply to information collected, received, or accessed outside of the App.

The App is designed to be accessed from the United States. Please refer to the Terms of Use, as users from outside the United States should not use this App.

## The App and Data Collection

Please carefully review the consent form for the study you are participating in or contact the study staff for that study to understand the types of information collected, used, and disclosed by the Colectiv system. Once you have reviewed and signed your consent form, you will be enrolled in your study either automatically or at a later date, based on the study's design.

The Colectiv Application can only be accessed by study staff and persons participating in studies or invited to participate in studies using Colectiv.

### a. Personal Data Collected through the App.

The study you participate in may collect several types of information from and about you through the app including:

- **Information provided by you**, such as name, date of birth, telephone number, other personally identifying information, health information (if applicable to your study), and any other information specific to the study you are participating in.
- **Information provided by other sources about you.** Your study may also obtain data from sources such as medical records, census data, etc. and they may or may not enter that data into the application. Please refer to your study consent form and your study staff for detailed information on the types of data being collected.
- **Information collected automatically as you navigate the App.** Information collected automatically may include usage details, domain address, and information collected through cookies. The application does **not** store information related to your IP address, hardware used to access the application, or your location.

Please note that, if your study requests it, you may be asked to voluntarily provide contact information of other individuals to invite to join your study.

- ### b. How we Use Your Information.
- When you provide your personal data through the App, we will use it to communicate with you regarding the study you are participating in. This may include invitation or reminder emails to complete study surveys, invitations to join study groups, SMS and push notifications (study and software text notifications) as study reminders, or any other study related communication. Additionally, data collected via the application will be passed to secure Duke servers where that data is stored. Your data can only be downloaded by members of the study team for the study in which you are participating. That study may use the data to complete their research goals and for any additional purposes for which you have consented.

### c. Disclosure of Your Information

The study you participate in may disclose information that is collected about you or that you provide directly via Colectiv as described in this privacy notice:

- to fulfill the purpose for which you provide it. For example, to process your study survey;
  - with your consent; and
  - as permitted by law or to comply with any court order, law, or legal process, including to respond to any government, regulatory, or law enforcement request.
  - For all studies using the system who are NIH funded or otherwise hold a certificate of confidentiality (CoC) from the federal government, the CoC restrictions around data sharing apply.
- d. Accounts.** By creating an account on the App, you agree to (a) provide accurate, current and complete information, (b) maintain the security of your account credentials, (c) immediately notify us if you discover or otherwise suspect any security breaches related to the App or your account. By creating an account on the App, you agree to receive communications from Your Study (e.g., via email, push notifications, or SMS messaging) about Your Study.
- e. Security.** We have implemented reasonable measures designed to secure your personal information from accidental loss and from unauthorized access, use, alteration, and disclosure. The safety and security of your information also depends on you. Where we have given you (or where you have chosen) a password for access to the App, you are responsible for keeping this password confidential. We ask you not to share your password with anyone.
- f. Protecting Children's Privacy.** The App is intended to be used by individuals age 18 and older. We do not knowingly collect personal data from persons under 18 years of age. If we become aware that we have collected personal data from a child under 18 years of age, we will promptly remove such information. If You believe we have collected information from your child, please notify us through "Question and Comments" below. This does not pertain to information collected about a person under 18 that is collected from a parent or guardian or other adult with the parent or guardian's permission.
- g. Updating Your Information.** If your information needs to be updated, corrected, or deleted, please notify Your Study's staff. Your personal data can only be deleted in accordance with our data retention policy, and as permitted by law. Further, personal data may remain in databases, access logs, backup media, and other records. We cannot update or remove information from records of third parties.

- 3. Changes to this Privacy Notice.** We have the discretion to update these terms at any time. When we do, we will revise the “Last Updated” date at the bottom of this page. We encourage you to frequently check this page for any changes to stay informed about how we collect and use your information. You acknowledge and agree that it is your responsibility to review these terms periodically and become aware of modifications.
  
- 4. Questions and Comments.** If you have any questions or comments about these terms as they relate to the use of the Colectiv app, please contact [colectiv@duke.edu](mailto:colectiv@duke.edu). If you have general questions about the study you are participating in, please contact the staff at the institution conducting your study.

Last Updated: August 3, 2022