**General Data Protection Regulation (GDPR) CONSENT FORM**

**INSTRUCTIONS:** For studies involving participants from the European Economic Area (EEA) while they remain within the EEA, it's necessary to fill out this additional data processing disclosure form alongside the primary consent document. This form is intended to clarify for potential participants the methods by which their personal data will be handled in the context of this research, in compliance with the General Data Protection Regulation (GDPR).

**REMEMBER:** Instructions are highlighted in red. Please remove these instructions before the document is submitted for IRB evaluation.

**Research Study Title:** [Enter the title of the research study here]

**Study ID:** [Enter the BB study number here]

**Principal Investigator or Lead Researcher:** [Enter the name of the lead researcher here]

**Funding Information:** [Detail all forms of financial and in-kind support received for this research. If the study is not funded externally, indicate the associated school or department] The funding for this research comes from \_\_\_\_\_\_\_\_\_\_\_\_\_.

Details regarding the objectives, execution, and personnel involved in the research project can be obtained from the primary consent form associated with this study, which will be provided to you as a separate document (referred to as the “Primary Consent Form”). This additional document outlines the methods used for the collection, processing, and retention of your data within the scope of the research. We (the research team and BeyondBound) handle the processing of personal data pertaining to this study based on your agreement. Please sign below to confirm that you have comprehended how your personal data will be managed, your associated rights, and that you agree to your data being collected, processed, and stored as outlined herein.

**Your Personal Information:**

Please list the types of data that will be utilized in the research, ensuring thorough detail. Specifically, it is crucial to outline any "sensitive personal information" as per GDPR definitions, which includes data regarding an individual’s: (i) racial or ethnic background, (ii) political stances, (iii) religious or philosophical convictions, (iv) trade union affiliations, (v) genetic information, (vi) biometric details, (vii) health-related information, (viii) details of sexual life or orientation. The data categories listed below serve merely as examples and should be adapted to fit the specifics of the research:

In the course of your participation in this research project, we will gather or produce personal data concerning you, which includes:

* your given name and surname, birth date, methods of contact, identification number in medical records, and your past medical events;
* details you provide, such as responses in forms, surveys, or questionnaires related to the research;
* specific genetic information (especially……………………);
* health-related data (notably your blood group, pulse rate………);
* behavioral information (specifically……………………).

Include the following only if you acquire personal data from sources other than direct observations or information provided by the participant. If not applicable, please omit this section:

We will also collect personal data about you from external sources, such as:

* Details regarding your social engagements from your Facebook profile;
* Information concerning your academic achievements from your educational records;
* Data accumulated automatically through your interactions with [specify any websites or applications used to gather usage data from participants].

Include this if it applies to your methodology, otherwise, remove this section:
To ensure your privacy is maintained, we apply pseudonymization (assign a unique code) to your personal data. [Optionally, you can add details about who can access the pseudonymized data, who holds the key to the coding, and under what situations re-identification might take place].

**Application of Your Personal Information:**

Employing data for research extension is seen as a "compatible use," and this terminology is applicable here. Should there be potential for your data to be utilized for purposes beyond research, obtaining your re-consent will be necessary.

The primary use of your personal data will be for conducting this research project, as outlined in the Primary Consent Form. Should the outcomes of this study suggest that additional research could be valuable, your personal data may be processed further to facilitate research expansion into different areas or fields. Additionally, your personal data will be used as required to fulfill legal and regulatory obligations, which includes sharing your information with regulatory bodies and government officials tasked with monitoring and regulating studies like this one.

**Entities Receiving Your Personal Information:**

Please detail all parties that will have access to your personal data, including contracted service providers tasked with data management or other services on our behalf (e.g., cloud storage providers). Specify the service provider's name. Modify or delete the highlighted bullet points to suit the specifics of your study. Maintain the information on organizations and individuals if they are referenced in the Primary Consent form. The point concerning disclosures to third parties must be retained.

Your personal information will be disclosed to the entities listed below:

* The Regulatory Entity for X (located in the US) ...
* Agents operating under our direction: services such as a cloud storage provider and a data processing agency...
* Groups and individuals identified in the Primary Consent Form who are involved in the execution, support, or are recipients of data or findings from this research;
* External entities, including governmental bodies, in cases where we are legally bound to do so, such as instances where we must divulge your personal information to regulatory entities and government officials responsible for the supervision and oversight of studies like this research endeavor.

**Your Rights:**

As per the General Data Protection Regulation (GDPR) and corresponding national legislation, if you are a resident of the European Economic Area (EEA) during your participation in this study, you are entitled to the following rights, subject to the conditions and limitations outlined in Chapter III of the GDPR:

* To verify whether your data is under processing and to access or receive a copy of your personal data;
* To request amendments to your personal data;
* To request deletion of your data, provided you make a justified request;
* To request the transfer of your data to another entity;
* To request a restriction on the processing of your data (meaning we will limit who can access your information) upon a justified request;
* To retract your consent for the processing of your personal data at any given time.

Upon withdrawing your consent, we will cease to gather further information about you and may delete the personal data we have previously collected. Withdrawing your consent will not impact the legality of the data collection, utilization, and dissemination conducted with your consent prior to your withdrawal. Furthermore, we may continue to retain or use your personal data as necessary to fulfill legal and regulatory obligations.

To assert your rights, please reach out using the contact details provided below with a request. When making a request, kindly include your name, the project's name, your reasons for the request, if applicable, and any additional information you believe may assist us in fulfilling your request.

**Additional Information:**

Your personal data will be stored for the duration necessary to achieve the objectives and applications outlined in this document, including meeting any legal, accounting, or reporting requirements. Furthermore, we may retain your information if required by law or for other valid reasons.

If the retention duration is influenced by specific factors, the following wording should be applied to explain those factors:

The length of time we will keep your personal data may vary based on [insert factors that affect this duration].

Our institution is located in the United States; hence your personal data will be transferred to this country, which has not been recognized with an adequacy decision by the European Commission. Consequently, there may be potential risks for your personal information under this jurisdiction. By agreeing to this consent form, you are acknowledging and consenting to the transference and processing of your personal information in the United States. Nonetheless, we commit to taking all necessary precautions to ensure your privacy is safeguarded in line with relevant data protection regulations.

If you have any questions or concerns regarding the management of your personal data, please reach out to us using the provided contact details. If you are dissatisfied with our response or the way your personal data is being protected, you have the right to lodge a complaint with the data protection authority in your country or in a relevant jurisdiction concerning this processing, as stipulated in Article 77 of the GDPR.

**Contact Information for GDPR Inquiries:**

This study has received approval from an Institutional Review Board (IRB). Should you need to contact someone regarding GDPR-related queries, you can reach out at:

Phone: (646) 217-0403

Email: info@beyondbound.org

Please consider contacting the above if:

* Your inquiries, concerns, or complaints are not resolved by the research team.
* You are unable to make contact with the research team.
* You prefer to discuss matters with someone other than the research team.
* You seek clarification regarding your rights as a participant in the research.
* You wish to obtain further information or provide feedback concerning this study.

**Signature for Adults 18 and Over**

By signing below, I agree to the collection, processing, and storage of my data as outlined in this document.

Please sign your name here: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Enter the current date here: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Please print your name here: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

*For the Individual Obtaining Consent:*

The printed name of the individual obtaining consent here: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature of Individual Obtaining Consent with Agreement:

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date: \_\_\_\_\_\_\_\_\_\_\_\_