**Parental Consent and Child's Agreement**

**Note:** This consent form is utilized when **both** the parent and the child are invited to participate in a study. The parent provides consent for their participation and grants permission for their child's involvement. Additionally, the child is requested to give consent to participate. For the child to partake, the parent must consent to the child’s involvement. Clarify whether a parent can participate without consenting to the child's participation, or if the child chooses not to participate. Refer to the detailed Guidance on Children as Research Participants, Parental Permission, and Child Assent for further information.

Ensure to remove all text marked in "red" prior to submitting the document for IRB evaluation.

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

**Principal Investigator:** [Enter the name of the principal investigator]

**Student Investigator:** [If relevant, include the name of the student researcher, especially if the project is conducted by a graduate or undergraduate student as part of a degree or certificate program]

**Supported By:** [Detail all forms of financial and in-kind support for this research. Mention your school or department if there is no external funding] This research receives support from \_\_\_\_\_\_\_\_\_\_\_\_\_.

**Conflict of Interest Disclosure:**

[This section should be filled if there exists any conflict of interest. If not, please omit this section.] This disclosure aims to inform and allow you to assess whether this relationship impacts your decision to allow your child to engage in this research study: [detail the nature of the conflict of interest and outline measures implemented to mitigate its impact.]

[This part should be included if the researcher is also your child's treating physician. If not applicable, please disregard.] The physician overseeing your child's medical care is also leading this research study, which presents a dual interest in both your child's health and the success of this research. You are entitled to discuss the specifics of this study with an independent individual who is not associated with the research team, prior to making a decision on your child's participation.

**Collaborating Institutions:** [Include this section if there are any institutions collaborating on this research project – if not relevant, please omit.]

**Key Information about this research study:**

This section provides a brief overview of the study to assist you in deciding whether you and your child should participate. More comprehensive details are provided further in this document.

* The aim of this study is to \_\_\_\_\_ [Explain the primary goal of the study in clear, straightforward language].
* In this study, you and your child will be required to \_\_\_\_\_\_\_\_\_ [offer a concise description of the activities involved. For example: "Your child will be requested to fill out a questionnaire and participate in a follow-up interview."].
* The expected duration of your and your child's participation in this study is \_\_\_\_\_\_\_\_ [specify the time frame, such as "10 minutes; hours; days; months; weeks; years; until a certain event occurs"].
* The principal potential risk involved in participating is \_\_\_\_\_\_\_ [Identify the main risks associated with the study. Avoid stating "there are no risks." If risks are primarily related to breaches of privacy or confidentiality, mention this explicitly and describe how these risks are being mitigated].
* The primary benefit from participation in this study is \_\_\_\_\_\_\_.

**Why are my child and I being invited to participate in this research study?**

You and your child are being invited to this study because \_\_\_\_\_\_\_\_\_\_\_\_\_. [Ensure you detail the reasons for your and your child's inclusion, aligning with the criteria outlined in the study's documentation, which specifies who is suitable and who is not for this research.]

**How many people will be involved in this study?**

We expect that around [Insert number] parents and children will take part in this research study. If this research is conducted at various sites, then: We anticipate that approximately \_\_\_\_\_ participants will join the study through BeyondBound, out of a total of approximately \_\_\_\_\_ participants at all institutions involved in the research.

**What do I need to understand about participating in a research study?**

* A member of the research team will provide information about the study to both you and your child. [Omit if irrelevant.]
* The decision to participate is entirely voluntary for both you and your child.
* Both you and your child have the option not to participate.
* You and your child can initially consent to participate and can opt out at any later stage.
* Neither of you will face any consequences for deciding not to participate or for withdrawing later.
* Both you and your child are encouraged to ask any questions before making a decision.
* Neither you nor your child is obligated to answer any questions that make either of you uncomfortable. [This point should be included for studies involving surveys, interviews, and/or focus groups.]

**If you and your child decide to participate in this research, here is what will be expected from both of you:**

In understandable language and straightforward terms, we will outline the activities and procedures of the research. The steps will be presented in the order they will occur, along with the frequency of each activity and procedure. If the study involves several steps or visits, we may provide a diagram or table for easier understanding.

* You'll be informed about the duration and frequency of study visits, activities, and procedures. You'll also learn who you and your child will be interacting with during the study.
* We'll clarify whether the procedures will be conducted with you and your child together or separately.
* Details about the timing and locations of the research activities will be provided.
* We will describe the nature of the questions that will be posed to you and your child.
* We will differentiate what activities are part of the standard or routine practices [for example, in an educational setting, we will distinguish between regular teaching methods and what is being implemented as part of the study. If the study involves any form of clinical care, such as mental health services, we will clarify what constitutes standard treatment versus what is conducted for research purposes].
* If applicable, we will inform you if the study involves audio or video recording or photography, and whether these activities are mandatory for participation or optional.
* [If the study involves random assignment to different groups:] The assignment of you and your child to a specific study group will be random, akin to tossing a coin. Neither you, your child, nor the research team will have a say in the group assignment. You and your child will have an \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ [equal/one in three/etc.] chance of being allocated to any of the groups.

It is important to clearly understand the roles and responsibilities of both the parent and the child throughout the study.

**Will participating in this study benefit me or my child in any way?**

We cannot guarantee that you or your child will receive direct benefits from participating in this research. However, potential advantages may include \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_. [Please specify any anticipated benefits of taking part. Begin with any potential direct benefits to you or your child, followed by potential benefits to others. Remember, financial compensation for participation is not considered a direct benefit and should be detailed separately under the section titled “Will I be paid or receive anything for participating in this study?”]

**Could participating in this study pose any risks to me and my child?**

It is important to consider and understand the foreseeable risks involved in this study. While we strive to minimize these risks, they may include:

* Physical Risks: [Detail any physical discomfort or risks that may arise from participation, including the likelihood and severity.]
* Psychological Risks: [Discuss any potential emotional or psychological discomforts, such as anxiety or distress, particularly those that might arise from interview topics or the nature of the research.]
* Privacy Risks: [Consider the likelihood of breaches in confidentiality and the measures in place to protect privacy.]
* Legal Risks: [Address any potential legal implications or exposures that might occur as a result of participation.]
* Social Risks: [Outline possible social consequences, including stigma or changes in personal relationships.]
* Economic Risks: [Identify any financial impacts, such as costs incurred by participating, that might affect participants.]
* Group or Community Harms: [Discuss any risks that extend beyond the individual to affect communities or groups associated with the participant.]

For all studies collecting potentially identifiable data: One inherent risk in any research is the possibility of a breach of confidentiality — that private study information could be accessed by unauthorized individuals. We will implement all possible measures to reduce this risk, with further details provided in this consent form.

**What should be done if either my child or I decide against participating in this research, or choose to withdraw later?**

Your and your child's participation in this study is completely voluntary. It is your right to choose whether to take part and to allow your child to take part, or to abstain entirely. If either you or your child opts not to participate or decides to leave the study later, this decision will not negatively impact your respective affiliations [insert specific impacts such as academic status, healthcare access, etc., if necessary].

You and your child may terminate your participation in the research at any time, with no negative consequences.

Details on what occurs with the data if participation is ended:

If you withdraw, decide to withdraw your child, or if your child decides to leave the study, the research team will seek your consent to use the data collected up to that point.

OR

If you or your child decide to withdraw from the study, any previously collected data will be discarded.

**How will the researchers ensure the confidentiality of our data?**

The research team will implement a series of measures to maintain the security and confidentiality of participant information. These measures include the application of encryption techniques, the segregation of identifiable data from the main body of research data, and the retention of only non-identifiable summaries of interviews or focus group discussions. For detailed information on standard research data protection practices, please visit BeyondBound's website at: https://beyondbound.org.

In the event that the research receives funding from the NIH or intends to request a Certificate of Confidentiality, specific statements regarding the protections and constraints afforded by the Certificate of Confidentiality will be integrated here – for the exact wording, refer to the Supplemental Consent Language Document.

Additionally, if the study involves the use of focus groups for data gathering, further details concerning the limitations on the privacy and confidentiality of data within such settings will be included, as outlined in the Supplemental Consent Language Document.

**Who is permitted to view the data gathered in this investigation?**

We will strive to restrict access to your and your child's personal data, including records related to this research, to individuals who require this information for review purposes. Absolute confidentiality cannot be guaranteed.

Your and your child's data might be accessed or utilized by individuals beyond the research team during or after the conclusion of this study for various reasons. For instance:

* Officials from the governmental bodies, sponsors of the study, auditors, and the Institutional Review Board might need to review your information to ensure the research is conducted properly and safely.
* Researchers collaborating from other institutions who participate in this research. [insert this item ONLY if relevant to your study]
* For health and safety concerns, the research personnel might disclose information to relevant authorities, such as if there is a risk of harm to yourself or others, or for reasons related to public health. [insert this item ONLY if pertinent to your study]

[In studies designed to uncover or that might inadvertently reveal information regarding child abuse or neglect, the following statement must be included: All employees and associates of BeyondBound are mandated by the laws of Nevada and by BeyondBound policies to report any suspicions of child abuse or neglect.]

Should we become aware of any current or ongoing child abuse or neglect, we may be obliged or authorized by law or BeyondBound policies to report this information to the relevant authorities.

OR

We do not intend to inquire about abuse directly from your child, but if they disclose any instances of child abuse or neglect to us, we might be required or authorized under law or BeyondBound policies to report this to the relevant authorities.

If your study is likely to uncover information that falls under Federal regulations regarding sexual harassment and sexual violence, you must include specific language in the consent form about Title IX reporting obligations. Please refer to the Supplemental Consent Language Document for the exact wording regarding Title IX reporting obligations.

[When relevant, clarify if and how the research assessments, educational materials, or clinically relevant results, including individual findings, will be shared with participants, and under which circumstances.] Typically, the evaluations conducted in research settings are intended solely for investigative purposes and may not have immediate implications for [developmental, educational, or healthcare decisions.] However, if the findings from the research have implications for the health of you or your child, the research team will/will not reach out to share these discoveries.

**How could the data obtained in this investigation be utilized in the future?**

The information gathered about you and your child in this research will be preserved for record-keeping associated with this study [and might be used in subsequent research endeavors]. If the study data include identifiable details: Your and your child’s names, along with other identifiable information, will be securely stored separately from the rest of the data collected during the research.

For studies extending over time, please note: The researchers [intend to/might] re-establish contact with you as part of the ongoing research.

Data devoid of identifying details from this research may be distributed to the academic community, publications presenting the findings, and to databases and repositories employed for research purposes. [If identifiable information of participants will be collected, add this:] Before sharing the study data, we will either anonymize or encode any personal details that could directly identify you or your child. However, the complete anonymity of your or your child's personal information cannot be fully ensured.

Should there be an intention to keep or distribute identifiable data for future unspecified research, a distinct IRB submission must be prepared, inclusive of a detailed protocol, consent form, and supplementary documents (e.g., research registry). If the Principal Investigator (PI) of this study wishes to preserve your contact details to inform you about upcoming research opportunities for you or your child, you will be informed towards the conclusion of this process. This data will not be circulated among other researchers but will be kept solely for prospective research involvement with this PI. Consent for this will be sought at the conclusion of this document. Participation in this current study does not require agreeing to the future use of your identifiable data for subsequent research.

[Omit if there is no intention to share identifiable data] The findings from this study may be disclosed in academic articles and presentations, but will exclude any data that could identify you or your child unless you explicitly consent to the inclusion of such identifiable information in such outputs.

**Will there be any compensation for participating in this research for my child or me?**

Should you and your child decide to participate in this study, you will be compensated with [indicate the form of compensation, such as cash, gift card, check] in the total amount agreed upon for your involvement. [Clarify whether the compensation is provided for each participant, and to whom it will be given, for example, if the payment will be issued to the parent rather than the child]. This compensation will be provided even if you or your child decide to withdraw from the study before its completion.

Please consider the following details pertinent to your study:

* If there will be a prorated payment for any reason (this includes situations where a participant leaves the study prior to completing all procedures).
* If the study involves any additional bonus payments, or if any part of the compensation depends on the decisions or performance of the participant or a group of participants.
* If the study includes a raffle or lottery, detail the amount and total number of payments to be awarded; the likelihood of winning (if available); the estimated timing of the draw; and the method by which winners will be informed.
* If there will be reimbursements for transportation, parking, or other costs incurred due to participation in this study.

If there is no financial compensation or reimbursement provided for participating in this research, include the following statement: There is no financial compensation or reimbursement for participating in this study.

**Here is additional information that may be beneficial for you and your child:**

[This section should be included if your child will be participating in an educational study requiring surveys or interviews:] Please note, under the Protection of Pupils Rights Act 20 U.S.C. Section 1232(c)(1)(A), you are entitled to review the survey questions or educational materials that will be presented to your child. If you wish to review these materials, please contact [insert the name of the Principal Investigator and their contact details] to request a copy.

[If HIPAA protected information is being collected, ensure to apply the appropriate HIPAA Authorization terms as specified in the Social and Behavioral consent template HRP-1721.]

**Whom can you contact for more information?**

Should you or your child have any inquiries, issues, or grievances, please feel free to reach out to the Principal Investigator [insert Name and contact details] and [insert the name of another investigator, such as a student, if applicable]. [For studies conducted internationally, add the U.S. country dialing code for the contact numbers of the study team, along with the details of any local collaborators.]

This study has undergone and received approval from an Institutional Review Board (IRB) – a committee established to safeguard the rights and welfare of research study participants. Should you have any of the following concerns:

* If the research team has not addressed your questions, concerns, or complaints to your satisfaction.
* If you are unable to get in touch with the research team.
* If you wish to speak with someone other than the research team.
* If you have questions about your rights as a participant in this research.
* If you desire to obtain further information or offer feedback regarding this study.

You are encouraged to contact the IRB at (646) 217-0403 or via email at info@beyondbound.org.

**Optional Components:**

[This section should be included only if there are optional aspects of the research. If not applicable, remove this section.] The activities outlined below represent optional parts of this study. Neither your participation nor that of your child in the main body of the research is contingent upon agreeing to these extra activities. By placing your initials beside each statement, you authorize both yourself and your child to engage in these optional sections of the research. Please note, your child will similarly be afforded the opportunity to independently consent to or opt out of these specific components of the study.

**Parental Consent for the Parent's Involvement:**

| **I Agree** | **I Disagree** | **Statement** |
| --- | --- | --- |
|  |  | The researcher may [specify: audio record, video record, or both] during the sessions to assist in analyzing the data. These recordings will remain confidential and will not be shared with anyone beyond the core research team. (Indicate whether audio recording, video recording, or both will be used. If the recording is mandatory for participation, this section should be omitted.) |
|  |  | The researcher may [specify: audio record, video record, or both] during the study for use in academic presentations or publications. This might involve revealing my face or voice, which could lead to my identification within these materials. Although the researcher will strive to minimize this risk, I understand the potential consequences of such exposure. |
|  |  | The researcher may reach out to me in the future to inquire about my interest in engaging in additional studies conducted by the principal investigator of this current research. |

**Parental Consent for the Child’s Involvement:**

| **I Agree** | **I Disagree** | **Statement** |
| --- | --- | --- |
|  |  | The researcher is permitted to [specify: audio record, video record, or both] my child to facilitate data analysis. These recordings will be kept confidential and not disclosed to anyone outside the core research team. (Indicate whether audio recording, video recording, or both will be used. If the recording is mandatory for participation, this section should be omitted.) |
|  |  | The researcher is allowed to [specify: audio record, video record, or both] my child for use in academic presentations or publications, where visual or auditory presentation of my child may aid in conveying the research to other professionals. It is possible that my child may be recognized in these instances, but efforts will be made to minimize this risk. I acknowledge and understand the potential risks of such identifiable information being used. |
|  |  | The researcher has my permission to contact me in the future regarding my interest in having my child participate in subsequent studies conducted by the principal investigator of this study. |

**Child Agreement for Involvement in the Study:**

| **I Agree** | **I Disagree** | **Statement** |
| --- | --- | --- |
|  |  | The researcher is permitted to [specify: audio record, video record, or both] me to assist in analyzing the study data. These recordings will remain confidential and will not be shared with individuals outside of the primary research group. (Indicate whether audio recording, video recording, or both will be used. If the recording is mandatory for participation, this section should be omitted.) |
|  |  | The researcher may [specify: audio record, video record, or both] me for incorporation into academic presentations or publications, where visual or audio elements of my participation may enhance the understanding of the research by other professionals. I acknowledge there is a possibility I could be recognized through these materials, despite efforts to minimize this risk. I understand and accept the potential risks of such identification. |
|  |  | The researcher has my permission to contact my parent or guardian in the future to inquire about my potential interest in participating in future studies conducted by the principal investigator of this research. |

**Parent Consent and Permission for Participation of Children Aged 12 or Older**

Your signature confirms your agreement to participate and grants permission for the specified child to engage in this study.

Place Signature of the Child here: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Enter the Date here: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Place Printed Name of the Child here: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Printed Name of Parent [ ] or Individual Legally Authorized [ ] Date

Consenting to Participate and Granting Permission for the Child to Participate

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature of Parent [ ] or Individual Legally Authorized [ ] Date

Consenting to Participate and Granting Permission for the Child to Participate

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Printed Name of Person Obtaining Consent, Permission Date

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Printed Name of Person Obtaining Consent, Permission Date

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature of Person Obtaining Consent Date

Note: Investigators must verify that individuals who are not the child's parents have the legal authority to consent to the child's participation in the research. If there are any doubts or questions regarding this matter, please consult with legal counsel.

Electronic Consent and Permission (analogous to written signed consent but acquired remotely via an electronic platform):

To secure proper signed consent and permission, it is necessary to collect a verified electronic signature. The electronic form should include fields for the participant to type their name and the current date, ensuring that consent and permission are both informed and legally binding.

 **Verbal Parental Consent, Permission, and Child Agreement:**

There are circumstances where it may not be feasible to collect a signature on the consent form from participants. For example, when obtaining permission, agreement, and conducting data collection via telephone or video conferencing, the process of acquiring a physical signature from the parent or child can become overly cumbersome, complicating the process of securing the necessary permissions and agreements. Additionally, in studies examining illegal or socially stigmatized actions, requesting a signature on the permission and agreement document from the parent or child might increase the risk to participants. Furthermore, within certain international research settings, it is not typical for members from specific cultural groups or communities to provide signed consent forms. The rationale behind the decision not to collect signatures from the parent or child on the permission/agreement document must be comprehensively explained in your study protocol.

If your research does not involve obtaining a signed permission and agreement form or an electronic signature, you must comply with the standards for a waiver of documented informed consent. The protocol should provide a substantial justification for this waiver, in line with the federal guidelines specified in the CHECKLIST Waiver of Written Documentation of Consent.

If there will not be a signed form from either the parent or child, eliminate the signature section mentioned earlier, and treat this document as an informational sheet for the research. When initiating contact with the parent and child for the purpose of data collection, it's essential to verbally go over the primary aspects of the permission and agreement with both parties to confirm their understanding and consent to participate in the research prior to starting the collection of data. If there is an intention to audio-record the verbal consent and agreement of the parent and child, this intention must be clearly stated and elaborated within the protocol documentation.

| **Question** | **Response** |
| --- | --- |
| [Parent/Guardian] Do you consent for your child to participate in this study? | Record the parent’s response: Yes No |
| [Parent/Guardian] Do you agree to participate in this study? | Record the child participant’s response: Yes No |
| [Child/Student] Are you willing to participate in this study? | Record the parent participant’s response: Yes No |

Participant Name or Study ID Number (If the participant's name is not being recorded on the consent and assent document to reduce risk, please record the study ID number instead):

[Parent] \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[Child] \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
Signature of Person Obtaining Consent Date

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
Signature of Person Obtaining Consent Date

**Online Consent and Permission with Child Agreement**

**(permission and agreement obtained without physical or electronic signatures):**

Should your study not involve obtaining a physically signed consent and permission form or an electronic signature, it is necessary to comply with the criteria for a waiver of documentation of informed consent. Your research protocol must provide a thorough justification for this, meeting the federal waiver standards as detailed in the CHECKLIST Waiver of Written Documentation of Consent.

In the case of parental consent and permission alongside child agreement conducted online, remove the standard signature section mentioned previously. Instead, utilize the following language for online permission and agreement:

If you desire a copy of this Parent Consent and Permission with Child Agreement document for your records, you have the option to print it directly from the screen. If you are unable to print the document and wish to have a copy for your records, please reach out to the Principal Investigator using the provided contact information.

For participation to proceed, the parent must provide consent and permission while the child must express their agreement. It is required that both the parent and the child select "I agree" to be able to participate in the study.

| **Question** | **I Agree** | **I Disagree**  |
| --- | --- | --- |
| [Parent/Guardian] Are you willing to participate in this study? |  |  |
| [Child/Student] Are you willing to participate in this study? |  |  |

If you choose not to participate in this study, please select “I Disagree” or click on the 'X' at the corner of your browser to close the window.