**Informed Consent Template**

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*As with any study being conducted using human subjects, an informed consent form prior to conducting the research is necessary for any subject participation, and making data publicly available or for open science use should be reflected in said consent forms. This document lays out the sections within a typical informed consent form, and aims to point out which sections are of particular importance and provide example text for open science in red font.*

**Introductory Paragraph**

This section should welcome participants to the study and include information about title, location, and researchers. This also serves as an invitation to be in the study.

**Purpose of the research**

This section should explain why the individual was chosen for participation in the study.

* Can explain how an individual's qualities made them a candidate.
* Can explain the purpose of the study and goals, as well as characteristics that would make a participant qualified for the study.
* Should clearly lay out the goal of the study and reason for conducting the project.
* (optional) For open science practices, can frame the desire to make all deidentified data available to the public.
  + Spurring on new ideas, furthering research collaborations, and making data more accessible are examples of how making data open can be a purpose of the study.

**Procedures**

This should include an explanation of what exactly a participant will do and how the research will be carried out. If any parts of the procedure are experimental or controversial in nature, this should clearly be laid out in this section.

**Length of the project/Time Duration**

This section should explain the length that the project will last, the frequency of testing/experiments, and generally the amount of time a participant can expect to devote to the project.

**Discomfort or Risks**

This section should list any discomfort that may result from participation in this study. This should include any immediate or delayed harms, as well as those that are the direct or indirect result of participating in the study.

If outlined prior that data is expected to be used for open science or made publicly available, include a quick statement that making data available poses the minimum amount of risk to participants since all data will be deidentified to the point that no one outside of the researchers will be able to link an individual to their data or to the study as a whole to the extent possible.

[“Any data made publicly available (or shared with other researchers by request/application) will be deidentified and made so that it cannot be linked to you in anyway as much as possible. It is impossible to guarantee that your data will never be linked back to you, but through extensive deidentification making your data available to the public will involve only the minimal amount of harm or risk that is possible to you.”]

It is important to note here that one cannot guarantee that an individual will not be reidentified, but rather that you will take all the steps possible to reduce this possibility.

[“Due to the nature of open data sharing, it is impossible to guarantee that data will not be reidentified or linked back to you personally or to estimate the likelihood that this will happen. Rather, we will take all steps in our power to minimize this risk to you as a participant. These steps will include (removing identifiers, aggregating some data, increasing minimum cell sizes, etc.). If any of your demographic or other information puts you at risk for being identified based off where your live or the population you are a part of, additional steps will be taken to ensure this information is not enough to tie the data back to you.”]

*Note: Specific deidentification techniques will more than likely be entirely new terms or ideas to participants, so detailed explanations of these processes in easy to understand terms is necessary. Other helpful tips would be to include links to web pages or articles explaining these techniques in easy to understand terms, or contact information for whom any questions related to this can be addressed.*

**Benefits**

This section should describe the potential benefits to being in the study, including the direct benefits to the individual participant, as well as benefit to others.

*Note: Compensation is not a form of benefit and as such should not be included in this section.*

**Statement of confidentiality**

This should include a statement on how any confidential or potentially identifiable information will be treated or stored, including long term plans for the data after the project has ended. This should include specific information regarding any written or physical records of the data. This includes plans for destroying the data when necessary.

This section is highly important to address when planning to make data publicly available, and should again bring to the participant’s attention that the data will be made publicly available and some description of the plan to do so (specific data-repositories, open to share with other researchers by request, etc.). This should provide an explanation that data will be deidentified and what that means. Data reidenfitication and deidentification may be unknown terms to participants, and as such should be clearly explained.

[“Any information that can link you/your child to this study will be removed prior to any data being made publicly available or shared with other researchers who request the data. There will be no information that can link your participation to the study, and as such no one outside of those directly involved with the research will know that you took place in this study. We cannot guarantee that reidentification is impossible, but will take several steps to ensure that your data is as safe and private as is currently possible.”]

When applicable, can describe specific processes or variables that will help lead to data deidentifcation. Again however, these are not commonly used terms or ideas thought about.

[“Names, addresses, school ID’s, etc. will be removed from all data prior to analysis and data being made publicly available. Statistical techniques will be used to ensure that other variables such as race, gender, and age will not be able to link you to the study. Any records including this information will be stored in a locked location that only the researchers have access to/destroyed/stored on a secure computer/etc.”]

**Compensation for participation**

This section should discuss what direct compensation a participant receives. Again, this is different from the benefits of the study.

**Research funding**

This section can list any funding agencies or institutions associated with the project. If there are conflicts of interest due to meeting the needs of a funding agency, this is the place to discuss them.

**Voluntary Participation**

This section should make it clear that participation in the study is entirely voluntary, and that an individual can withdraw from the study at any time and for any reason.

For open data, this should include a section that says the individual understands that their data will be shared with outside researchers or made available, but that they can opt out before said data is shared.

[“By signing this consent form, you acknowledge that understand that you may withdraw your data at any time before it has been anonymized/deidentified and combined with other data. Once data has been anonymized and uploaded/shared with other researchers, we cannot retroactively go back and remove your data from the larger dataset.”]

If your study has a small population from which to draw and you fear that making data publicly available will cause some individuals to not participate in the study, you can have it so that making their data publicly available is an option they can opt out of.

*Note: Having this option would have downstream effects on your dataset and project. The data originally analyzed by researchers would be different from those made publicly available due to participant dropout for the publicly available portion. As such, this option should only be considered if the project will likely be unable to be completed as is due to participant fear of data being made available.*

[“If you would like to participate in the study but are concerned about the public nature of the data, you can opt out of having your data made publicly available while still participating in the study. In this instance, your data will be viewed only by the researchers, and will not be included in the dataset that will be made available to the public.”]

*Note: Choosing to make data publicly available to outside researchers by request/application that needs to be approved, could be another way of easing participants’ minds about data sharing, and thus would not require this section to be in here.*

**Contact information and where to address questions**

This section should list the contact information of the researcher/project manager, as well as any other places/individuals to address questions.

If you know in advance how the data will be made publicly available, you can link to that website/information about the repository that will be used.

[“The deidentified data will be uploaded to the [REPOSITORY NAME] data repository, and as such many questions about the repository/open data can be answered here [FAQ/ABOUT PAGE URL].”]

OR

[“Information about the project will be posted on [REPOSITORY NAME] data repository where a deidentified version can be requested by outside researchers. Questions about the repository can be addressed at [FAQ/ABOUT PAGE URL], and any questions regarding screening outside researchers or deidentifying the data can be addressed to [RESEARCHER NAME AT EMAIL ADDRESS].”]