**University of Utah Model Informed Consent: Future Use of Information**

The following model language outlines the required components for future use of information at the University of Utah. The appropriate option should be selected based on the project. Modify as appropriate and as directed.

**Future Use of Private Information**

As part of this study, we would like to keep information collected in during this project so that researchers may use it in the future in other research projects. When we use the term “data repository”, it refers to the storage of the information that is collected.

* **What will be kept?** We would like to keep [insert specific description of information].
* **What will my information be used for?**

*Option for specific disease/condition:* Information collected about you may be used for future research about [insert specific disease or condition] to help us learn more.

*Option for no specific disease/condition:* We don’t know what kind of future research will be done but we hope to learn more about diseases and how to treat them.

* **Who will keep my information?**

*Option for University of Utah-managed data repository*: Your information will be kept by Dr. [insert name] who manages the data repository at the University of Utah.

*Option for a sponsor-managed data repository:* Your information will be kept by the study sponsor, [insert sponsor name], who manages the data repository.

* **Do I have to allow my information to be saved for future research?**

*Option for mandatory data repository (e.g., sole purpose of research study is to save information for future research):* If you do not want your information to be saved for future research, you should not participate in this study. No matter what you decide to do, your decision will not affect your medical care.

*Option when choice given to be included in data repository (note: participation in a data repository must be optional for treatment/intervention trials):* You do not have to participate in the data repository to be in the main part of this study. No matter what you decide to do, your decision will not affect your medical care. You can tell us your choice by initialing one of the choices below:

|  |  |
| --- | --- |
| **\_\_\_ YES,***(initial)* | my information may be saved for future [specify a specific condition/disease]research. |
| **\_\_\_ NO,***(initial)* | my information must be destroyed at the end of this research project. |

* **Will my information be personally identifiable?**

*Option for de-identified data:* The information we collect from you will not have your name or other personal information linked to it. Your de-identified information may be shared with researchers at the University of Utah and at other institutions without additional informed consent from you or your legally authorized representative. The only information we will keep is information like your age and what disease you have.

*Option for coded data:* Your information will be coded so that your name is not kept with the rest of the collected data. Dr. [insert name] and the University of Utah will keep your name in a separate place so that we can link back to the rest of your data later we need to. Your information may be shared with researchers at the University of Utah and at other institutions without additional informed consent from you or your legally authorized representative. Dr. <<insert name>> will not give your name to other researchers who want to use your information and will only give them the data without identifiers.

*Option when choice given to de-identify data:* We would like to code your information so that your name is not on it. Dr. [insert name] and the University of Utah will keep your name in a separate place so that we can link your data back to you later if we need to. But if you do not want us to keep your name or any other identifying information with your data, you can choose to have your data remain anonymous. Your data may be shared with researchers at the University of Utah and at other institutions without additional informed consent from you or your legally authorized representative. You can tell us your choice by initialing one of the choices below:

|  |  |
| --- | --- |
| **\_\_\_ YES,***(initial)* | my personal identifiers can be kept with my data. All information will be kept secure and confidential. |
| **\_\_\_ NO,***(initial)* | my name and identifiers must be removed from my data. My data cannot be linked back to me. |

* **What if I want to withdraw my information from the data repository?**

*Option for de-identified data:* Because we will not keep your name or other identifying information when we store your data, you will not be able to have your information removed from the data repository later.

*Option for coded data:* You can have your information removed from this data repository later. You will need to contact [insert name] at [insert contact information].

*Option when choice given to de-identify data:* You can have your information removed from this data repository later. You will need to contact [insert name] at [insert contact information]. If you decide to have your identifiers removed from your data, you will not be able to withdraw your data later because it cannot be linked back to you.

* **Will my information be used for commercial profit?**  The use of your data and biospecimens may lead to new tests, drugs, devices, or other products or services with commercial value. These products or services could be patented and licensed. There are no plans to provide any payment to you should this occur.”
* **Will future results or findings be given to me?**

*Option for not disclosing future results:* Because the results from future research will not directly affect your health care, we will not share the results from future studies with you or your doctors.

*Option for not disclosing future results because of de-identification:* Because your information cannot be linked back to you, we will not share the results from future studies with you or your doctors.