**The following example language can be used in consent forms to outline how data might be shared.**

**Example 1**

*Researchers sometimes compile data from many different research studies to try to answer bigger questions that the individual research studies cannot answer by themselves (this is called a “meta-analysis”). Other times, researchers think of new research questions that their data can answer that they did not think of when a study was first conducted. The data that you provide as part of this project may be used as described in these examples in future research by the primary investigator or another researcher without additional consent from you or a legal representative. However, only your anonymized, de-identified data would be used for these purposes.*

**Example 2**

***Mogen we uw gegevens gebruiken voor ander onderzoek?***

*Uw (gecodeerde) gegevens kunnen na afloop van dit onderzoek ook nog van belang zijn voor ander wetenschappelijk onderzoek naar de mogelijke gevolgen van ingrijpende gebeurtenissen. Dit onderzoek kan ook buiten de Europese Unie plaatsvinden. In die landen gelden niet de privacyregels van de Europese Unie. Maar uw privacy zal op een gelijkwaardig niveau worden beschermd. Er worden geen herleidbare (ongecodeerde) persoonsgegevens gedeeld. In het toestemmingformulier geeft u aan of u het goed vindt om uw gegevens voor ander onderzoek te gebruiken. Geeft u hiervoor geen toestemming? Dan kunt u nog steeds meedoen met dit onderzoek. Uw gegevens zullen dan alleen voor dit onderzoek worden gebruikt en zullen niet gedeeld worden met andere onderzoekers.*

***May we use your data for other research?***

*After this research study, your data may also be important for other scientific research into the possible consequences of major life events. This research may take place outside the European Union. The privacy rules of the European Union do not apply in those countries. But your privacy will be protected at an equal level. No traceable (unencrypted) personal data is shared. In the consent form you can indicate whether you agree to use your data for other research If you choose not to give permission to share your data, you can still participate in this study. Your data will then only be used for this research and will not be shared with other researchers*

**[Example 3](https://research.illinois.edu/sites/default/files/Representing%20Data%20Sharing%20in%20Informed%20Consent%20Guidance%20for%20Researchers_0.pdf)**

*We will keep private information about you confidential to the extent allowed by laws and university policies. When researchers publicly discuss or publish the results of this research, they will not tell anyone that you were in the study. However, government or university officials who are responsible for monitoring this study and journal staff who review the research results for accuracy may see information that identifies you, including your signed consent form.*

*If you give us your permission, we will use or share data from this study and your personal information [and “type of biological specimen” sample] for use in future research studies. We will not ask for your additional informed consent for these studies. The future research may be done here or at another place. The research may be similar to this study or completely different. To use your information future researchers must agree to follow the same laws and policies to protect your private information. They will not tell anyone that you were in their study. If you allow us to use or share your personal information for future studies, you can change your mind later and ask us to remove it. However, please keep in mind that we cannot take back information that other researchers have already used.*

*We will submit data from this study to a public access repository [and sample repository for biological specimens]. All private information that could identify you will be removed or changed before data [or samples] are put in a public repository. Anyone can use information from a public access repository for any purpose.*

[**Example 4**](https://research.illinois.edu/sites/default/files/Representing%20Data%20Sharing%20in%20Informed%20Consent%20Guidance%20for%20Researchers_0.pdf)

*We will keep private information about you confidential to the extent allowed by laws and university policies. When the researchers publicly discuss or publish the results of this research, they will not tell anyone that you were in the study. However, government or university officials who are responsible for monitoring this study and journal staff who review the research results for accuracy may see information that identifies you, including your signed consent form.*

*We will submit data from this study to a public access repository [and sample repository for biological specimens]. All private information that could identify you will be removed or changed before data [or samples] are put in a public repository. Anyone can use information from a public access repository.*

[**Example 5**](https://mrctcenter.org/resource/data-sharing-plain-language-informed-consent-form-section/)

*We will gather information about you as part of your participation in this research study. The information that we gather may include personal information, such as your name, address, and birth date; information from your medical record; and new information about you, such as the results or findings from study-related tests and study-specific procedures. To advance science, medicine, and public health, we will share information about you from this research study with other researchers, but only after personal information that may identify you has been removed. We remove your name, address, and medical record number, as well as other data that could identify you. If you would like more details about the kind of information that we remove from our files, we are happy to provide them upon request. The remaining information can be combined with other people’s data to help researchers’ understanding of how to stay healthy, why diseases develop, how to best diagnose and treat diseases, and how to develop new medicines or medical devices. We will do everything we can to protect your privacy before sharing your de-identified data with other researchers but, despite best efforts, there is still a very small chance that you could be re-identified. To minimize this risk, we will follow all relevant data protection laws. If, at any point during or after this study, you think that you may have been re-identified, please contact us and let us know. Because we remove your contact information from the files that we share, we will not have a way to contact you individually.*

[**Example 6**](https://sharing.nih.gov/data-management-and-sharing-policy/protecting-participant-privacy-when-sharing-scientific-data/considerations-for-obtaining-informed-consent)

*This study is collecting data and biospecimens from you. We would like to make your data and biospecimens available for other research studies that may be done in the future. The research may be about similar diseases or conditions to this study. However, research could also be about unrelated diseases, conditions, or other types of research. These studies may be done by researchers at this institution or other institutions, including commercial entities. Our goal is to make more research possible. We plan to keep your data and biospecimens****for [Insert time frame as indicated in the study protocol]****.*

*Your data and biospecimens may be shared with researchers around the world. However, the decision to share your data and biospecimens is controlled by****[indicate which entity has control]****. To get your data and biospecimens, future researchers must seek approval from****[indicate which entity has control]****. The researchers must agree not to try to identify you.*

* ***Option #1: If the data and biospecimens are coded and can be linked back to the identity of the participant:*** *We will protect the confidentiality of your information to the extent possible. Your data and biospecimens will be coded to protect your identity before they are shared with other researchers.****[indicate which entity has the code key]****will have a code key that can be used to link to your identifying information. The code key will be securely stored.*
* ***Option #2: If the data and biospecimens cannot be easily linked back to the identity of the participant:*** *Your name and identifying information will be removed from any data and biospecimens you provide before they are shared with other researchers. Researchers cannot easily link your identifying information to the data and biospecimens.*