

Databrary

Permission to Share Self-Reported Health-Related Information

Overview

This form requests permission to include self-reported health-related information about you in a secure data library on the Internet (databrary.org). The library allows authorized researchers to share data. Data sharing will help researchers to learn more and will lead to faster progress in our understanding of human development.

Giving permission to share is entirely separate from giving consent to participate in a research study. You do not have to give permission to share your health-related information in the library. Your choice will not affect your receipt of payment if offered for your participation in this or future studies.

What will be shared?

With your permission, we will include self-reported health-related information about you in the library.

Will the information be confidential (private)?

Your information will be confidential (private). All of your information will be identified by a code number, not by name. No information will be included in the library about how to contact you or your family.

Your image and/or voice may be seen or heard on video/audio recordings or still images in the library. Someone might be able to identify you unintentionally. But, the authorized researchers with access to the library promise to keep confidential the identities of all people in the library.

Who can access information in the library?

Only authorized researchers have access to information in the library. Researchers who are granted access must sign a contract that requires them to maintain confidentiality (keep information private) and not to use information for commercial purposes. Researchers promise to treat information in the library with the same high standards of care that they treat information collected in their own laboratories.

How long will information remain in the library?

Information in the library will be preserved indefinitely in a secure location. We do not intend to delete the information. We intend to store the information so that future researchers may be able to use it.

If in the future you no longer wish to have your health-related information stored in the library, please contact Databrary at ethics@databrary.org.

Permission

Permission to share with authorized researchers

☐ I give permission to share my self-reported health-related information with authorized researchers in a secure data library.

I trust that authorized researchers will use professional judgment and uphold ethical principles in determining what health-related information to share.

Compensation

There will be no compensation to you for the use of information in the library.

Signatures

My signature indicates that I understand this document and agree to what it says.

Your signature: _____ Date: _____

Researcher obtaining permission: _____ Date: _____

We will give you a copy of this form for your records. If you have any questions about the data-sharing library, please send email to ethics@databrary.org. For questions about your rights as a research participant, you may contact [APPROPRIATE CONTACT FOR LOCAL INSTITUTION].