

## **HIPAA Authorization to Use and Disclose Protected Health Information**

**Title:** Connect for Cancer Prevention Study

**<IHCS> Principal Investigator:**

**National Cancer Institute (NCI) Principal Investigator:** Montserrat Garcia-Closas, M.D., Dr.P.H.

**Funding Source:** NCI

### **Introduction**

Keeping your protected health information private is important to us. This HIPAA authorization document has more details about how we will use and share your protected health information, which may include information in your health and medical records. If you sign this document, you give permission to all clinics, hospitals, or other health care providers that you use, including [insert relevant contracted IHCS], directly or by an entity on its behalf, to use and disclose (release) your protected health information to the NCI for the Connect for Cancer Prevention Study (Connect). Your protected health information may also be used and disclosed by future researchers primarily to better understand the causes of cancer and how to prevent cancer as well as to use for general research purposes.

Once your protected health information is disclosed to NCI, it is no longer protected by the Health Insurance Portability and Accountability Act (HIPAA) and its regulations. Instead, NCI follows federal privacy laws to protect your information, including the Privacy Act of 1974, 5 U.S.C. 552a, Certificates of Confidentiality, 42 U.S.C 241, and the Common Rule, 45 CFR 46, as applicable. Below is an explanation of how your protected health information will be used and disclosed for Connect.

### **Description of the Connect for Cancer Prevention Study**

This research study is designed to identify the causes of cancer and how to prevent cancer in adults. It is led by the NCI in partnership with selected health care organizations in the United States. Connect will recruit a large group of people and follow them for many years. Connect will collect information from electronic health and medical records, ask for donated samples (biological specimens), and Connect will ask participants to answer surveys. All of this information will be protected under applicable Federal laws. The information collected from study participants will help researchers better understand the causes of cancer and how to prevent cancer in adults.

### **Protected health information that will be used and disclosed**

Your protected health information that will be used and disclosed for this research includes:

- Information that identifies you, like your name, address, and important dates
- Information from your health record, such as diagnoses, medications, results of physical exams, procedures, and lab tests you have before and during the study, including genetic test results, mental health diagnoses and treatment, HIV/AIDS status. The information disclosed will not include psychotherapy notes or alcohol or drug abuse diagnoses or treatments.
- Samples collected for this research or leftover samples collected during your health care visits. Examples include, but are not limited to:
  - Blood, urine, or stool from clinical care
  - Tissues from routine medical procedures, such as a biopsy or surgery
  - Samples from pap-smears (often used for cervical cancer screening)

### **Who will use and disclose your protected health information**

If you choose to join Connect, the protected health information listed above may be used and disclosed by all of your clinics, hospitals, or other health care providers, including [insert relevant contracted

**IHCS**], directly or by an entity on its behalf, for the research described here. People who may use and disclose your protected health information include:

- The National Institutes of Health (NIH) Institutional Review Board (IRB), other participating IRBs or privacy boards, the NIH Office of Human Research Protection, and public health and accreditation agencies, to be sure this research is done safely
- Connect researchers from your health care provider and the NCI
- Future researchers to study the causes of cancer, how to prevent cancer as well as to use for other general research purposes who agree to Connect privacy standards and information sharing rules

### **Authorization to use and disclose your protected health information is required to take part in Connect**

Your clinics, hospitals, or other health care providers, including [insert relevant contracted IHCS] are required by law to protect your protected health information. By signing this document, you authorize all clinics, hospitals, or other health care providers, including [insert relevant contracted IHCS], directly or by an entity on its behalf, to use and disclose your protected health information to the NCI. NCI will use and disclose your health information for Connect and future research as described in this document and the informed consent form.

Giving your authorization to use and disclose your protected health information for this research is voluntary. You do not have to sign this form. If you do not sign this form, you cannot take part in Connect. Your current or future health care or eligibility for benefits will not be affected by your decision.

### **Expiration of your authorization**

Your authorization does not expire on its own. Your protected health information will be used and disclosed until you revoke (take back) your authorization or the study ends.

### **Revoking your authorization**

You may change your mind and revoke this Authorization at any time. If you revoke this Authorization, protected health information about you will no longer be collected for Connect and you will not be able to continue in this study. Your health information that was already collected may still be used by the NCI to maintain the integrity of the current research. To revoke this Authorization, you must reach out to the Connect Support Center (Cancer.gov/connectstudy/support). The revocation is not effective until it is received by your health care provider.

### **Other items you should know about your privacy**

- No names, pictures, or other direct identifiers will be used in any public presentation or publication about this study unless you sign a separate consent allowing that use.
- Protected health information disclosed by this Authorization may be subject to redisclosure by the recipient and may no longer be protected by the Health Insurance Portability and Accountability Act Privacy Rule.
- If all information that does or can identify you is removed from your protected health information, the remaining information will no longer be subject to this Authorization and may be used or disclosed for other purposes.

## **HIPAA Authorization**

Please keep a copy of this document in case you want to read it again. It can be viewed or downloaded from the MyConnect participant app after you sign up.

**By clicking “Yes, I agree to join Connect” and typing your name, you confirm the following:**

1. I have read these forms.
2. As stated in the consent and HIPAA Authorization, I will allow the use, storage, and disclosure (release) of my survey answers, samples, and health information for the research as described above.
3. If I have questions, I can contact the Connect Support Center at [Cancer.gov/connectstudy/support](https://cancer.gov/connectstudy/support)
4. If I decide to leave the study, I can contact the Connect Support Center at [Cancer.gov/connectstudy/support](https://cancer.gov/connectstudy/support).

**[checkbox] Yes, I agree to join Connect**

Please enter your legal name. If you are a member of Kaiser Permanente, please enter your first and last name exactly as it appears on your Kaiser Permanente ID card.

Signature:

Print Name:

Date: