

## **Privacy and Security Notice for Individual Access Services (IAS) Yale University**

This Privacy and Security Notice (“Notice”) explains how we collect, use, protect, and disclose your health information when you use Individual Access Services (IAS) in conjunction with a Yale research repository. It is provided in accordance with the Trusted Exchange Framework and Common Agreement (TEFCA) requirements. This notice supplements the information provided in our HIPAA Notice of Privacy Practices available on our website <https://hipaa.yale.edu> and is effective for as long as we hold your information.

Yale will manage your health information as described in this Privacy and Security Notice and will protect the security of the Individually Identifiable Information it maintains in accordance with the applicable TEFCA Framework Agreement and HIPAA. This notice applies when you consent to participate in a research project that will exchange your Protected Health Information (PHI) through the TEFCA Individual Access Services. Please be aware that the research repository accepts PHI through the IAS but does not share health information back to health care providers.

### **Purpose of IAS at Yale**

The TEFCA framework allows healthcare providers to share patient information known as PHI even when using different medical record systems. The framework allows health care providers to share PHI for treatment as well as at the request of a patient using the IAS. In some research projects at Yale, you may be asked to consent to your PHI being shared with a Yale research data repository using the IAS. Yale is a HIPAA Covered Entity and your PHI will be protected as described in our HIPAA Notice of Privacy Practices as well as the additional information related to the data exchanged through the IAS provided here.

### **Categories of Information We Access and Maintain**

With your explicit research repository consent and HIPAA authorization as well as the TEFCA consent, we retrieve your electronic health records from accredited health information networks and TEFCA participants - such as hospitals, clinics, physician practices, and other health care providers where you have received care — to the extent those providers participate in TEFCA exchange. The nature of the PHI to be exchanged and the way the PHI will be used, disclosed and retained for the study you are participating in is described in detail in the research consent form.

### **Access and Disclosure**

The information exchanged through the IAS will be used and disclosed for the research study you are participating in as described in the research consent form. In addition, we may use and disclose your information as described in our HIPAA Notice of Privacy Practices and are required to secure this information as required by HIPAA. Your information will be disclosed only as permitted or required as specified in the TEFCA Common Agreement, our HIPAA

Effective Date: March 2026

Notice of Privacy Practices and applicable US Department of Health and Human Services guidance. Your information will not be sold or disclosed in a way that is different from the uses described here or in the research consent form unless we have your specific authorization to do so.

### **Notification of Compulsory Disclosures**

Unless prohibited by Applicable Law, Yale will provide written or electronic notice to affected Individual(s) within three (3) business days of receiving either a civil or criminal subpoena, court order, search warrant, or other compulsory legal demand for PHI received through the IAS or making PHI we received through the IAS available to law enforcement agencies. This notice is provided so that you have the opportunity to object to the demand, seek a protective order, or other appropriate remedy available under Applicable Law. If notice is legally prohibited (for example, under certain national security laws), we will comply with such restrictions.

### **Data Security**

As a HIPAA Covered Entity, your information is secured in compliance with HIPAA. We use commercially reasonable administrative, technical, and physical safeguards to protect PHI, including encryption in transit and at rest, access controls, and monitoring. The research repository is stored on secure servers with access limited to authorized study personnel and those who maintain the repository.

### **IAS Incident Notification**

If your PHI is reasonably believed to have been affected by a TEFCA Security Incident or breach of unencrypted information, we will notify you in accordance with HIPAA and TEFCA requirements.

### **Your Rights**

You have certain rights in the data we are collecting through IAS:

- The right to revoke your consent for us to retrieve your PHI through IAS;
- The right to request access and export your information except where you have consented to forego access during the course of a research study;
- The right to request that we delete your information. We will honor this request where technically feasible and with respect to future uses and disclosure unless deletion is prohibited by law or we are required to retain information as necessary for study integrity.
- The right to be notified in the event of an IAS incident impacting your information.

You may exercise your rights by either contacting the research study team as described in the research consent form or by contacting the privacy officer whose information is listed below.

### **Prohibition on Use to Assert Claims Against the Individual**

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Individually Identifiable Information cannot be accessed, used, or disclosed by Yale to assert any type of claim against you, except for the collection of disclosed and agreed-upon service fees.

### **Updates to This Notice**

We may update this Privacy and Security Notice from time to time. The current notice is publicly accessible on our website <https://privacy.yale.edu>

If we make a Material Change to how information is accessed, used, or disclosed we will update the document on the website and provide notice to enrolled individuals using the communication preferences you have provided to us. We will clearly describe the specific changes made so you can readily identify the changes.

### **Questions and Concerns**

If you have questions about this notice you may contact the Yale Privacy Officer at:

Yale University Privacy Office  
PO Box 208255  
New Haven, CT 06520  
203-432-5919  
[privacy@yale.edu](mailto:privacy@yale.edu)