



Internal Data Access Agreement

Before you can proceed to the main COPD Gene web-site page (with data), please read and sign this agreement.

1. Confidentiality and Privacy of Subjects

I have been granted access to the COPD Gene website to enter data (Coordinators) or to obtain study information or data (Investigators).

I certify that all data (genetic, imaging, phenotypic) obtained from COPD Gene will be used in a manner that protects the privacy and confidentiality of the subject participants.

An Investigator will not attempt to use data from this website or from any other COPD Gene source to identify subjects, to link specimens or data to personal information that is readily identifiable, or to contact COPD Gene subjects with respect to their specimens, CT images or data unless those COPD Gene subjects are from the Investigator's own clinical center and the IRB from that clinical center approved contact of the subject.

Contact of subjects by clinical coordinators or other study staff will be made in accordance with local IRB approvals.

2. Restricted Use of Data

I certify that all data obtained from COPD Gene will be used for research purposes only and at this institution only. The data will not be allowed to come into the possession of any other persons except those engaged in research under my direct supervision who accept these restrictions. I will store de-identified datasets securely on password protected computers. Potentially identifiable data such as genetic data are to be stored preferably only on desktop computers but if stored on mobile devices like hard drives or laptop computers, those data shall be encrypted.

3. Publications and Acknowledgement of COPD Gene Support

I have reviewed and agree to follow the COPD Gene Publications Policies and Procedures for publications that incorporate data from the COPD Gene database and to acknowledge COPD Gene in all publications and presentations of studies utilizing data from COPD Gene. I will submit all publications and abstracts generated from COPD Gene data to the COPD Gene Publications Committee for review and approval prior to submitting for publication.

4. Agreement with COPD Gene Policies

The data must be destroyed if requested by the COPD Gene Executive Committee. De-identified datasets are not time limited unless the COPD Gene Executive Committee requests data destruction.

The COPD Gene Executive Committee will be notified within twenty-four (24) hours of the user becoming aware that there has been any unauthorized data sharing, breaches of data security, or inadvertent data releases that may compromise subject data confidentiality.

The COPDGene data, in whole or in part, may not be sold to any individual at any point in time for any purpose. I will not enter into an agreement with any other entity to provide the data in return for monetary compensation, data or any of other items of value.

An investigator may not move the COPDGene data from one institution or company to another, in whole or in part, without the written approval of the COPDGene Executive Committee.

Analysis of the COPDGene data must conform with subject consent groups for genetic studies. Some COPDGene subjects have agreed to allow use of their genetic information into any disease, while others limited their sample use to smoking-related disorders.

My typed signature signifies my agreement with all of the above.

Signature

Date (mm/dd/yyyy)