



Global Lung Function Initiative

Data Sharing Agreement June 6, 2017

The Global Lung Function Initiative (GLI) has collected respiratory function outcomes from researchers and health care professionals from around the world. The GLI Network administers the lung function data repository, whereas the data are securely stored by the European Respiratory Society (ERS). All data are managed and stored according to current international best practice.

Collaborators who wish to contribute data to GLI Network must have one representative sign and submit a data sharing agreement.

Representative Name

Institution

I confirm that these data were collected in accordance with institutional ethical review board guidelines, and that all participants gave informed consent to collect their data for research purposes. I confirm that an ethics committee or similar organizations have given permission for the data provided to be shared with the GLI Network. In addition, I confirm that all investigators associated with these data have agreed for them to be shared with the GLI Network.

I agree to the terms and conditions listed within this document and confirm that all data sent to the GLI network will be anonymised prior to submission.

Signature

Date



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**The GLI Network is a Clinical Research
Collaboration supported by the ERS**

The GLI Network includes:

The GLI Executive Committee is the highest level committee within the GLI Network and associated GLI Task Forces. The GLI Executive Committee acts as custodians of these data and is responsible for the review and development of lung function references ranges, and other relevant projects, derived from this data as appropriate. The committee purpose is to oversee the management and strategic direction of the GLI network to enable it to achieve its strategic vision, goals and priorities.

The GLI Scientific Review Committee (SRC) will be a permanent subcommittee of the GLI Network. The GLI SRC will be tasked with developing policies and governance and provide advice to the GLI Executive on access and research issues related to the new and existing GLI data. In addition anyone who has contributed data to a GLI project, those involved in the management and/or analysis of data, or those with a general interest in the activities of the GLI Network, can become a member of the GLI Network.

Data acquisition

Any person, group or non-commercial organization that has collected lung function data is welcome to contribute data for inclusion in the GLI Repository provided it meets the following inclusion criteria:

- Data are anonymous and assigned unique IDs
- There are at least 50 subjects.
- Essential demographic and anthropometric data are recorded for each subject (e.g. age, sex, height etc.)
- Informed consent was used to collect the data. Subjects recruited after the signature of this agreement must have specifically consented for data to be shared with third parties outside of the institution not only for use within the GLI Network but as well by any other third party without restriction. Subject must have also consented not to be informed about research results generated through the use of their data.
- Ethics committee or similar regulatory body have given permission for the data shared with the GLI Network.

Data ownership

The person, group or organization that has undertaken data collection will remain the owner of the data, with all rights arising from that, unless agreed otherwise. By sharing data with the GLI Network, the contributor agrees that their data may be used by the GLI Network to allow for exploration and the generation of new ideas or explore internal questions.

Under no conditions, data could be sold to third parties for commercial purpose. However, the GLI Network Executive retain the rights to claim access right fees for making the data available to third parties. The amount of the fees would be aimed at supporting the work of the different involved parties but not to make profit.

Data management

The hosting of the GLI Network data will be under the responsibility of the European Respiratory Society (ERS) until further notice from the ERS Executive Committee using the current database and electronic data collection system. Further development of the system will be managed by the GLI Network Executive. The ERS will make the explorable dataset available to members and/or third parties that includes the use of the data for publications and new research projects without seeking additional permission from data owners, whenever access is granted by the GLI Network Executive. The development of new research projects using the combined dataset will be coordinated by GLI Network in partnership with the ERS.

The GLI Network Executive will be responsible for the GLI data quality control and therefore the GLI Network reserves the right to exclude data from the final data repository (e.g. clear outliers). If questions arise about details of a dataset, these will be resolved by contact between the GLI Network SRC and the owner of the data. For security, all data will be stored on a secured, password protected network, with access restricted to those who have been approved to use the data. The GLI Network Executive will be responsible to grant the access to the electronic data collection system.

Publication

We encourage any results arising from the GLI Network data to be published in peer-review journals and/or as abstracts at the European Respiratory Society International Congress and/or other local and international meetings. We kindly request that The GLI Network be acknowledged, as well as ERS in all publications.

Please forward all publication details to the GLI Network to be posted on www.lungfunction.org.



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