American Thoracic Society
Policy on Use of ATS Member Data

Introduction

As ATS becomes more sophisticated with its collection, storage and management of data the Society may be approached for access to this information. Such requests could come from ATS members, others in the medical community, government entities, members of the media, industry, and others as well.

The ATS Data Use Policy, outlined below, complies with the ATS Privacy Policy as well as government regulations, such as the European Union's General Data Protection Regulation. It is subject to change based on revisions of the applicable laws.

Sources of ATS data

Almost every department at ATS collects various types of personal information as part of their work. These departments include:

- Assemblies and Committees
- International Conference
- Development
- Documents and Officials Statements
- Education
- Ethics and COI

- Finance
- International Programs
- Journals
- Membership
- Public Advisory Roundtable
- Research Program

Types of data collected

The types of data collected will vary, depending on the department and need, but can include:

- Personal data (name, work or office address, phone number, email address, gender, race, ethnicity, etc.)[1]
- Professional data (employer, job title, employment history, work address, areas of interest, etc.)[2]
- Disclosures of industry payments and relationships for conflict of interest (COI) management
- Conference related data (sessions attended, exhibitors visited, response to ARS questions, etc.)
- Professional accreditation data (CME, MOC, nursing CE)
- Credit card information [3]
- Associated Metadata derived from the input of information stated above, and interactions with any ATS operated systems (such as user access logs, machine statistics, IP addresses etc.)

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[1] All personally identifiable data is subject to applicable laws and regulation and will be stored for the duration the ATS deems necessary within the limits of said legal requirement regulation and in accordance with the ATS Privacy Policy.

[2] Ibid.

[3] Credit Card information will be collected with the intent of processing via approved 3rd party vendors ATS will not retain or store this data.

Use of data for external purposes

This policy is intended to govern the use of ATS-generated data that is used for external purposes. That is to say, it will appear in publications, handouts, on one of the ATS websites, etc.

No data of any kind that can be linked back to an individual will be made available. Aggregated, anonymized data related to the following categories will be made available:

- Membership
- Conference attendance and activities
- ATS activities – including committees and assemblies
- Journal activities

Data Access Policy

It is important that ATS data only be used for legitimate purposes that help advance the Society and its mission. Therefore, a subcommittee of the Planning and Evaluation Committee, the **Data Subcommittee,** will screen each request to obtain data, similar to how the Survey Subcommittee has worked to date. The Data Subcommittee will consist of a) the Chair of the Planning and Evaluation Committee or a designated surrogate, b) a member of the Executive Committee, and c) the Chair of the Behavioral Science and Health Services Research Assembly or a designated surrogate.

It will be staffed by the Sr. Director of Information Strategy and Management.

The Data Subcommittee will operate under the general principle that the use of ATS data should be conducted as part of official ATS projects. Therefore:

1. Individuals who want to use ATS data as part of their personal, non-ATS-related research will not be allowed.

2. Assemblies (including their working groups and interest groups) and committees that want to obtain ATS data should submit an application through the annual Program Review Subcommittee (PRS)-led process.

3. Assemblies (including their working groups and interest groups) and committees that want to access data as a needs assessment to inform a PRS application should submit a request to the Data Subcommittee and, if approved, will only be allowed to use the data within the subsequent PRS application (i.e., it should not be published).

4. Other needs, such as government advocacy, membership, or peer society initiatives etc. require a request to the Data Subcommittee for case-by-case consideration.

The Data Subcommittee has the authority to reject any data request.

Specific steps to obtaining approval to access ATS data

1. Investigators should submit a brief (abstract length) summary of a) the specific data they are requesting and b) the rationale for the data request to Stephen Altobelli at: saltobelli@thoracic.org who will send the request and accompanying materials to the Data Subcommittee for review.

2. Feedback and requests for revisions will be sent to the investigators by the Data Subcommittee. The investigators should make any changes suggested or required and then re-submit the revised request. Several cycles of review and revision may be necessary.

3. If the subcommittee rejects the request, the investigators will be notified. If the request is approved, the Chief of Operations will coordinate with ATS staff the collection and distribution of the data.

4. The request, and subsequent datasets, will be stored at ATS for as-needed future reference and safekeeping.

For further information, please contact Stephen Altobelli, Chief, Operations (saltobelli@thoracic.org) or Doron Ben-Avraham, Senior Director, Information Strategy and Management (dben-avraham@thoracic.org).

Use of member data for internal ATS purposes

Specific member data, including race and ethnicity, cannot be presented in any generalized online format without explicit individual permission, due to various international and national privacy laws. Therefore, even data that is requested and used solely for internal planning purposes, for example, developing new educational products, making more informed decisions regarding future conference programming, committee assignments, or special ad hoc task forces or work groups, will be subject to a modified access process

The ATS member application/renewal form and the conference registration form now include an opt-in data sharing provision that allows ATS leadership to identify members based on ethnicity and gender. This member data will not be shared unless the permission option is checked. The specific language is as follows:

Ethnicity and gender-related approvals

ATS is committed to fostering diversity and inclusion across all ATS activities and events. We invite you to indicate with which of the following groups you identify and how you describe yourself. This information helps ATS evaluate current practices and determine areas for improvement. We will use the information internally to populate committees, for programming conferences, improving assembly diversity and committee assignments and to set up special projects/taskforces.

With your consent, we may also share this information and your contact details with ATS members who wish to contact colleagues that meet specific criteria.

Providing this information is voluntary, but we hope you will assist us in our efforts.

Ethnicity *	Gender *
Select	Select

☐   By checking this box, you signify your consent to ATS processing the above demographic information internally to populate committees, for programming conferences, improving assembly diversity and committee assignments and to set up special projects/taskforces.

☐   By checking this box, you signify your consent to ATS sharing the above demographic information and your contact details with ATS members who wish to contact colleagues that meet specific criteria.

- Through the Membership Directory, the general ATS membership (and only members) will have access to the following member data:

  - ATS ID
  - Name
  - Company/Institute
  - Phone
  - Email Address
  - Primary Assembly
  - Secondary Assembly
  - Board Certification
  - Specialties
  - Work Settings
  - Country of Residence