Review Article

The European Society of Thoracic Surgeons (ESTS) thymic database

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Abstract: The European Society of Thoracic Surgeons (ESTS) thymic database is a satellite database of the ESTS registry collecting patients with thymic tumors (thymomas, thymic carcinomas and neuroendocrine thymic tumors) among the ESTS Institutions. The database is free of charge for any ESTS member, easily accessible to any ESTS institution, web-based, prospective, periodically maintained and updated. It may serve as an institutional database for the storage of data about patients with thymic tumors at no cost for each participating institution. It may be used by any ESTS member to propose studies using one of the largest thymic databases worldwide. The present review focuses on the history and the development of the ESTS thymic database (retrospective and prospective) and its structure with a particular reference to the concept of the minimum dataset and the Clinical Care Analysis (CCA) box. A brief overview about the role of the ESTS thymic database in the global effort for the new TNM staging system of thymic tumors is also provided. In the supplementary, there are clear instructions to get access to the thymic database using the ESTS official website. The ESTS thymic database represents a powerful tool available to all ESTS members which can be used for studies on the management of these rare tumors.

Keywords: Database; thymus neoplasms; European Society of Thoracic Surgeons (ESTS)

Submitted Dec 28, 2017. Accepted for publication Apr 16, 2018.
doi: 10.21037/jtd.2018.05.09
View this article at: http://dx.doi.org/10.21037/jtd.2018.05.09

Introduction

The European Society of Thoracic Surgeons (ESTS) Database was established in 2001 as an attempt to collect the experience about thoracic surgical procedures for lung cancer among ESTS members. The initial number of participating centres was limited but the project encountered an unprecedented enthusiasm and the number of procedures has steadily increased over the years. The last report in 2017 included more than 110,000 patients from 240 units, 145 of which contributing with more than 100 procedures.

Due to the positive feedback from the participating institutions, the core dataset (Lung Cancer Registry) was progressively implemented with some satellite databases dealing with other thoracic diseases and procedures.

The Thymic Registry was introduced in 2013 with the intent to provide an up-to-date, online prospective platform for the collection of the claims and EMR (electronic medical record) data of patients with thymic tumors among the ESTS members. The thymic registry is supervised by the ESTS thymic working group and by the ESTS Database Committee, and it is supported and periodically maintained by KData Clinical, the official platform of the

ESTS Registry.

The present review will include:

- A brief history of the development of the ESTS Thymic Working Group and the ESTS Thymic database.
- A description of the structure of the ESTS Thymic Prospective Database.
- An overview of the collaborative projects between the ESTS Thymic Database and some international associations dealing with thymic tumors (ITMIG, IASLC).

History of the ESTS thymic working group and the ESTS thymic database

The ESTS Thymic Working Group was approved and instituted by the ESTS Council in 2010 with the intent of creating an interest group of people in the ESTS dealing with thymic tumors. After the publication of a survey among the ESTS thymic community about the current practice in the management of thymic tumors (1), the first major project of the group was to set up a thymic retrospective database open to all interested ESTS institutions. The feedback from the ESTS community was enthusiastic and we were able to collate more than 2,000 patients treated from 1990 to 2010 from 35 institutions, mostly from Europe but also from Asia and North America. The ESTS thymic retrospective database constituted the largest thymic database ever collected at that time. The analysis of the results on the overall population of patients with thymic tumors (2) and the subgroup analysis on thymic carcinomas (3) were published and presented at international conferences. Since then, a number of studies using the retrospective ESTS thymic database alone or in cooperation with other international thymic databases were published and presented at ESTS and other international meetings, representing important contributions to the advancement of the knowledge of these rare tumors (4-7).

The limitations of the retrospective collection of data with the unavoidable selection and treatment biases led us to consider the creation of a prospective database. The ESTS Council approved the budget for the setup of an online prospective thymic database using the official ESTS platform and in 2013 the thymic database was the first satellite database to be included in the ESTS Registry.

The participation to the ESTS prospective thymic database is strongly encouraged among all ESTS Institutions. Following agreements with other major International thymic organisations, no competition exists with other international thymic datasets and ESTS members are therefore encouraged to upload their patients with thymic tumors into the ESTS thymic registry using the credentials provided by KData Clinical (the official ESTS platform). Instructions how to get access to the ESTS thymic database is provided in the present review (supplementary). It is noteworthy to emphasize that each participating institution can use the ESTS prospective thymic database as its internal database, at no costs. The ESTS thymic registry is periodically updated (the present format was introduced in 2015) and subject to a yearly maintenance (usually at the end of the year). The results of the thymic database are published as a separate section every year in the ESTS Registry Report (Silver Book). The thymic report is also available in the ESTS website for all ESTS members.

One of the most interesting aspects of the thymic database is the possibility for each contributing Institution to propose studies using the data from the thymic registry. We strongly encourage each contributor to propose new studies using the ESTS thymic prospective dataset. This would be an excellent opportunity for young researchers to make important contributions to thymic research using one of the largest thymic databases in the world. A study draft should be sent to the ESTS Thymic Working Group Steering Committee and to the ESTS Database Committee. The draft will be discussed by the Committees and in case of acceptance, the contributor will receive the data for the study. Our co-authorship policy includes that one person from each center which substantially contributed to the ESTS thymic registry will be included in any manuscript submitted using the ESTS thymic database under a list linked to PubMed.

Finally, the ESTS thymic database played a fundamental role in the development of the 8th edition of the TNM classification of thymic tumors (8) under the coordination of the IASLC Staging and Prognostic Factors Committee (SPFC). Details about the cooperation between ESTS and other major international organisations for the study of thymic tumors will be provided in the last section of the present review.

The structure of the ESTS thymic prospective database

The current platform of the ESTS thymic prospective database is effective since 2015, replacing the initial

Table 1 ESTS thymic minimum dataset—minimum standard data fields to be completed for data analysis

Gender (male/female)
Date of birth
Date of surgery
Paraneoplastic associated syndromes (MG, etc.)
Final pathologic diagnosis (thymoma, thymic carcinoma, NETT)
WHO histology
Thymic carcinoma histology
NETT histology
Pathologic Masaoka stage
Final pathologic resection status (R0, R1, R2[§])
Pathologic TNM stage (IASLC/ITMIG staging, 8th Ed. TNM)
Outcome at discharge (alive/dead)
Chemotherapy (intent, date initiated)
Radiotherapy (intent, date initiated)
Date of death or last follow-up date
Vital status

[§]: R0, complete resection; R1, incomplete resection (microscopic); R2, incomplete resection (macroscopic). ESTS, European Society of Thoracic Surgeons; MG, myasthenia gravis; NETT, neuroendocrine thymic tumor.

format. The structure includes an introductive section with demographic data which gives access to the Electronic Medical Record (EMR) data sections.

There are four EMR data sections, preoperative, intraoperative, postoperative and follow-up.

The preoperative section includes two subsections: risk factors (comorbidities), and diagnosis & staging. In the diagnosis & staging subsection, detailed information about the presence of associated paraneoplastic syndromes and characteristics of imaging reports (CT scan, RM and PET scan) are included, based on the ITMIG terminology for radiology reports (9). The staging subsection contains information about the clinical and pathologic staging according to Masaoka-Koga (10) and the IASLC/UICC/AJCC 8th edition of the TNM classification (8).

The intraoperative section includes one subsection where information about the type of the procedure, the final pathologic diagnosis and the resection status are indicated.

The postoperative section includes two subsections: perioperative treatments and outcome. In the perioperative treatment subsection information about the use of chemotherapy and radiotherapy is requested, including the intent (induction, adjuvant, palliative) and the date initiated. In the outcome section, the date of discharge and the outcome at discharge are indicated.

Finally, in the follow-up section there are information about the date of last follow-up, the vital status and the recurrence status.

The number and types of data fields in the thymic registry make it likely that not all information can be uploaded at the same time. It may happen, for example, that the patient demographics and some basic operative information are initially uploaded, while the histologic and perioperative information need to be added later on, when histology becomes available.

One of the most crucial aspects of any prospective database is the completeness rate of the data fields, which may vary from as low as 20% to as high as 90%. The process of completing the missing data fields is sometimes tedious if all data fields are treated as equally important. There are however some data fields which are of particular importance for the analysis. For this reason, we introduced the concept of the "minimum dataset", which includes a limited number of data fields (N=16) which are considered essential in order to analyse the patient record. The list of the essential data fields is indicated in *Table 1*. The minimum dataset includes essential information about demographics (gender, age), preoperative EMR (associated paraneoplastic syndromes), intraoperative (histology, final diagnosis, resection status, staging by Masaoka and TNM), postoperative (perioperative treatments, vital status, date of last follow-up).

Another interesting resource of the ESTS thymic database is the dashboard or Clinical Care Analysis (CCA) where each contributor can have a visual evidence of the data in form of bar graphs for some essential data fields. Also, the completeness rate for each data field of the minimum dataset is shown in the CCA.

The international collaborative projects involving the ESTS thymic database

After a period of relatively tepid interest for the thymic neoplasms at the end of the last century, the last decade has witnessed a tremendous surge of enthusiasm in these rare tumors. The milestone in this process was the creation in 2010 of the International Thymic Malignancies Interest Group (ITMIG) with the aim of gathering individuals from different disciplines (surgery, radiotherapy, chemotherapy, pathology, radiology) and providing them the necessary infrastructures and platforms to advance the research in the diagnosis and treatment of thymic tumors (11). ITMIG produced an impressive amount of contributions about the definitions of standard terminology in outcome (12), pathology report (13), minimally-invasive techniques (14), imaging reports (9).

Along with ITMIG, many regional interest thymic groups were created, mostly associated with national or international societies. Among these, the most important are the Japanese Association for Research on the Thymus (JART), the Chinese Alliance on Research in Thymomas (ChART), the Korean Association for research on the Thymus (KART), the Réseau Tumeurs THYMiques et Cancer (RYTHMIC). All these organisations have large thymic databases, although the only online, web-based, prospective thymic databases so far are the ITMIG, ESTS and RYTHMIC databases.

ESTS and ITMIG have long been working together for the harmonization of their thymic databases. The ESTS and ITMIG retrospective databases were fairly compatible in terms of data fields and definitions. This resulted in a considerable number of common projects and studies and in the publication of several papers using both databases (4,5). The collaborative work between ESTS and ITMIG has recently produced a landmark result, that is the harmonization of both prospective databases as regards to the minimum dataset, which are now identical in terminology, wording and type of data fields. This will certainly facilitate any future common project between the two Organizations.

The International Association for the Study of Lung Cancer (IASLC) launched in 2010 the Staging Project for the release of the 8th edition of the TNM classification of the thoracic tumors. For the first time in history, the IASLC Staging and Prognostic Factors Committee (SPFC) decided to create a thymic staging domain with the aim of proposing a TNM staging system for the thymic tumors. The thymic domain asked the major thymic interest groups worldwide to collaborate in the data collection. The ESTS promptly replied and contributed with the data from its retrospective thymic database. The results of this extraordinary collaborative effort involving ITMIG, ESTS and JART was the creation of an impressive retrospective thymic database with more than 8,000 cases which allowed to formulate the 8th edition of the IASLC/UICC/AJCC TNM classification of thymic tumors (8).

After the completion of the 8th edition of the TNM, the IASLC SPFC is now working at the next phase of the Staging Project which will eventually lead to the release of the 9th edition of the TNM expected in 2024. ESTS will certainly provide the necessary support to the project with its prospective thymic registry which contains more than 1,100 patients as of November 2017.

Conclusions

The ESTS thymic database represents a fundamental storage of information about patients with thymic tumors. It is free, easily accessible to any ESTS institution, web-based, periodically maintained and updated. Any participating Institution can have access to its own data and it can also be used as internal database for any study using your own data. Any participating Institution can propose a study using the data of the whole database and, upon acceptance from the ESTS Database Committee, it can receive the data for the analysis. We believe that the ESTS thymic database represents an invaluable source of data to be used by the ESTS community for important studies in the advancement of the management of thymic tumors.

Acknowledgements

None.

Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

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Cite this article as: Ruffini E, Falcoz PE, Guerrera F, Filosso PL, Thomas P, Novoa N, Moser B, Pellicano D, Passani S. The European Society of Thoracic Surgeons (ESTS) thymic database. J Thorac Dis 2018;10(Suppl 29):S3516-S3520. doi: 10.21037/jtd.2018.05.09

Instructions for access to the online ESTS thymic prospective database

Eligibility criteria: ESTS active member (ESTS membership status is checked before providing database credentials).

(I) Log in at http://www.ests.org;
(II) Click on “Collaboration” → European Database;
(III) Click on “Database Registration Form” → Registration Form;
(IV) Download the Registration Form;
(V) Complete the form with the required information and send it to the addresses provided (KData Clinical Administrators);
(VI) You will receive the credentials for your institutions for logging into the database;
(VII) Direct access to the ESTS Registry: log in at https://ests.kdataclinical.it.

Once logged into the database:

(VIII) Click on “Search/Add” → “Add new patient”;
(IX) You need to complete the fields with the demographics data;
(X) Then you will see a menu with the thymic sections (Preop Thymus, Op Thymus, Postop Thymus, F.up Thymus);
(XI) Start completing the fields;
(XII) The mandatory fields (i.e., the minimum dataset fields) are highlighted.