

A country wide adaptation of the European Society of Thoracic Surgeons lung cancer core database: the Hungarian model

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Background: Registering details of thoracic surgical activity has a long tradition in Hungary. Implemented first as a procedure based register, characteristics of the treatment, complications and outcomes has been noted for the last three decades. Although the limitations of the used database hindered the scientific analysis in the dataset and restricted the possibility of benchmarking. The European Society of Thoracic Surgeons (ESTS) database is offering a specialty-specific, procedure-specific, web-based electronic database for data contribution enabling international comparisons. Our aim was to accommodate and implement the ESTS database as the new Hungarian national thoracic surgical registry.

Methods: In 2014, cooperation of the ESTS Database Committee and the Hungarian Society of Thoracic Surgery evolved a new structure for contributing national thoracic surgical data, called the ESTS database “Hungarian model”. The European dataset was translated into Hungarian, extended questionnaire and continuous data access helped the completion of the dataset. The “Hungarian model” was incorporated into the common practice of all the thoracic surgical centers in Hungary.

Results: In the first year of its implementation the “Hungarian model” of the ESTS dataset became the platform to use for contributing thoracic surgical data in Hungary. All the data included in the dataset were completed and periodically analyzed to form the annual Hungarian report (“the Hungarian Silver Book”). The dataset is permanently accessible for national scientific analysis and serves as a basis for quality improvement intentions.

Conclusions: The Hungarian model proved to be able to serve as a national database. The complete dataset of the thoracic activity has become eligible for scientific analysis and international benchmarking, highlighting the most important core messages of the ESTS database project of improving quality and patient safety thoracic surgeons. By creating a framework for a national registry the system is incorporating an alternative for other thoracic surgical societies.

Keywords: Thoracic surgery; registries; database

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Introduction

Recording patient data has the potential to elevate the quality of healthcare delivery meanwhile giving improved clinical decision support, disease surveillance, and population health management (1). Center based registers are driven by mandatory requirements which track disease characteristics, patterns of care, and treatment outcomes in well-defined populations; advantages of using national registry include wide geographic reach regardless of treating facility and better external validity excluding referral biases associated with institutional systems (2).

Hungary has long history of collecting and recording patient data of thoracic surgical activity. In the early 1980's, Professor Frigyes Kulka (*Figure 1*) established the first Hungarian national thoracic surgical register as an initiative for quality improvement and patient safety among Hungarian thoracic surgeons. Working at the National Korányi Tuberculosis and Pulmonological Institute he initialized and organized the contribution and analysis of patient data involving all 13 individual thoracic surgical centers in Hungary. The evoking aims of the register were—apart from monitoring the national thoracic surgical activity—creating the background for national benchmarking, assuring quality of treatment and the potential for national scientific analysis (3,4).

The initial system of data collection was organized along surgical preferences assessing the number of different pathologies and surgeries performed by each individual center. The procedure-based dataset included the summary of complications occurred and co-morbidities with their effect on hospital stay.

During three decades of collection the circumstances of data contribution changed and the initial system has gone through several evolution steps following its introduction. The first paper based reports became computerized, and text format was converted to spreadsheet version enabling easier scientific work-up of the results. National standards were recently expanded by the European guidelines followed the need and the obligation of international benchmarking (5). The use of a procedure-based register restrained the spectrum of statistical analysis as some of the patient-based calculations were not computable that way (6). Meanwhile the need of an online contribution platform became not only important but preferred, attributing major security issues on the other hand exceeding the professional sight of a physicians' society dealing with an overgrown structure of precisely designed registry of expanded thoracic



Figure 1 Frigyes Kulka.

surgical activity. The inevitably important upgrading of the Hungarian thoracic surgical register met the idea of the European Society of Thoracic Surgeons (ESTS) database implemented in the last decade. The appreciably extending, well organized European system endorsed the capability to deploy important attributes lacking in the Hungarian register being a voluntary specialty-specific, procedure-specific, prospectively maintained, periodically audited and web-based electronic database, collecting data of all general thoracic procedures (7). The system of the European society has been proven to maintain the dataset of an individual thoracic surgical center, but its structure projected the potential to become a nationwide database host. After careful consideration of the possible harmonisation of the Hungarian register and the ESTS database registry a vision of a hybrid structure evoked gaining all the advantages of the European registry formed according to the needs of the Hungarian thoracic centers.

Methods

In 2014 collation between the society of the Hungarian thoracic surgery and the database committee of the ESTS with cooperation of the Dendrite Clinical System Italia srl created a new structure of data contribution and access system dubbed “the Hungarian model”. This new structure gained benefits of the ESTS data registry broadened

Table 1 Characteristics of the Hungarian thoracic surgical activity between 2014 and 2016

Year	2014	2015	2016
Number of surgeries	4,864	4,919	5,186
Lung resections	2,764	2,885	3,037
Primary lung cancer cases	1,668	1,722	1,860
Percentage of VATS in lobectomies (%)	33.0	40.18	41.1
DLCO (%)	11.6	12.2	19.7

DLCO, diffusing capacity of the lungs for carbon monoxide.

with three attributes added to enhance its use as national database:

- (I) The possibility of data contribution and access in Hungarian, to dismantle language barriers arising at data upload. The aim was to better control the provided data quality and reducing the administrative obligations of the physicians including administrators in data management.
- (II) Expandable questionnaire based on national interest. Including viewpoints in the database requested by the native Society of thoracic surgeons helps to form the national dataset. The long history of the Hungarian data registry needed to be continued in some areas which were not completely covered by the European dataset.
- (III) To gain more advantage from a web-based database system a 24/7 data access was proposed to enhance untrammelled and faster data management.

Results

The Council and the Database Committee ESTS accommodated the new structure of data registry and gave professional help for the fast implementation in Hungary. All the expressions and information of the dataset were translated into Hungarian and embedded by the Dendrite Clinical System Italia srl into the European dataset. All the Hungarian thoracic centers received individual login tools, and physicians with Hungarian allocation could face the translated ESTS registry dataset supporting the use in the native environment.

Starting the Hungarian model

After constructing the ESTS “Hungarian model” in 2014 the Hungarian society of thoracic surgery started

subsequent establishment of the new registry in the everyday use. Data uploads of the individual centers were assisted and supported, in regular thoracic surgical meetings academic and personalized help was available. Getting accustomed to the spirit of the European system continuous data contribution was emphasized. In the first year of implementation the complete annual national dataset was uploaded to the ESTS database. A complacency questionnaire among the Hungarian thoracic surgeons revealed, that 72.2% of the society members considered the new contribution system as clear cut and logical, 77.8% welcomed the online platform, and 50% suggested to improve the uploaded data access.

Table 1 contains some of the key numbers of the Hungarian thoracic surgical activity in the last three years. The results expectedly matching the European average but in some aspects there are positive and negative anomalies. As an example, the indicators of the Hungarian VATS interventions are exceeding European national average (33.0–41.1% *vs.* 12.9–29.3%), but the prevalence of the preoperative diffusing capacity of the lungs for carbon monoxide (DLCO) lags markedly behind the international mean (19.7% *vs.* 55.43%). The detailed annual analysis of the latter data shows an improvement in the last three years after the first results of the “Hungarian Model” were revealed.

Management of the Hungarian model

Data contribution and access are individually managed by the institutions. Annual deadline for contributing all patient data is 31th December of each year, parallel to the ESTS database terms of use. Completeness of the institutional dataset is the obligation of the contributing center; the following cumulative analysis builds upon the submitted patient data. Statistical work up is provided by the Kdata Clinical srl (former Dendrite Clinical System Italia srl)

according to a bilateral consensus, the viewpoints of analysis are led by the manner of the European database (“Hungarian Silver Book”). The complete sets of data are incorporated into the ESTS database for further workup. Institutions have 24/7 unrestricted data access to their own activity, the summary of the complete national database is controlled by the assigned national ESTS regent. On request with the permission of the leadership of the Hungarian society of thoracic surgery the complete national data are accessible for scientific analysis.

Discussion

With the construction of the “Hungarian model”, we gained a new system combining the favours of a European registry and the interest of a national database. The translated dataset, the expandable questionnaire and the continuous data access for analysis turned the ESTS database a welcomed platform for the Hungarian thoracic surgical centers.

Benefits of the ESTS Hungarian model

Implementing the ESTS Hungarian model has certain positive impact not only at the local patient management, but on national and international level. Apart from the opportunity to participate in a European quality improvement effort for general thoracic surgery there are well defined practical benefits. The vernacular ESTS database can provide a thematically well-organized web based patient registry containing all important key data of practice. The system enables the comprehensive analysis of individual cases, as well as cross section statistics (8). The focus of analysis can be adjusted from an individual patient, clinical condition or surgical intervention or the treating surgeon to a level of the whole center. Since there is a nationwide consensus in Hungary for contributing to the ESTS registry, there is immediate basis for national multi-level benchmarking. The performance assessment by risk-adjusted outcome and/or process indicators, allow comparing an institutional performance against national and international benchmarks (7).

Data for research projects can be used to assess new technologies/pathways of care that can ultimately lead to improved patient care and outcomes. Those data, collected in a standardized ESTS-endorsed Dataset, can be downloaded at local level and used for your internal quality analyses or institutional research purposes.

Measures taken since the use of the ESTS database Hungarian model

Feedback from the ESTS database composite score analysis had a clear message on national level indicating the need for extending DLCO measurements during the preoperative patient investigations. The hints of the European database could give a firm basis for individual center negotiations resulted in increased preoperative DLCO percentage. The improved circumstances and the fact, that the ESTS Hungarian model is used for more than 3 years successively, the majority of the Hungarian thoracic surgical centers could consider focusing on becoming applicant to the ESTS institutional accreditation program. Two-eleventh centers are already gained accreditation in the last years (Debrecen, Szeged) motivating all other future applicants to achieve elevated treatment quality control through the hints of the database. To enhance and ease up the efficacy of patient data record and contribution in the European registry measures are taken to create a nation-wide standardized documentation formula for thoracic surgical patients incorporating all viewpoints of the ESTS dataset proceeding from the tumor board records up to the follow up documentation of the patients.

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Footnote

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

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