

# Innovative Design of Tumor Registry Database Program for Musculoskeletal Oncology Service

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**Purpose:** To demonstrate an innovative program design which combines tumor registration and electronic health records that suit Thai orthopedic oncologist practice.

**Methods:** The Thai Musculoskeletal Tumor Society (TMTS) database program is a Microsoft Access database created for bone and soft tissue tumor services. Only significant parameters are recorded and all data forms are based on user-friendly concepts. Apart from exporting data to a web-based tumor registration, all input data will be utilized to facilitate complex oncology work such as printing out patient records or patient transfer forms, showing disease demographic data, retrieving particular case series, and post-operative time calculations with management planning.

**Results:** The TMTS database program was designed for new emerging orthopedic oncology units with limited resources to possess a standard tumor database for clinical use and to promote research collaboration between small and large tumor centers.

**Conclusion:** By adopting the specialty-specific TMTS database, we expected increases both in efficiency of tumor patient care and collaborative multi-institutional research.

**Keywords:** Thai Musculoskeletal Tumor Society, Tumor registry, Tumor Database, Electronic Health Record

**The Thai Journal of Orthopaedic Surgery: 39 No.1-2: 9-15**

**Full text. e journal:** <http://www.rcost.or.th>, <http://thailand.digitaljournals.org/index.php/JRCOST>

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## Introduction

Tumor registration is very useful in orthopedic oncology. It can provide information about quality of treatment and facilitate clinicians in choosing proper management. National or multi-national musculoskeletal databases have been initiated in many countries for more than two decades. Tumor records retrieved from national databases were applied to conduct clinical research and publish treatment guidelines based on their collective data<sup>(1,2)</sup>.

In 2011, the first version of the Thai Musculoskeletal Tumor Society (TMTS) registration system using case report forms commenced. Corresponding surgeons had to fill out the forms after their operation and send all of the papers to the RCOST (Royal College of Orthopedic Surgeons of Thailand) tumor subspecialty secretary by fax or email once a month. But after 6 months, there were very poor responses from participating institutes and the project was eventually canceled.

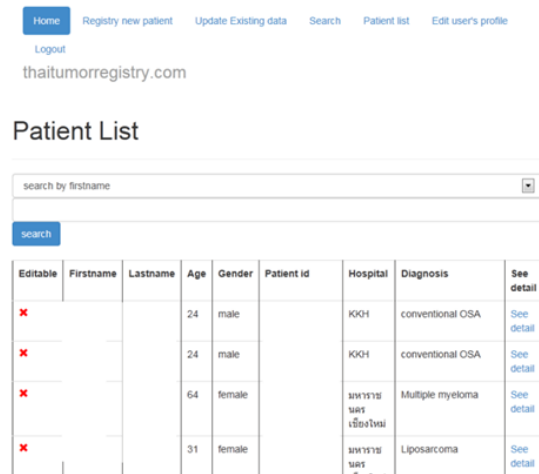
The causes of the first version failure were reviewed and it was found that many problems were related to the Thai orthopedic oncologists working context. There were thirty active members in 2011, of which twenty surgeons had completed their training less than five years previously and were obligated to establish musculoskeletal tumor services with insufficient support. They were in charge of all bone and soft tissue tumor cases in hospitals that resulted in long surgical waiting lists. To conclude, most of subspecialty tumor members had no time for extra paper work, no assistance and limited funding.

The second version of the TMTS tumor registry (Fig. 1), developed in early 2014, is a web-based registration system which aims to reduce time for sending reports and improves availability. Nevertheless, the other difficulties still remained, so database program development was proposed as a resolution. The main concept of the program is to create a database application which integrates the registration process into daily orthopedic oncology services without increasing any burden from additional paper work and also improve patient care efficiency.

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**Fig. 1** The second version of the TMTS tumor registry

## Materials and Methods

The TMTS database program is a Microsoft Access database which combines EHR (Electronic Health Records) and the registry system to work on the same platform. The program can be used for sending tumor data for registration on the web-based TMTS tumor registry and conducting clinical research. Overall features of the program were designed from orthopedic oncologists' working pattern which involves out-patient care, surgery, and multi-disciplinary conferences.

Having the requirement to input several parameters means a workload that needs more time or personnel to fill in. On the other hand, small clinical benefit can be gained from a database if there is little information in it. The TMTS database program contains only essential variables which were carefully selected; any issues or documents which are already recorded somewhere else in the hospital system and require a request to retrieve were not included. The physician can input a patient's clinical information similarly to standard clinical notes by following the on-screen textboxes and all necessary parameters will be collected. All input data will be utilized for supporting clinical

care so that the user will realize the advantages of the program and value of data completion.

The program has a user-friendly interface and can be operated by a single user. In general, there are only four textboxes that need to be filled out including date of visit, follow-up notes, diagnosis, and tumor location then other details can be completed later. It usually took less than 5 minutes to complete the form depending on the user's typing skills. If significant data is missing, it can be corrected on the next visit or while doing a case review.

In the orthopedic oncology field, there are two types of treatment outcome assessment, oncologic and functional. An oncologic outcome is the main result determined by disease progression status and survival time such as localized recurrence, distant metastasis, and disease-specific mortality. Oncologic outcomes can be recorded in the follow-up section of the program which can be turned into a dataset for further analysis. Functional score assessment is the secondary outcome which represents patient's quality of life and advantages of surgical reconstruction techniques. If functional outcomes are not assessed at specific times and functional data is missing, analysis of results may be difficult and unreliable. In contrast, collecting functional scores on every visit causes unnecessary paper work and wastes time. To solve this issue, the automatic tumor-type specific scheduling function of the program can remind both the physician and patient what and when should be done on each visit and avoid missing evaluations and early revisits because of incomplete investigation.

## Results

### *Patient identification section*

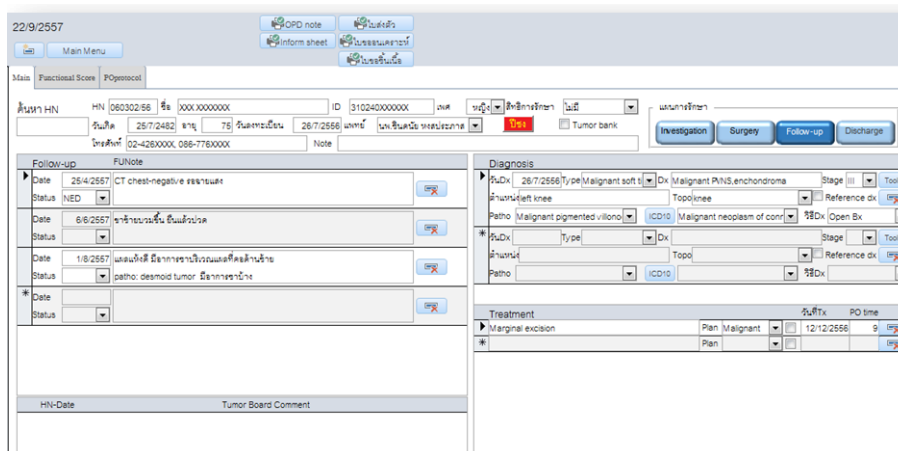
This section contains patient identification data including patient name, hospital number, national identification number, gender, birth date, registration date, healthcare plan, contact number, and corresponding doctor. The national identification number is an important detail because it can be used to check alive/dead status from central civil registrations and for referring patients between medical centers. (Fig. 2)

**Fig. 2** Patient identification section

**Medical records section**

The medical record section has three modules. (Fig. 3) The first module is the follow-up record including date of record, patient disease status [no evidence of disease (NED), alive with

disease (AWD), and died of disease (DOD)], and a free-style clinical record. The tumor board comment window is located below this section to display opinions from multidisciplinary meetings.



**Fig. 3** Medical record section

The second module is the diagnosis record which contains various tools for classifying a tumor and its location. In this part, there are both free-text records and a systematic international classification of disease (ICD) registration combo box for both pathology (ICD-O-3) and diseases (ICD-10CM) which automatically pop-up for selection when typing. Because of the complexity of ICD-10CM registration, an ICD helper button was created to assist inexperienced registrars to identify the appropriate ICD description for the disease by navigating through a different window which illustrates a list of tumor type-specific diagnoses. In addition, a staging tools button provides automatic TNM staging classification for bone and soft tissue tumors which is difficult to remember due to classification complexity. Other tools include

automated Tomita and Tokuhashi’s scores for prognostic prediction in cases of spinal metastasis.

The last module is treatment data which is used to record surgical treatment and select appropriate postoperative plans. The postoperative time will automatically be calculated from the date of operation. Treatment plan toggle buttons are located at the top. These buttons determine different plans of treatment (investigation, surgery, follow-up, and discharge). The names of patients and their information will be listed in surgical waiting or investigation lists according to their treatment plan. Patient names and contacts will be listed in the loss of follow-up list if they are on follow-up status, but do not come to the clinic for more than 365 days. Patients who have a discharge status will be excluded from the loss of follow-up list.

**Functional outcome**

The screenshot shows a software interface for functional scores. It features a table with columns: Date, Limb, Pain, Function, Emotion, S or H, W or D, G or L, MSTs, and TESS. The table contains data for dates from 01/06/2557 to 33. There are also buttons for 'TESS form Upper limb' and 'TESS form Lower limb'.

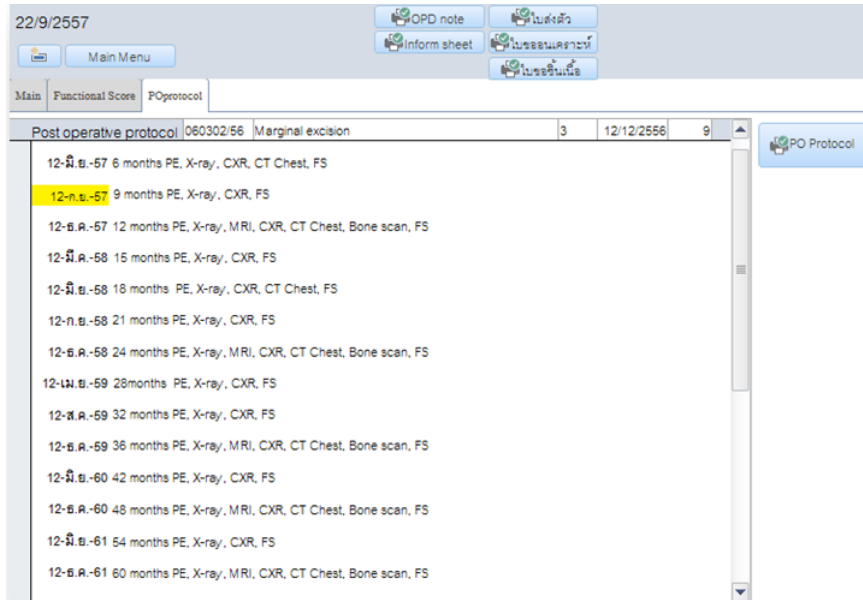
Date	Limb	Pain	Function	Emotion	S or H	W or D	G or L	MSTs	TESS
01/06/2557	Lower	4	2	2	0	1	2	1.8	4.4
02									
03									
04									
05									
06									
07									
08									
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33									

**Fig. 4** Functional scores

Two types of functional scores are available in the program for archiving. The MSTS score (Musculo-Skeletal Tumor Society score) is a clinician-oriented subjective score which assess pain, function and emotional acceptance. A Thai-translation of the TESS score (Toronto Extremity

Salvage Score) for upper or lower extremities are available in an electronic and paper form by clicking on the button beside an electronic form to print questionnaires to be given to the patient for self-assessment just before coming back on following visits. (Fig. 4)

**Post-operative protocol**

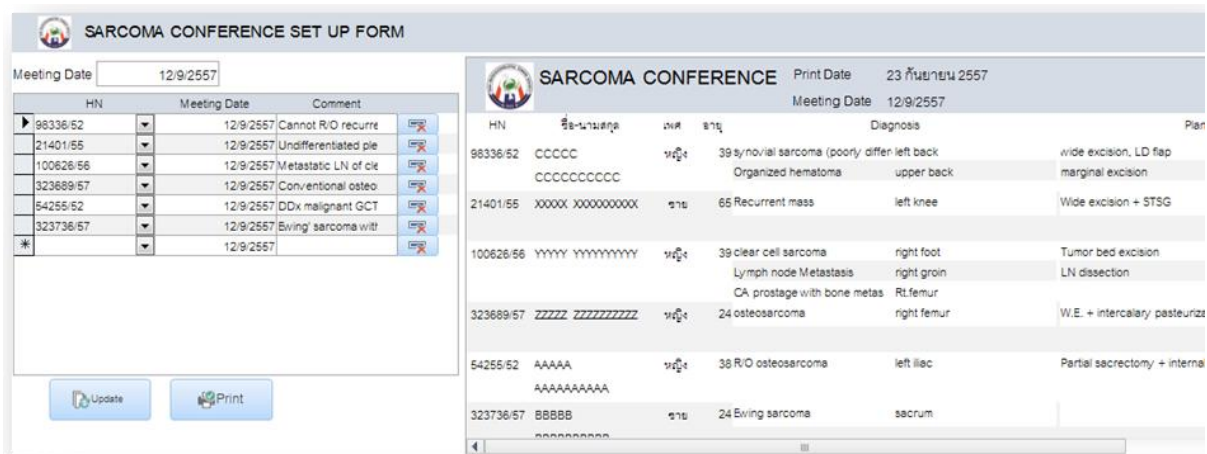


**Fig. 5** Post-operative protocol

Specific protocols for benign, intermediate-grade, or malignant tumors will be demonstrated according to postoperative plan selection in the operative treatment section. (Fig. 5) The estimated date for the current visit will be highlighted in yellow to notify the clinician what

investigation and clinical evaluation should be carried out in the current visit and what should be expected for the next one. With this strategy, incomplete investigation which unnecessarily wastes time and also delays the proper treatment will be minimized.

**Tumor board setup application**



**Fig. 6** Tumor board setup application

A multidisciplinary approach is a crucial part of cancer management. The tumor board setup section can help the listing of patients for the conference by just entering the meeting date, hospital number, and then clicking the update button. Suggestions from the meeting can be noted in the tumor board comment box on the same window and all opinions will be viewed in the patient's medical record form. (Fig. 6)

### ***Exporting data and printing reports***

One function of the TMTS database program is to export data for TMTS tumor registration and clinical research. A Microsoft Excel file can be created for research purposes by selecting the type and behavior of tumor and then clicking the export button. The program will automatically select relevant data and send it to the TMTS tumor registry manager via e-mail by clicking 'sending data to TMTS registry' on the main menu screen.

Printing documents can save a lot of time compared with paper forms. Several reports can be printed such as out-patient notes, referral documents, tissue request forms, surgical waiting lists, investigation lists, loss of follow-up lists, and patient inform sheets. The latter one contains the diagnosis and stage of disease in a comprehensive style which is easy to understand for patients, so they will know important information about their disease and plan of treatment.

### ***Equipment and expenditure***

The TMTS database program supports simultaneous operating using a split database technique for up to 10 users, but every computer unit must be in the same local area network (LAN). Free cloud data storage services (e.g. Dropbox, One drive, Google drive) enable users to connect to the database from remote locations, however only a single user can operate at a time because cloud applications cannot merge the same file from two different locations.

The budget for establishing a database system includes a desktop computer or notebook with a Microsoft Office installation which has a total cost of around 15,000 Baht (300\$) per unit and 1,500 Baht (30\$) for a LAN switcher if simultaneous multi-users (up to 10 users) is required. The program is free-licensed for TMTS members.

## **Discussion**

The electronic health record (EHR) has been widely adopted by many hospitals in the U.S. since 2009, and proven itself by providing benefits in overall patient care<sup>(3)</sup>. EHR also allows multi-center research to be conducted which is a crucial approach especially for orthopedic oncology which has very low prevalences of disease in the general

population. However, a favorable outcome of EHR is relying on the quality of the information in terms of completeness and accuracy. Therefore, only good medical records can result in better patient care, while lacking information by inaccuracy or missing data will make no difference<sup>(4)</sup>.

Currently, more than seventy percent of Thai hospitals are using paper-based clinical records for data collecting systems with partially implemented electronic records for some specific tasks such as scheduling surgical operations and ordering medication. So far, paper documents are the most convenient method for collecting clinical data; however, paper-based medical records are usually scattered among hospital information systems and difficult to gather and update. Most of the electronic health record systems that are used in Thai hospitals are not design for special clinics which need more specific details to make data clinically useful.

One problem of EHR implementation into clinical practice is personal acceptance by the user. Some clinicians may not realize the true benefits of EHR, have a poor attitude toward EHR because of the burden, and deny using it. The program should motivate users by identifying specific requirements and solving their problems<sup>(5)</sup>. In addition, there are demanding features for specialty specific EHR such as redundant data input elimination, research support applications, reporting tools for quality indicators, and an interface with institutional software<sup>(6)</sup>.

Treating sarcoma patients is complicated and involves multiple specialties to achieve the best outcome. Improper management and follow-ups can lead to patient mortality. By creating a program for Thai orthopedic oncologists, we can expect an increase in quality of patient care and collaborative research between small and large medical centers. If patient records are properly registered and classified, an accurate data of specific diseases can be sought out by the TMTS database program and be ready for reviewing in a minute. Continuous improvement of the program through user comments will reassure usability and sustainability of the database. If the second version of the TMTS registry is successful, this project can be a model for other subspecialties in the RCOST or other national sarcoma groups that have a similar context.

## **Acknowledgements**

We are grateful to all of the members of the Thai Musculoskeletal Tumor Society for the great inspiration in the way of both service and academic in orthopaedic oncology. We also appreciate Napat Thanakornvathana for her dedicated work on database registration.

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## การพัฒนาโปรแกรมจัดเก็บฐานข้อมูลทะเบียนโรคมะเร็งสำหรับการดูแลรักษาผู้ป่วยเนื้องอกกระดูกและระบบเนื้อเยื่อเกี่ยวพัน

กฤษณ์ เจริญลาภ, พบ, ชินคนัย หงสประภาส, พบ

**วัตถุประสงค์:** เพื่อนำเสนอ โปรแกรมที่พัฒนาขึ้นมาใหม่โดยเป็นการจัดเก็บฐานข้อมูลทะเบียนโรคมะเร็งในรูปแบบเอกสารอิเล็กทรอนิกส์ ทำให้ง่ายต่อการสืบค้นข้อมูล และเหมาะสมในทางปฏิบัติสำหรับแพทย์ออร์โธปิดิกส์ด้านเนื้องอกกระดูกและระบบเนื้อเยื่อเกี่ยวพัน

**วิธีการศึกษา:** โปรแกรมจัดเก็บฐานข้อมูลของอนุสาขาเนื้องอกกระดูกและระบบเนื้อเยื่อเกี่ยวพัน ราชวิทยาลัยแพทยออร์โธปิดิกส์แห่งประเทศไทย เป็นโปรแกรมที่พัฒนาขึ้นโดยใช้โปรแกรมพื้นฐานของ ไมโครซอฟท์แอคเซส โดยเลือกจัดเก็บข้อมูลที่สำคัญในรูปแบบที่ง่ายต่อการลงข้อมูล โปรแกรมนี้สามารถเลือกส่งข้อมูลบางส่วนไปยังฐานข้อมูลทะเบียนโรคมะเร็งส่วนกลางผ่านการเชื่อมต่อทางอินเทอร์เน็ตได้โดยง่าย นอกจากนั้นยังสามารถเลือกคำสั่งในการพิมพ์แบบลงบันทึผู้ป่วยนอก ใบส่งตัวการรักษา บอกรายชื่อพื้นฐานของผู้ป่วย บอกระยะเวลาภายหลังการผ่าตัด รวมถึงแนะนำแนวทางการรักษาในการตรวจติดตามแต่ละครั้ง ได้อีกด้วย

**ผลการศึกษา:** โปรแกรมจัดเก็บฐานข้อมูลของอนุสาขาฯ เหมาะสำหรับการเริ่มต้นเก็บข้อมูลของสถาบันที่ก่อตั้งขึ้นมาใหม่ และยังมีทรัพยากรจำกัด เพื่อให้มีการจัดเก็บฐานข้อมูลที่มีประสิทธิภาพ สามารถนำข้อมูลที่ได้ ไปใช้พัฒนาการดูแลรักษาผู้ป่วยรวมถึงเสริมสร้างความร่วมมือด้านงานวิจัยจากหลายสถาบันได้เป็นอย่างดี

**สรุป:** คณะผู้จัดทำมีความคาดหวังว่าการนำโปรแกรมจัดเก็บฐานข้อมูลของอนุสาขาฯ ไปใช้ จะช่วยเพิ่มประสิทธิภาพในการดูแลรักษาผู้ป่วยเนื้องอกกระดูกและระบบเนื้อเยื่อเกี่ยวพันและเสริมสร้างความร่วมมือด้านข้อมูลในการทำวิจัยจากหลายสถาบันต่อไปในอนาคต

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