Information Systems Frontiers 5:4, 421–427, 2003

System Design and Implementation of a National Image Registry for Orthopaedic Oncology Image Management, Research and Teaching

James M. Blum*

University of Michigan Health System, Department of Anesthesiology, Ann Arbor, MI 48105

E-mail: jmblum@umich.edu

Albert Aboulafia

Sinai Hospital of Baltimore and Department of Orthopaedic Surgery, University of Maryland, Baltimore, MD, USA

Abstract. *Orthopaedic oncology is highly dependent on imaging studies to diagnose and treat patients. However, many types of bone tumors are rare creating a lack of teaching and research cases. We have developed a system to locally document and nationally register electronic images for teaching and research on bone tumors. The system minimizes storage requirements and maintains confidentiality using a unique approach. This paper demonstrates the system design and current implementation.*

Key Words. *orthopaedic oncology, image registry, image management, image database, clinical research*

1. Overview

The field of orthopaedic oncology is a unique branch of orthopaedic surgery that focuses on tumors of the musculoskeletal system. Many common cancers such as lung, breast, and prostate metastasize (spread) to bone causing skeletal weakening and pain (Coleman, 2001; Hage, Aboulafia, and Aboulafia, 2000). However, there are less than 8,000 primary malignant bone tumors diagnosed in the United States each year. This makes the study of these tumors difficult for both orthopaedic surgeons and researchers interested in discovering more about the natural history and treatment of primary malignant bone tumors.

Most bone tumors today are evaluated extensively using both radiological and histological (microscopic) techniques. With the advent of digital imaging, it is becoming simple for orthopaedic oncologists to establish large collections of images related to their cases. However, due to the rare nature of malignant primary bone tumors, software to help organize and catalog these images has not been made commonly available. Furthermore, research and teaching is usually dependent on files established at a single institution, basic tumor registries or from cases available in textbooks and published literature (Bruguera and Newman, 1998; Ellis, 1997). Exchange of cases and information about the existence of cases not published in the literature is dependent on professional relationships. This hinders the ability of individuals to learn about unique cases or establish large indexes of information to run quantitative studies on bone tumor cases. In fact, it makes it difficult to establish effective therapies for some types of tumors (Ellis, 1997; Nuyttens, 2000; Samuels, 1999).

We have developed a software package to address the above concerns. First, the package allows an individual or group of physicians to maintain an index of their digital images related to each patient. The physician can code details about each patient's diagnosis, the location of the tumor, the stage of the tumor, etc. Furthermore, the physician can code information pertaining to the surgeries each patient has had, and record if an adjuvant treatment (such as chemotherapy or radiation therapy) has been prescribed. The software allows the physician to store his/her images and record the type of images. This makes it easy for an individual to prepare a presentation by finding a case with all the necessary

*To whom correspondence should be addressed.

imaging studies. The physician can then export these stored images for either hardcopy output for publication or integration into any presentation package.

The program makes it simple for an individual physician to manage his/her patient files, to perform research or educate other healthcare professionals. However, the software we have developed also enables physicians to register their cases and images in a central database. Many previous tumor registries have been developed; however, this is the first registry that we know of that attempts to index images with the tumor information. This registry will allow an individual to search for known cases of specific types of tumors and request images from the physician who registered the case. This system establishes a tumor and image registry, but leaves control of the intellectual property of the images with the attending physician and conforms to Health Insurance Portability and Accountability Act (HIPAA) privacy regulations (Gostin, 2001).

The system maintains patient confidentiality on the national registry by establishing a unique code for each patient on the local physician's system. This unique code is then registered on the tumor and image registry without personal patient information. This makes it possible for the registry to be open without concerns of breaching confidentiality. Often, images contain detailed information identifying an individual. If a physician request images from a colleague, the responding physician can modify any images or patient information to maintain patient confidentiality. Overall, we believe this system offers an excellent balance on three points of making information available, maintaining control over intellectual property, and respecting the privacy of patients.

2. System Design and Implementation

The system is based on a local system and a central database server. This is shown in Fig. 1. For the individual physician, a local database sits resides on his/her computer to store information and images on his/her patients. This database contains confidential information that identifies individuals by name with the images associated with their cases. The second part of the system is a central database that resides on the Internet. Physicians upload a subset of their local data to the central database. This database holds a subset of non-identifying information describing diagnoses and the images which can be searched using a client.

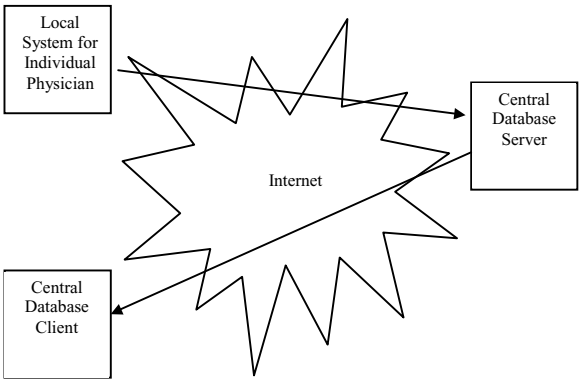

Fig. 1. *Basic system diagram.*

Local system

Development of the local system took several factors into consideration. First, the system needed to be easy to use and widely distributable. This encouraged us to look at the Microsoft Windows platform for our software. A multi-platform system developed in Java was under consideration. However, other factors made this an unappealing option including speed of execution and the lack of a reliable, easy to install database engine written in Java.

The next issue considered for the local system was the software development language and environment. A high-level development language such as Visual Basic or Delphi with a database system backend was considered along with fourth generation development DBMS language/environment. A rapid development environment was required for the project. Our expectation was to go through several stages of development in establishing our first release of the software. Furthermore, the software needed to be easy to install. Hence, we decided on Microsoft Access for the first version of our software. We used Microsoft Access Developer Edition to create a royalty free, distributable version of the database.

The local system was developed with the local schema in Diagram 1. Each patient has a record established detailing information about his/her diagnosis, medical record number, etc. The diagnosis and other information that can be coded are linked to specific tables. This allows for the rapid modification of accepted diagnoses and treatment options.

Next, each surgery and each image are recorded in respective tables. These tables have pertinent information that allows an individual to gain a basic

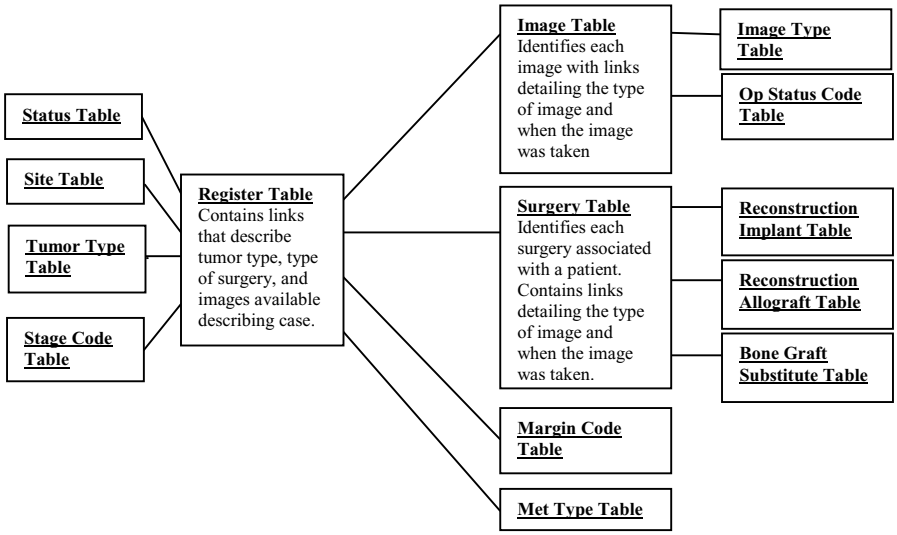

Diagram 1. *Local database schema.*

understanding of what procedure was performed or what type of imaging has been obtained. Information regarding the location of individual images is also stored in the image table. All information that can be coded is coded using tables illustrated in Diagram 1.

Information from the client is sent to the registry server using a standard ODBC interface. After a user enters a username and password, data is sent to the server over a standard TCP/IP connection.

Registry server

The registry server had significantly different architectural concerns than the local system. Difficulty of installation and ease of use were not primary considerations. Major considerations for use were Oracle 9i Database, Microsoft SQL Server, and MySQL. The decision was made to use MySQL as the backend solution. Although the product is freeware, we believe it provides a level of functionality and scalability that will be sufficient for the registry (*MySQL Reference Manual for version 3.23.42*, 2001).

MySQL is available on numerous Unix platforms and Microsoft Windows systems (*MySQL Reference Manual for version 3.23.42*, 2001). The decision was made to use Windows 2000 Server as the server operating system because of support concerns at the institution hosting the server. Support for a Unix system may be difficult to obtain in a time of need.

The registry system database architecture is very similar to that of the client system, as demonstrated in Diagram 2. Notable changes are the addition of unique national identifiers for each table entry (to prevent duplicate primary keys), a record of the registering person, and the removal of the medical record number and first and last name.

Data is entered through a standard ODBC connection from local systems. Only users currently registered can view or add information to the registry. Submission of data is straightforward as will be explained later in the article.

Registry client

Access to the registry database is accomplished through a Microsoft Access Client Database. The client again connects via a standard ODBC connection. The client is kept as a separate database to allow for more frequent incremental updates with distribution separate from the main database system. It is conceivable that a person would want to have the registry client on a notebook or home machine without having the overhead or security concern of the local system.

Examples

Local system To enter information on the local system a user stars the OrthoView database and is presented with a main menu of six distinct options (Fig. 2). Upon clicking "Add Patient Data" a screen appears which allows the user to enter the necessary patient

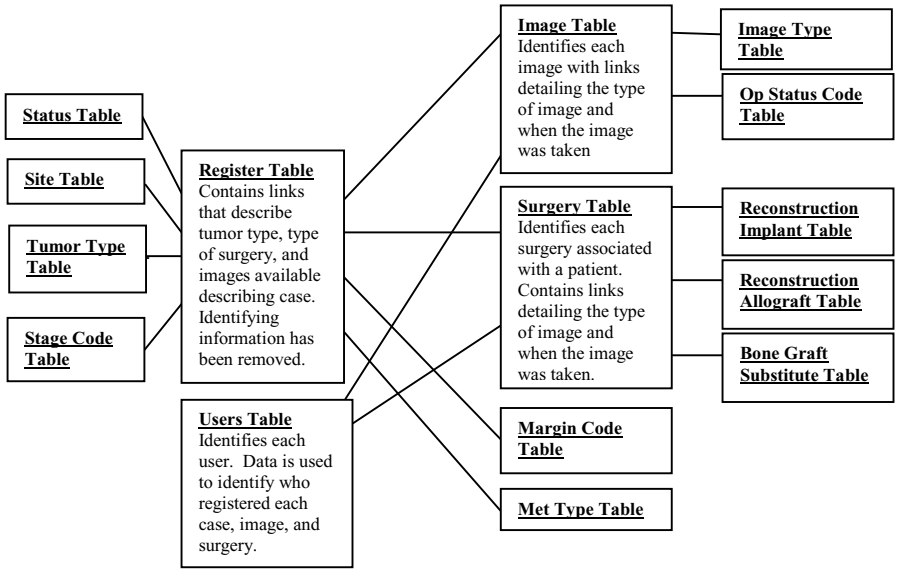

Diagram 2. *Registry database schema.*

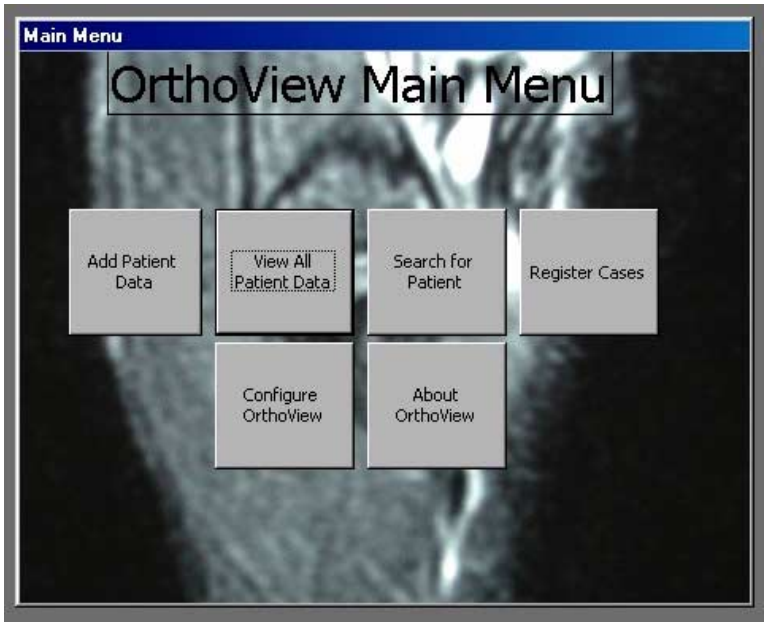

Fig. 2. *Main Menu.*

information (Fig. 3). The user can then enter information regarding the surgeries a patient has had and select images to add to the local database.

After adding patients to the database, a user may want to view all patients they have entered. Clicking on "View All Patient Data" allows a user to scroll through each patient in the database and see all the pertinent information regarding a patient's treatment and the images stored regarding that patient (Fig. 4). A user can also search for a patient based on almost any of the criteria listed on the main page of the system using a standard filter form provided by Access.

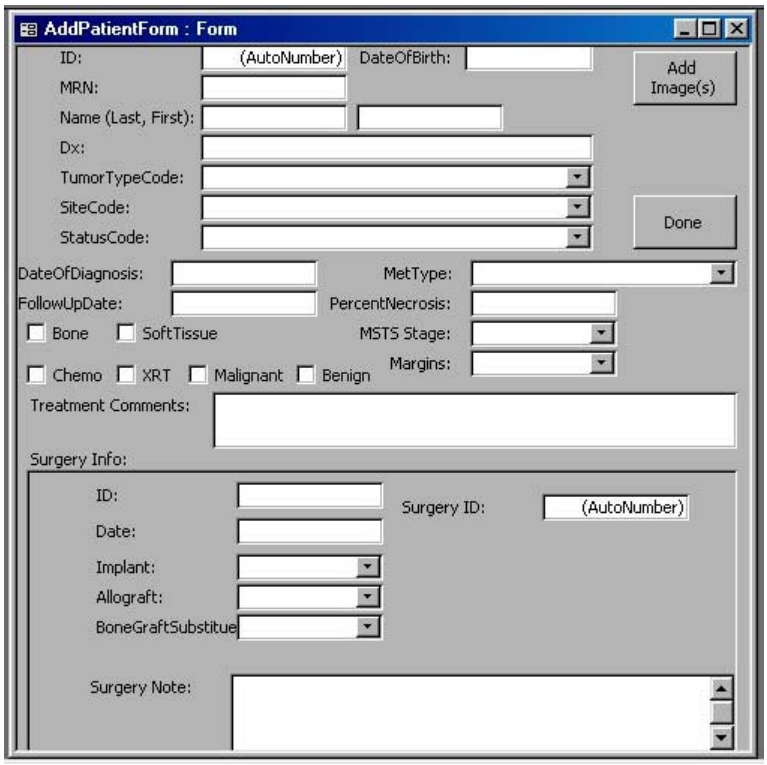

Fig. 3. *Add New Patient window.*

After a user has found a patient, the user has the ability to modify information about that patient by simply clicking one button. The user can also extract a single image or all images for a patient by clicking one button. This feature is particularly useful for preparing presentations or submitting papers. A user can simply click "Save All Images," extract the images to portable media, and prepare a presentation at a later date without having to bring an entire database of images. Users can also use this feature to send data to colleagues in e-mail or on removable media.

A large preview thumbnail of each images is shown in Figs. 3 and 4. As a user scrolls through the images in the database, the thumbnail image changes to reflect the currently selected image. If an image needs to be edited, the user simply needs to click on the thumbnail image, and the users default image-processing software is launched. By default modifications to the image are stored to the original image location. This allows users to easily maintain collections of publishable images if they choose to do so.

After a user has entered patients, surgeries and images into the OrthoView database, the users may choose to register cases with the case registry by clicking "Register My Cases." All the user needs to do is fill in his/her username and password to be granted access to the system and add his/her information. Information is available immediately and is not subject to prior approval of any controlling body.

Registry search When a user would like to access the national registry, he/she runs the OrthoView National Registry Access Database Front-end. This front-end has a common user interface to that of the local OrthoView program. The only significant change to the interface is the replacement of the thumbnail window with a window displaying information about the user who entered the case. A user is able to search for information on any field on the search screen. Currently, if a user is interested in obtaining images from a case found in the national registry, he/she must send e-mail to the user who posted the case and request information based

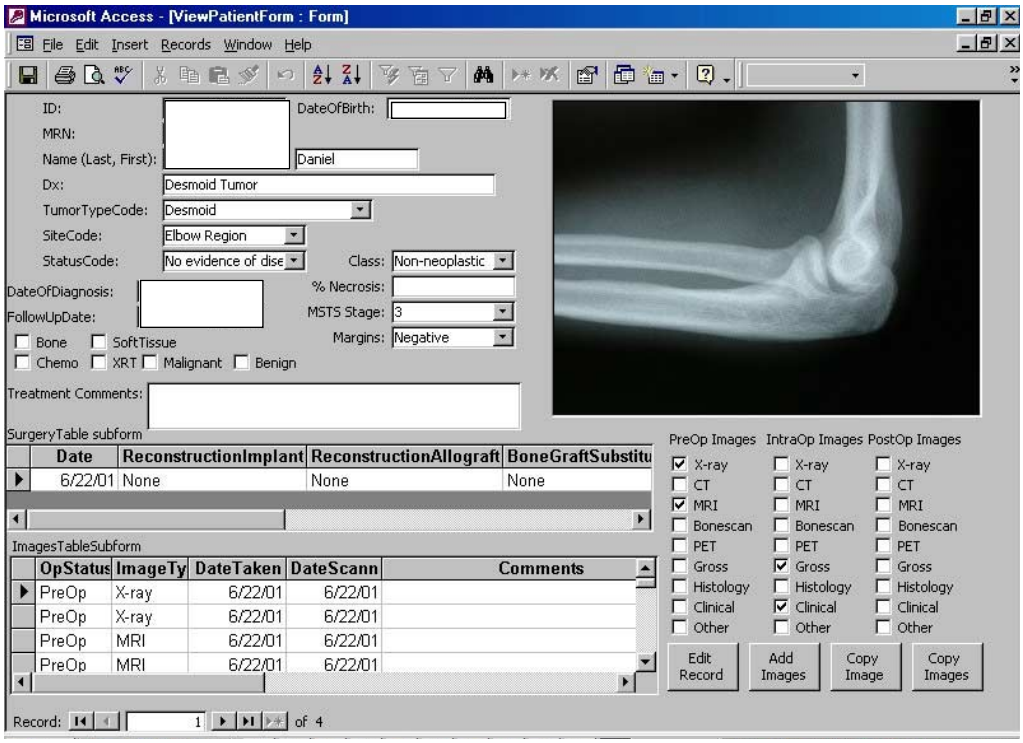

Fig. 4. *View All Patient Data window.*

on the case ID number present on the search form. The user responding to the e-mail would then be able to extract images from his/her local database and send the images via e-mail. While this is a slightly tedious task, it helps to maintain the privacy, security and intellectual property rights discussed above.

Limitations

Currently, the greatest limitation of the local system is the lack of a powerful database engine. The current system uses the Microsoft Jet database engine provided with Access. Although this engine simplifies use of the system, it limits the multi-user nature of the system (*Q&A: Microsoft Jet 3.0*, 1996).

Next, the system is difficult to update. The local version of the software is reliant on several tables that are included for recording case/image/surgery information. Ideally, we would like to have the front-end and two separate databases that could be easily replaced and updated on a regular basis. Unfortunately, this would lead to a higher administrative burden on the user, reducing the ease-of-use of the program and potentially lead to complications. As the system develops over future generations, we may find ways to enhance these properties.

The system backend appears to be well suited for the current task. We are concerned about the potential size of the database, but we believe any performance issue that arises with the national registry backend can be addressed through hardware upgrades. To date, we are not concerned about the choice of MySQL as our database server.

The front-end to the national registry is of some concern. Users may have difficulty configuring ODBC connectivity for their system. We are attempting to address this through good documentation and providing all necessary software for connectivity to users. However, only time will tell if this becomes a significant issue.

Finally, OrthoView does not use a standardized controlled medical vocabulary such as SNOMED. In our discussions with other orthopaedic oncologists, it was felt that the SNOMED terminology did not allow for enough detail and flexibility in describing tumors. However, we are looking to incorporate a controlled vocabulary in future versions of OrthoView.

3. Future Directions

OrthoView was developed to help study all types of bone and soft tissue tumors seen and treated by orthopaedic oncologists. However, immediate interest is in using the software to address issues surrounding extra abdominal Desmoid tumors. Desmoids are rare tumors. Thus, there is not a standardized way of treating these tumors (Batsakis and Raslan, 1994). Some physicians argue excision of the tumors with careful monitoring may be sufficient treatment (Pignatti, 2000). Others recommend radiation therapy and/or chemotherapy (Ballo, Zagars, and Pollack, 1998; Samuels, 1999; Suit and Spiro, 2001).

It is our hope that users of OrthoView will register their Desmoid tumor cases along with some indication of their treatments. After this information is collected, we may then have enough data to organize clinical trials of treatments that appear to have the most promise. We may also be able to prospectively collect and relate image/histology data to the response to treatment. OrthoView could easily facilitate the data collection for this future clinical trial.

In terms of modification of the software, we hope to see enhanced functionality in assisting the exchange of information. We are currently working on integrating an e-mail client on both OrthoView and the OrthoView National Registry Front-end to make it easy to request and send images. Furthermore, we are considering building the next version of OrthoView in Visual Basic to enhance execution times and reduce potential installation complications.

4. Conclusion

OrthoView is an example of how informatics is assisting the research and teaching of rare diseases. The visual nature of bone tumors is representative of many other medical disciplines including all of radiology and pathology. With easy accessibility to digital imaging, researchers will need the ability to organize and share vast libraries of images. We believe the concept of providing physicians with data management software that seamlessly anonymizes and submits data to a national registry is an excellent way to promote collaboration within medicine while maintaining intellectual property rights and patient privacy.

References

Ballo MT, Zagars GK, Pollack A. Radiation therapy in the management of Desmoid tumors. *Int J Radiat Oncol Biol Phys* 1998;42(5):1007–1014.

Batsakis JG, Raslan W. Extra-abdominal desmoid fibromatosis. *Ann Otol Rhinol Laryngol* 1994;103(4 Pt 1):331–334.

Bruguera JA, Newman RJ. Primary tumors of the elbow: A review of the leeds regional bone tumour registry. *Orthopedics* 1998;21(5):551–553.

Coleman RE. Metastatic bone disease: Clinical features, pathophysiology and treatment strategies. *Cancer Treat Rev* 2001;27(3):165–176.

Ellis PM, Tattersall MH, McCaughan B, Stalley P. Osteosarcoma and pulmonary metastases: 15-year experience from a single institution. *Aust NZJ Surg* 1997;67(9):625–629.

Gostin LO. National health information privacy: Regulations under the Health Insurance Portability and Accountability Act. *JAMA* 2001;285(23):3015–3021.

Hage WD, Aboulafia AJ, Aboulafia DM. Incidence, location, and diagnostic evaluation of metastatic bone disease. *Orthop Clin North Am* 2000;31(4):515–528, vii.

MySQL Reference Manual for version 3.23.42. MySQL AB, 2001.

Nuyttens JJ, et al. Surgery versus radiation therapy for patients with aggressive fibromatosis or desmoid tumors: A comparative review of 22 articles. *Cancer Treat Rev*, 2000;88(7):1517–1523.

Pignatti G, et al. Extraabdominal desmoid tumor. A study of 83 cases. *Clin Orthop* 2000;(375):207–213.

Q&A: Microsoft Jet 3.0. Microsoft, 1996.

Samuels BL. Management of recurrent desmoid tumor after surgery and radiation: Role of cytotoxic and non-cytotoxic therapies. *Surg Oncol* 1999;8(4):191–196.

Suit H, Spiro I. Radiation in the multidisciplinary management of desmoid tumors. *Front Radiat Ther Oncol* 2001;35:107–119.

James Blum is a resident physician in the Department of Anesthesiology at the University of Michigan.

Albert Aboulafia is an attending physician at Sinai Hospital of Baltimore in the Department of Orthopaedic Surgery and Assistant Professor of Orthopaedic Surgery at the University of Maryland.