

## **A Disease Registry and Disease Management System for Patients with Malignant Melanoma**

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### **Abstract**

*Strategies and interventions designed to better understand melanoma can help reduce the risk and rate of the disease. Current registries and information systems are generic in nature and not tailored to a specialist's workflow or clinic needs. Efficient data collection systems and application of effective workflow models can lead to significant improvements in quality of healthcare. We have developed a unique longitudinal tracking system for the treatment and outcome management for patients with melanoma. The system's design was informed by healthcare providers, a review of existing systems and published literature. Several modules have been established to address the concerns of the healthcare clinic, including: patient demographics, imaging, patient surveys, security, reporting and analysis. This framework is capable of displaying disease imaging screens, visually and interactively tracking melanoma sites, automatically computing staging scores, and tracking all surgeries and outcomes. Conditional patient access provides an interactive model of care to the clinic.*

### **Keywords:**

Information storage and retrieval; Electronic health record; Information systems

### **Introduction**

The past decade has seen a dramatic increase in the incidence of malignant melanoma, with an estimated 1.97% of people being diagnosed within their lifetime [1-5]. As the leading cause of death from skin disease, malignant melanoma accounts for approximately 1.2% of all cancer death with an estimated 8,790 disease-related deaths in 2011 [4,6,7].

Despite efforts to allay the impact and incidence of melanoma, disease-related mortality has remained relatively unimproved over the past decade. The current 5 year survival rate for people with advanced disease, or who have relapsed after initial treatment is less than 5% [2]. Strategies and interventions designed to better understand melanoma can help reduce the risk and rate of the disease.

The growing complexity of medical care has triggered the use of computers for acquisition, storage, and retrieval of medical information. Efficient data collection systems and application of effective workflow models can lead to significant improvements in the quality of healthcare, namely an increase in patient safety and a reduction in healthcare costs [8-12].

Most electronic patient record platforms are generic in nature (i.e. are not based on specialist workflow) creating cumbersome controls for specific clinic needs. By developing a platform with these

characteristics in mind, we have created a platform that inherently improves the patient clinical experience and facilitates direct patient engagement through the use of portals.

Utilizing these building blocks we designed an electronic, longitudinal tracking system for the treatment and outcomes management for patients with melanoma. We felt that the data collection and analysis facilitated by this system could provide critical data markers that help improve the care of clinical processes.

This paper describes the development and design of an electronic clinical management system for a melanoma clinic in Ontario, Canada.

## Methods

### System Design

We have developed a longitudinal data tracking framework which utilizes a MySQL backend database management system (DBMS) and a PHP/AJAX front end web platform. We established several modules to address the concerns of healthcare institutions including: patient demographics, imaging, patient surveys of patient important outcomes, security and secure authentication, reporting, and analysis. To establish relevant data parameters, we worked with an oncologist with expertise in this area; conducted a review of the literature and reviewed other melanoma data collection systems, globally. Data was collected on patients, registration, diagnosis, pathology (with imaging), staging, treatment, surgeries, sentinel node biopsies, node dissection, radiotherapy, systemic therapy, outcome and/or follow-up, and current patient status.

By creating a high quality interactive customized workflow based on intuitive data collection screens and a clinical tracking tool, we have helped standardize the data representation similar to a standard melanoma clinical workflow. This approach helps minimize tool adoption rate times and reduces the need for paper-based tracking systems, reducing data entry errors and increasing clinical efficiency. Our system is capable of displaying disease imaging screens, visually and interactively tracking melanoma sites, automatically computing staging scores, and tracking all surgeries and outcomes. Conditional patient access provides an interactive model of care to the clinic.

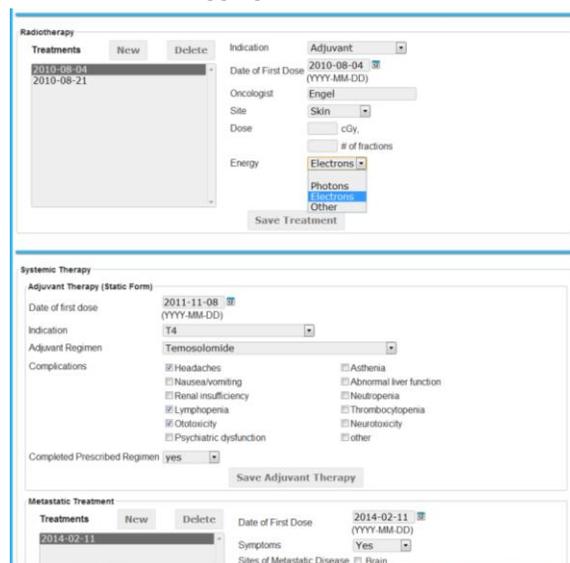
### Collecting Patient Information

In a traditional system, baseline information is typically manually collected by a healthcare provider. These forms are transcribed or coded into an electronic database of patient records. Direct data

entry leads to various quality control issues. To address this challenge, our lab designed the platform to be used not only with kiosk systems, but with web capable tablet systems as well.

We have established various techniques to improve quality control and to ensure accuracy of patient records. First, demographic data can be directly imported into the database onsite by the patient or nurse. Second, field validation is used to ensure that no data is missing or incorrectly filled (i.e., values out of permissible range). Administrators are able to designate these fields and form validation on each entry. Third, data collection forms are clinical workflow oriented, with built-in data validation (data flagging), auto-complete, and dropdowns to facilitate fewer entry mistakes as shown in Figure 1. The resulting increase in quality control ensures accurate patient record entry—the more accurate the demographics, the more accurate the statistical analysis.

Figure 1 shows clinical workflow oriented data collection forms with auto-complete and dropdowns for fewer entry mistakes as well built-in data validation (data flagging).



*Figure 1- Data collection forms*

A patient portal module was also created to collect and easily store feedback and data on patient quality of life. Based on the results of the quality of life survey (filled out by each patient), educational information is displayed back to the patient regarding disease-specific issues such as the effects of their medications. This module can also be used to collect and monitor patient knowledge, medication compliance, satisfaction with the platform, and

health-related quality of life. Additionally, patients can use this module to visually indicate the location of any pain which can be viewed by a clinician to determine cause and treatment.

These surveys can be completed in a patient waiting room using either a web-enabled tablet or kiosk—these devices can be reserved for waiting rooms and used to simultaneously collect patient feedback, educate patients on their illness, and even indicate to patients when the clinician is ready to see them. Patients can also provide an email address or mobile phone number so they can continue to receive educational material after their visit.

**Imaging**

An imaging platform with all associated patient diagnostic images is located within each patient record (Figure 2). By including images in the electronic patient record our platform provides an additional layer of comprehensiveness. Clinicians can access the platform and analyze the images with all associated test results to verify findings; images are downloadable to a clinician’s personal device if further analysis is required. Users can also highlight and focus on selected areas of the image via simple imaging tools such as magnify and reorient. The interactive visual displays of our platform offer screen demarcation of melanoma site, variable sizing and coloring option, and information regarding initial diagnosis. A collapsible on-screen imaging module accompanied with information and measurements is available for pathology and the general patient.

Figure 2 shows a collapsible on-screen imaging module accompanied with the measurements related to the images being shown.

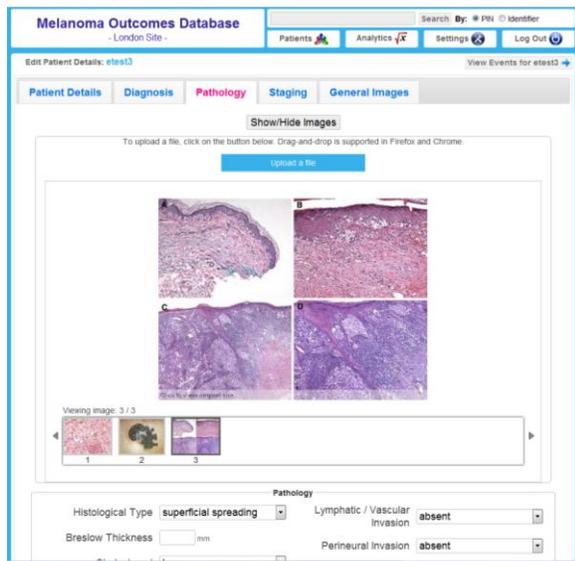


Figure 2- Imaging for pathology and general patient

**Access and Security**

The platform utilizes sftp and https (SSL-enabled authentication) encrypted pages to prevent intrusion from external malicious attacks. A social access control mechanism was also established within the system to prevent internal attacks; this was partially accomplished by assigning each user with a level of access within their domain. A hospital grade firewall housed and secured the internal database and all data was backed-up nightly in case of failure or corruption; system retractibility is also ensured by tracking and logging all database actions via transactions.

**Reporting and Analysis**

The platform supports reporting and analysis features, which can display any dataset in various forms for ease of representation. The analysis module of the platform provides real-time on-demand Staging frequencies on patients, filtering options on stage, information on medication and complications; and customizable graphing and plotting interfaces (Figure 3). In the event that the built-in tools do not have the desired functionality, datasets in various common formats (CSV, Excel, SAS) can be extracted for further analysis of patterns and trends.

Figure 3 shows real-time on-demand Staging Frequencies on patients with filtering options on stage, drug, complications etc. and customizable graphing and plotting interfaces.

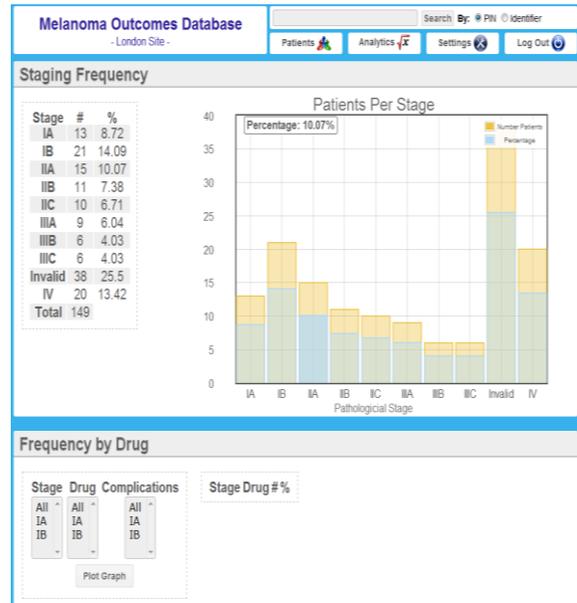


Figure 3- Analytics module

## Conclusions

Developing and establishing effective and dynamic data collection systems can lead to the elimination of physical chart-pulls; a reduction in medical errors and prescription clarification with pharmacies; the implementation of electronic review of patient medical history from a single, accessible location; the notification of required tests, exams, or follow-ups for patient care; an improvement in reporting on patients and practices and communications between healthcare personnel; and the trending of patient vital and/or test results.

Electronic data collection has the potential to significantly improve the quality of today's healthcare systems leading to improved patient safety and reduced healthcare costs [10-12]. However, while digitized systems enable easier and more efficient data extraction than traditional manual systems, it is important to promote the standardization of backend systems and to ensure that data not be held in silos and defined by large legacy systems where valuable information can remain uncultivated.

Our platform provides an interface for data subsets within a common platform view. By providing an interface for imaged data (X-RAYS, MRIs, CT scans etc.), we can use conventionally recorded clinical data to enhance review and analysis. Additionally, our interface can help inform clinical decision making by conducting preliminary disease or risk modeling using multiple datasets with other relevant databases.

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