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InfoFrame – An Intelligent Informatics Data Collection Framework

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Abstract

Health care providers, clinicians and medical researchers are increasingly faced with heterogeneous data collection and reporting standards from a wide variety of public and private organizations. The storing and categorizing of clinical data related from multiple sources not only leads to several heterogeneous databases, but also results in difficulties in automating analysis on gathered datasets.

In this work, a flexible real-time data collection framework that is able to adapt and lend itself to the multiple datasets without compromising future usability and research potential is presented. Features include the ability to easily connect and leverage current database systems with legacy data via bridging technologies, auto-complete of lookup listings from external sources (such as medication and physician repositories) and strict data validation on all data entry fields.

1. Introduction

Currently a multitude of unresolved data collection issues exist, including the variations in measures and standards of health care protocols, different reporting paradigms and personal autocratic whims within various clinics. [1-4] As a result we see an increase in expenditures related to data, reduced quality of data (rendering it inaccessible in various instances), loss of research opportunity and poor performance measurements. [5] Ultimately, resultant expenditures continue to be unyielding and monitoring of patient care drastically affected.

Over the past decade, electronic data collection, on both a local and national scale, has penetrated all levels of the hospital system. For those left behind, initiatives to establish electronic data collection systems are underway. [6] Lack of training to accommodate this transition has created a significant burden on health care providers. Mandatory transparency and increased awareness of the *inner workings* of our hospitals has resulted in requests for data regarding quality, public health, performance, and other administrative processes in sometimes an uncoordinated and even conflicting manner. Due to the alarming increase in these initiatives over the past few years, with limited technological understanding, funding and staffing, progress in this area has been increasingly difficult for health care providers.

Currently, many databases are constructed from various national, provincial and private databases consisting of heterogeneous datasets with incomplete and incompatible data fields. [7][8] Combining these data sources leads to the inevitable consequence of mismatched data, such as – various gaps of missing data riddled across various databases, incompatible fields, redundant and duplicate data markers, conflicting fields and multiple standards. [9-13] Efficient data collection systems with proper workflow models have the potential to greatly improve the quality of health care. [14][15] Other systemic benefits may include:

- The elimination of physical chart-pulls for patient calls, visits, diagnostics or other requests.
- Electronic review of patient medical history in a single, easy-to-find location.
- Notification of required tests, exams, or follow-ups for patient care.
- Trending of patient vitals and/or test results.
- Potential reduction in medical errors.
- Reduction in prescription clarifications with pharmacies.
- Potential for improved supporting documentation.
- Improved reporting on patients and practices.
- Improved communication between healthcare personnel.
- Patient-centered care.

If we consider the costs of errors and poor quality alone, globally in the billions of dollars, it seems almost inconceivable that a coordinated effort has not been realized. At the very least the potential gains of electronic data collection will have a positive effect on health and costs. [16-18] Though, it is true that, implementation is a problem where data is held in silos defined by large legacy systems, policy based organizational walls, or other boundaries. Even though data extraction from the digitized systems is more efficient than manual systems, it is still a challenging process due to the lack of standardization of backend systems.

2. Methodology

The use of online data collection systems present many issues that need to be considered. Antiquated hospital systems are increasingly in a state of flux due to support of older antiquated technologies and newer ones. There are inherent security and privacy issues that need to be handled when patient information can be accessed through the internet. Such problems are further complicated due to the data collection inefficiencies directly, which severely influence our health care facilities.

2.1. Inefficiencies Coupled with Data Collection

Data acquisition requirements present a formidable challenge for all organizations. In migrating from the traditional paper-based systems to electronic systems, many hospitals have chosen to store their patient information and records in a non-distinct-field and non-minable format. Though this method allows for easy digitization of legacy reports, it results in many errors when generating reports or trending. Hospitals are now recognizing that the move to this non-minable digital format does not reveal the necessary data for quality reporting and analysis without a considerable concerted effort, thereby forgoing any benefits to the medium entirely. Here information is not easily translated into knowledge.

This has negatively impacted on how healthcare providers view electronic data collection and reporting, which affects the quality of data and documentation. [19-22] Other concerns include:

- *The many variations within data collection tools and taxonomies.* Depending on the service provider, there exist several taxonomies for collecting similar data. A single organization may use many different disparate electronic collection systems in order to complete one patient chart (as pieces in one may be missing in the other). Validating and viewing the data across these systems can be tedious and often result in erroneous data within the complete electronic patient record. This translates to additional costs and constant monitoring of data to make sure systems are updated simultaneously in order to ensure granularity and consistency.
- *Documentation, reporting and data quality issues.* These challenges include incomplete clinical documentation, failure to understand coding and performance measurements, dependence on manual data abstraction, and inconsistent policies and practices for using secondary data as a source of quality information. [23]
- *Increases in service provider staff resource requirements.* This often increases in conjunction with reporting requirements due to the differences in reporting requirements set by the various requestors of performance and quality data. [24]

3. System Design of InfoFrame

To address some of the chronic problems in data acquisition and integration, we have developed a data collection framework that addresses these methodological issues previously described. The proposed system relies on a MySQL backend database management system (DBMS) and a PHP/AJAX front end web platform. Several modules have been created in order to adequately deal with the concerns of the health care institutions. Those that are currently in operation include: patient demographics; an imaging platform; a portal for patient surveys; access controls and security; reporting and analysis.

An example of a patient list view is shown in Figure 1, when viewed through a common web browser.

3.1. Patient Demographics Acquisition

One of the foundations of any health record is patient demographics. It represents the core data to be stored for any medical institution. Accurate demographics equates to eventual accurate statistical analysis.

In traditional systems, a triage nurse (or assistant) collects baseline foundation data manually. In other words, either the patient or the nurse completes forms by hand. These forms are eventually transcribed or

coded to an electronic database housing all patient records. This traditional system introduces a redundancy to the entry mechanism which leads to various quality control issues, such as errors in completing initial handwritten forms, errors unintentionally transcribed to the database during coding, etc.

In order to alleviate such issues our platform was designed for use with not only kiosk systems, but for use with web capable tablet systems as well. We provide templates for specific devices such as the iPad© among others. The acquisition tool allows for demographic data to be directly imported into the database, which could be done onsite by either the patient or nurse. Furthermore, field validation is applied to ensure data is not missed or incorrectly filled (with values out of permissible range). Such techniques allow for further increases in quality control thus ensuring accurate patient record entry.

Figure 2 depicts a screenshot of the patient demographics acquisition. Administrators can designate any field as required and form validation on each entry exists.

3.2. Imaging Platform

It is essential that an electronic patient record be comprehensive in all its content. For this reason we have built an imaging platform where all associated patient images (whether CT, Ultrasound, MRI, etc) are located within their record and is accessed within the platform (such that an external PACS system need not be accessed).

This allows the clinician to analyze a complete patient record, including all associated test results in order to verify findings. Simple imaging tools (such as magnify and reorient) allow the clinician to highlight and focus on various aspects of the patient images. Clinicians can also download the image to their machine for further analysis, if desired.

This imaging platform is currently being extended to include multimodal datasets, online registration and segmentation algorithms.

3.3. Patient Surveys Portals

A patient portal module was built to collect feedback and quality of life data from patients. Patients provide valuable information that is easily stored within the patient record. This module is governed by a set of policies that can also educate a patient based on their survey results. Once obtained, educating patients about disease-specific issues e.g., the effects of their medications is displayed back to the patient. Furthermore, it can be used to collect and track patient knowledge, their medication compliance, satisfaction and health related quality of life.

These surveys can be filled out while the patient is waiting for the clinician on either web-enabled tablets or kiosks. Several devices can be reserved for patient waiting rooms which can collect feedback and educate the patient about their illness simultaneously. They can also be used to inform the patient that the clinician is ready to see them. Furthermore, patients can provide additional contact information (email address or mobile number), which would allow the system to send educational material, via email or text messaging, to the patient following their visit.

Figure 3 depicts an example of a patient survey and feedback form. Patient lifestyle habits allowed the clinic to make more accurate decisions on diagnosis and future outcomes. These feedback systems provided a means for the clinic to improve their workflow and operations center. Other information such as area's of pain are denoted visually by the user allowing the clinician to pinpoint the cause of pain when a patient comes in for a visit. By using visualization aids, we felt that we would increase acceptability of the end users while increasing update of the product across clinical settings.

3.4. Access Control and Security

A robust authentication system was designed into the platform to prevent intrusion from external malicious attacks. This is ensured by using sftp and https (SSL-enabled authentication) encrypted pages for all access within the system.

This is coupled with a solid access control mechanism to prevent internal attacks that are trusted within an organization. Each user is assigned a level of access within their domain.

The internal database is housed and secured behind a hospital grade firewall. Data is backed up on all systems each night in the event of failure or corruption. Furthermore, all database actions are tracked and logged providing system retractability.

3.5. Reporting and Analysis

Reporting features have been built into the system so that analysis and targeted outputs can be given to the end users of the system. Any dataset can be displayed in various forms for ease of representation.

Trends and patterns within the dataset can be extracted for further analysis if the built-in tools do not

have the desired functionality. Various common data formats are available for the end-user to export their data into (including CSV, Excel, and SAS).

4. Conclusions

InfoFrame, our robust platform, will provide the following:

- An interface for data subsets within a common platform view,
- An interface for imaged data (X-RAYS, MRIs, CT scans, etc) to align with conventionally recorded clinical data, for the purpose of enhanced review and analysis,
- An interface for multiple datasets with other relevant databases (e.g. addressing the need for homogeneity) conducting preliminary disease or risk modeling to help inform clinical decision making – when dealing with data extracts,
- An interface for multiple global search terms (universal search features)
- A local data reporting and simplified in browser modeling ability (simple analytics of various fields, mainly a reporting feature).

Given the ability to leverage these features, this framework should be sufficient in providing the needed functionality to simplify workflow and improve efficiency of patient management within health care facilities. This framework is currently being trialed in a variety of clinics to test its efficacy. These include various cancer clinics (melanoma, prostate, etc), heart and stroke clinics, and neonatal intensive care units. Easy to use data collection platforms that are based on workflows and intelligent functionality seems to have good uptake in a clinical settings and enhances the opportunities for research and quality care.

5. Acknowledgements

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6. References

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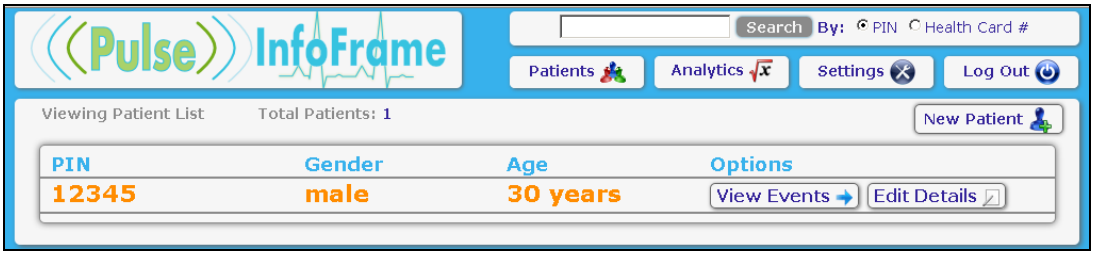

Figure 1. Patient list view interface through a standard web browser

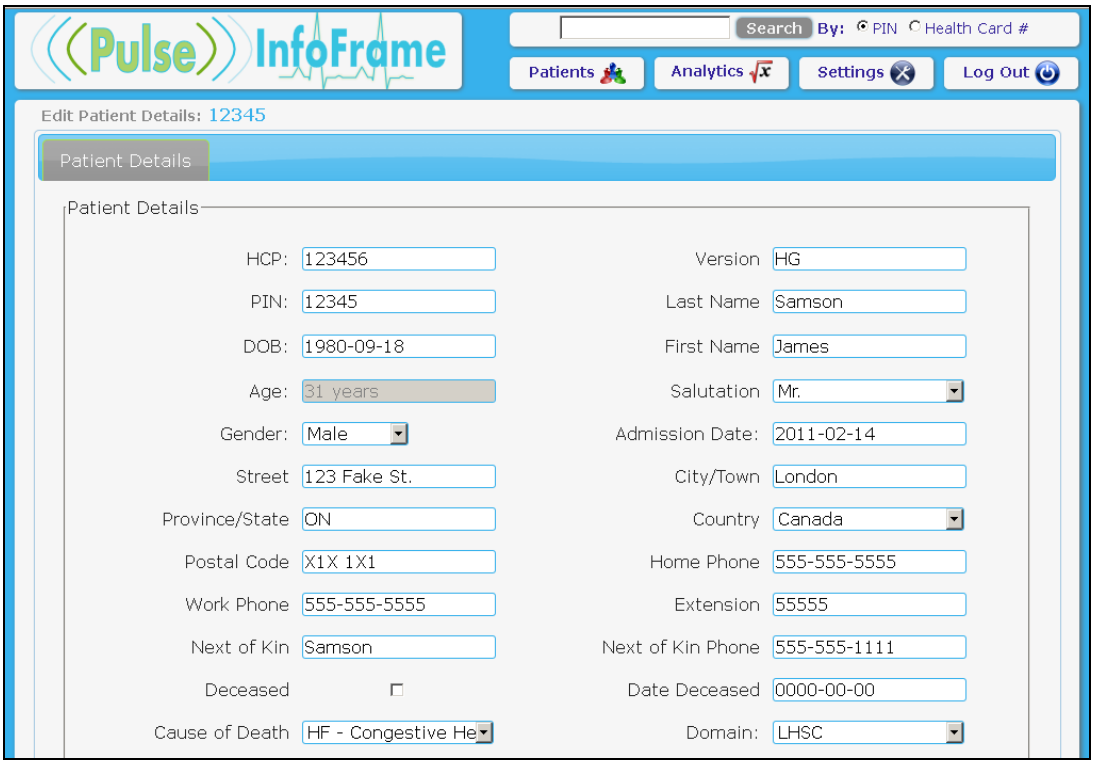

Figure 2. An example patient demographics acquisition module

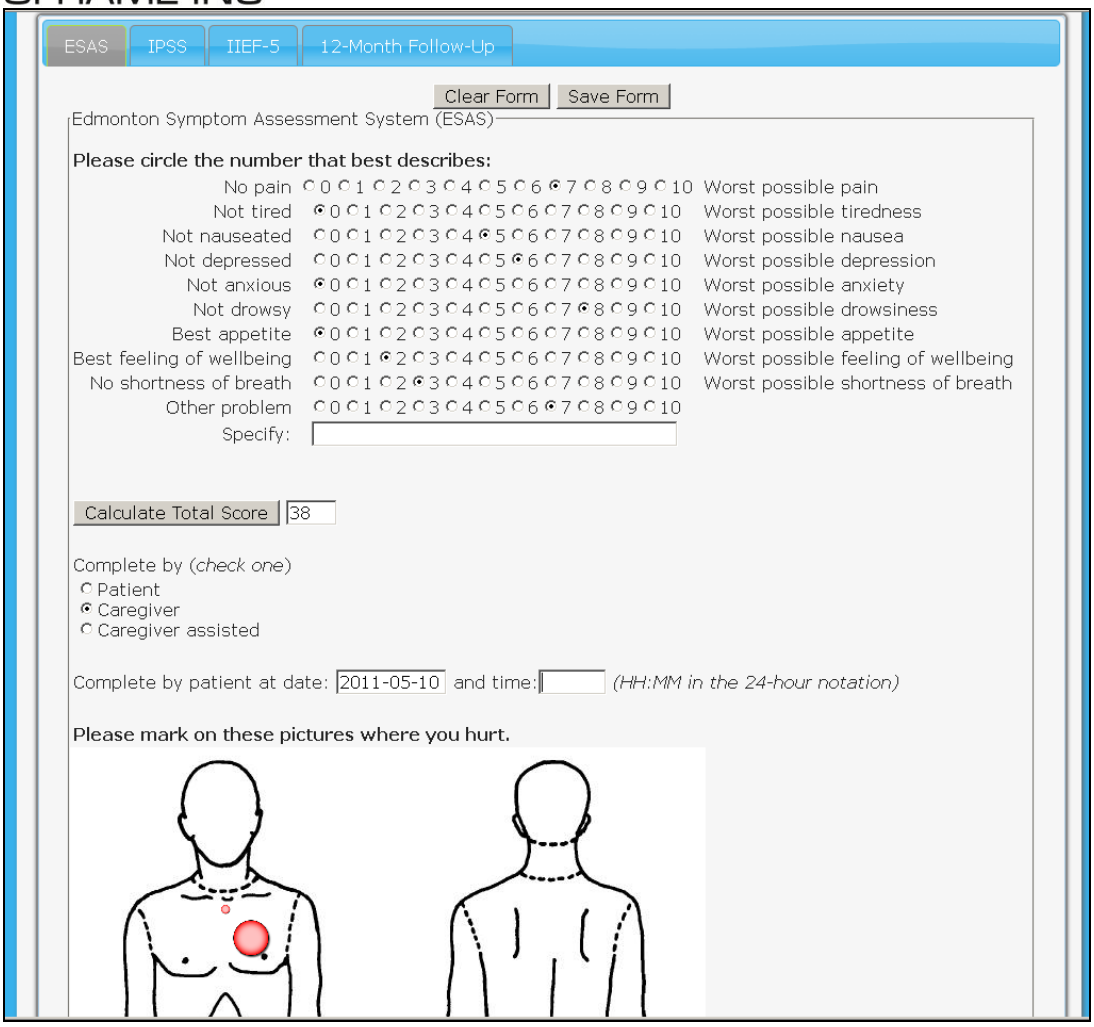

Figure 3. A screenshot of a patient survey.

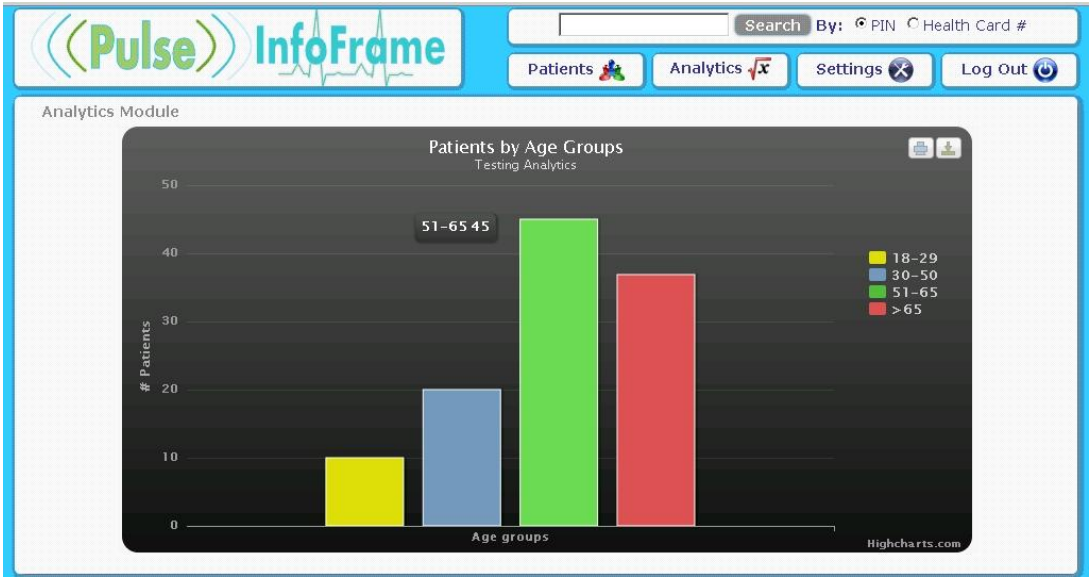

Figure 4. A screenshot of the graphing module.