Overview of Team Project

The purpose of the team project this semester is to design and prototype a framework and infrastructure that centers around a collaborative web portal for allowing three primary user groups, patients, providers, and clinical researchers, to interact with one another. The main focus of the project will be on the framework and the infrastructure, to put into place the techniques, technologies, and tools to facilitate a broad range of medical-based interactions among these three groups. The framework and the interactions are represented in Figure 1.

Figure 1. Architecture of Medical Health Informatics Web Portal.

In the figure, there are three primary groups of users all with different aims and objectives:

- Clinical Researchers: This group of users has been working in the clinical research area and may have developed new evidence-based medical treatments (or devices) for certain diseases. There is the desire to translate these results into the provider community in order to ensure that the most up-to-date medical practice is reaching all levels of the community. For example, at UCHC, their cardiology center publishes a twice-yearly Cardiovascular Gram (see Appendix A), both on its website and through mass mailings to providers. However, there is currently no means to obtain feedback on the evidence-based medical treatments, including whether the providers are reading the material, and more critically, if they are using the new treatment. In the latter case, the provider may want to interact with a clinician or clinical researcher at UCHC, but has no direct (and secure) vehicle of doing so; an on-line discussion forum may be of use in this situation, either for direct (one-to-one) interactions, or in more of a group setting. Thus, from the clinical researcher’s perspective, there are at least two goals: the electronic dissemination of new evidence-based treatment plans to the provider community; and, the collection of
various types of feedback (e.g., notification of the visits to certain web pages, registration of providers, input from providers on using the new treatment, etc.) to be used by the clinical researcher to further refine their work. This is represented in the bottom portion of Figure 1, both in the publishing of Education Materials and the existence of a Feedback Repository (e.g., database). The Education materials need to be flexible and multi-modal, with text, audio, video, and other formats supported. This Feedback Repository has potential long-term usage to track the success-rate of the new evidence-based treatment (device) via provider-supplied anonymous patient data/results\(^1\). In practice, this Feedback Repository would need to interact with a clinical research repository (or data warehouse) which is used to store ongoing data associated with a clinical trial. While beyond the scope of the project for the semester, there is a vital link between feedback from the community (either ad-hoc or rigorously collected) and ongoing (or prior) clinical research results. Ultimately, a natural extension of providing new treatment regime for providers, is to provide a listing of ongoing or soon-to-start clinical trials (Phases I, II, III, and IV) for both providers and patients.\(^2\)

- Health Care Providers: This group of users encompasses a wide range of professions, including: primary care physicians, physician assistants, nurse practitioners, education and discharge planning nurses, and so on. This group has one overriding objective, to improve medical treatment for their patients, particularly for those patients with diseases that require constant and vigilant monitoring (e.g., diabetes, asthma, congestive heart failure, high blood pressure, etc.). To support this activity, there are two paths of interactions for providers in Figure 1:

1. Providers are interested in learning about new evidence-based medical treatments (devices) and potentially interacting with clinical researchers on the treatments and usage in patients. This interaction was described in the prior bullet item; from the provider side, the ability to find out about these new treatments, learn about them, and communicate with the clinical researcher must be carefully structured for ease-of-use and usability; this will play a major role on its acceptance and success. For example a provider might want to have the data presented to them in short snippets on a daily basis or on a need-to-know basis. This may involve the use of different media (text, audio, video, interactive show, etc.) Eventually, an automated evaluation of potentially qualifying patients would also be helpful for providers; such a capability might be triggered as part of the provider’s EMR that identifies patients trending

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\(^1\) Please note that the actual collection of anonymous data/results on patients from providers may require some significant steps to overcome HIPPA requirements. Nevertheless, what we are considering for this project is the overall framework and infrastructure to support such collection; whether such collection is possible is future issue.

\(^2\) In order to consider this last note, at least as part of the specification process (please see the Project Deliverables and Time Table section), you will have to read about and consider how to make this happen at the point of care – again the framework to present the data is good – how it gets integrated into day-to-day patient care is another question. (how can data present in an EMR be mined to evaluate potential - you may need to think about reviewing some of the Clinical Decision frameworks that are out there. Dr. Thomas Agresta (agresta@nso1.uchc.edu) , an associate professor and Director of Informatics in Department of Family Medicine at UCHC has offered to assist if we tackle this issue.
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Team Semester Design/Development Project
Due Dates: Various Milestones for Semester

towards a potential future problem. Longer-term, such a capability may provide the opportunity for providers to earn continuing medical education credits.

2. For patients with chronic conditions (e.g., asthma, diabetes, CHF, high blood pressure, etc.), providers are interested in establishing a medium for a secure electronic dialog with them, that would include patient-supplied data (e.g., glucose level, BP, peak flow rate, etc.), with the goal of heading off adverse events and hospitalizations; this could be accomplished, for example, by having the infrastructure include software that can alert the provider when a patient’s trend data (e.g., glucose level for diabetes) exceeds some threshold for that patient for some time interval (set by the patient or the software). This essentially provides a means to track patient supplied disease management data, and may result in a number of actions, including contacting the patient to talk or to schedule a face-to-face meeting (patient appointment). This second path also requires easy to use provider user interfaces of multiple types (mobile devices and computer based) to allow notification when the providers are not in their offices; clearly adverse events will not always happen during regular business hours. In addition, this second path will require the permission from an individual patient to open a portion of their personal health record to certain providers. This is a complicated situation; in the event that it is a night or weekend, the covering provider may have neither access nor permission to patient data.

In summary, any patient interactions via the collaborative portal as given in Figure 1 should integrate with the provider’s local electronic medical record (EMR) system and its associated database. This allows the data collected from the portal to be available in one setting (EMR) when the patient is in for an office visit. If available, clinical trials organized by discipline and type, would also be useful for providers in their daily interactions with patients. For example, if a provider is treating a condition that is in a potential later stage, a clinical trial may be a last resort for the patient.

- Patients: This group of users are seeking a collaborative portal that provides a wide-range of functional components tailored to their needs and integrated with their providers. These include:

1. Personal Health Record (PHR): This is the key focal point of the patient aspect of the portal, to allow patients to manage their own personal health data, particularly for those patients who require chronic disease management. Patients will be able to access and manipulate their PHR; as shown in Figure 1; this means that a patient would have a PHR on their own local computer (purchased or open source product), or subscribe to a service that provides the PHR to the patient. This will include the capability to open portions of their PHR to providers that are selected from a list. For each selected provider, the patient can supply specific access (read or read/write) to individual portions of the PHR. There may also need to be a “download” process that allows a subset of patient data from a provider’s EMR to be loaded to initialize portions of the PHR. This component is targeting the PHR data, its initialization, and its management in terms of permissions (authorization to providers).
2. Disease Management: This component has many different capabilities that are structured around the premise that patients are seeking to manage their chronic disease (e.g., asthma, diabetes, CHF, high blood pressure, etc.) in order to avoid adverse events. Such a component could include: a. the patient entry of medical diagnostic data (e.g., glucose level, peak flow rate, etc.) for management of chronic diseases, coupled with upload/download functionality; b. the tracking of said medical data over time via various multi-modal graphical formats; c. secure on-line interactions (mobile device or computer-based) with their provider(s) for disease management (accomplished via the portal or a combination of the portal and another server – e.g., relayhealth.org); and, electronic notification (simultaneous hand-held and computer-based) when a trend has been identified by the provider that warrants immediate interaction with the patient (initiated by the provider).

3. Tailored Education Materials: This component should have education materials that have been selected to be tailored to each patient with respect to their need(s) and/or condition(s). This may also include a patient-focused education version of the treatment plan as generated from the clinical researcher provider materials. That is, for the on-line provider materials (Cardiovascular Gram) there may be corresponding patient versions that follow along with the plan being utilized by the provider. The division of Cardiovascular Gram into materials suitable to the patient (or to the provider), will require interaction with social and public health scientists to properly organize and present the material (and to obtain feedback) in many different formats (e.g., audio, video, etc.). From the perspective of our project this semester, the intent is to provide the infrastructure to support the publishing of such materials for patients and providers, when we are given the materials in the appropriate format.

4. On-Line Support Groups: This component allows all enrolled patients to opt-in to support groups. A patient may join an existing group or form a new group. The main functionality allows secure exchange and communication among patients via a chat-based, news-group type structure. Groups can be private (open by invitation only, with past “recorded” conversations unavailable) or public (anyone can join, with all past threads open for review). Ideally, this component can be constructed around open source bulletin board/chat capabilities (e.g., phpBB) and may leverage existing technologies (e.g., wikis) to organize documents (e.g., private and public threads of conversations). In addition, there must be the ability to securely email one another, again, via a secure email structure (akin to relayhealth.org).

As with providers, the user interfaces and interactions for patients will be critical, to facilitate adoption of the technology and continued usage. These are just the initial capabilities for patients; others are possible as the project evolves over the semester.

Overall, both provider and patient user interfaces will also be required for registration; we need to explore the appropriate model to see if the registration is patient-centered (anyone can enroll), provider-centered (provider registers him/herself and enrolls patients), or a combination.
The project as described to this point is focused on the end-user capabilities, for clinical researchers, providers, and patients. The major objective of this project for the semester is to emphasize the design and construction of an underlying infrastructure and architectural solution that can be utilized to support the functionality as described. As such, our focus will be specifying, designing, and prototyping these building blocks, using a wide variety of technologies:

- Ontologies: In computing, the term *ontology* refers to a model to represent both concepts and relationships among concepts for a given domain. Ontologies will have a vital role to play in this project; there are many emerging in medicine such as medical ontology research from the US Natl. Library of Medicine⁴, in efforts such as Open Clinical⁴, in medical ontology research as tracked by NIH⁵, and in XML.⁶

- Service-oriented architectures (SOA): Web-based solutions that rely on client-server interactions (e.g., PHP, scripting, SOAP, etc.).

- Open Source Server Side Solution: A wide range of possibilities including Java, Javascript, Perl, PhP, Python, Ruby, etc.).

- Standards and Messaging: Standards for patient/medical data modeling (e.g., XML, CDA, etc.) and exchange (e.g., HL7). This will also include interoperability to open source EMR and other external provider/clinical researcher technologies.

- Open source database platforms: Ranging from standard relational solutions (e.g., MySQL) to emerging XML database alternatives (e.g., Apache Xindice, Sedna, etc.).

- Data Encryption: Ranging from secure web pages (https and XML signature and encryption) to programmatic server-side security (e.g., Java or .NET encryption) to database security (e.g., MySQL encryption).

- Open Source EMR: Identifying an open source EMR for use in the project. One of the most widely known product is VISTA from the Department of Veterans Administration (federal level).

- Open Source PHR: Technologies such as HealthVault can provide a means for a patient to monitor and track his/her patient data over time.

- Open Source GUI Web Technologies: Possibilities on the client side include the Struts framework (http://struts.apache.org/) for simplistic user interfaces or open source Clean AJAX (http://clean-ajax.sourceforge.net/) for more sophisticated interactions.

- Open Source Hand Held Technologies: Web-enabled cell phones and PDAs will require a simple, easy to use solution for patients (to upload medical diagnostic data and receive

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⁴ http://www.openclinical.org/ontologies.html
⁶ http://healthcare.xml.org/resources/MMOOEBRR.pdf
alerts) and providers (to download patient data and issue alert). For example, there are Diabetes and Peak Flow monitor technologies being made to interact with HealthVault.

- Open Source Collaboration Technologies: For providing the infrastructure, it may be relevant to leverage wiki (e.g., mediawiki) or collaboration (e.g., phpBB) solutions.

For design and development, it is anticipated that we leverage standard software and database techniques and methodologies, including: design patterns, UML, ER diagrams and database modeling, etc. Again, the key issue is to put together the entire, extensible, framework.

**Project Deliverables and Time Table**

In terms of project deliverables, consider the following initial (subject to change) list:

**PD1. Identification of responsibilities for team.**

Solomon Berhe will be the principal architect and team leader for the project this semester. He will coordinate the team members, monitor progress, and be in charge of spearheading the overall architecture. The remainder of team responsibilities will be discussed in class, after everyone has read and reviewed the document.

**PD2. Using above pages as a basis to develop a more detailed specification.**

**PD3. Explore and select appropriate technologies for supporting PD2. Essentially provide a more detailed specification by selecting technologies from available candidates.**

**PD4. Identification of a subset of the specification (from PD2) with the chosen technologies (PD3) for development and prototyping.**

**PD5. Prototyping of these selected portions (PD4) of the infrastructure.**

Over the course of the coming weeks, we will discuss these deliverables as part of every class.

In terms of a time table, consider the following:

<table>
<thead>
<tr>
<th>Deliverable</th>
<th>Due Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>PD1</td>
<td>Establish and Finalize Team Responsibilities by February 6, 2008.</td>
</tr>
<tr>
<td>PD5</td>
<td>Prototype in Multiple Deliverables – after semester break. Schedule TBD.</td>
</tr>
</tbody>
</table>
Appendix A: Cardiovascular Gram at UCHC

The Pat and Jim Calhoun Cardiology Center at UCHC (http://heart.uchc.edu/) has a twice yearly publication *Cardiovascular Gram* to disseminate cardiology information to providers and the community (http://heart.uchc.edu/education/cardiogram/index.html). The links of the particular issues since 2005 are:

- http://heart.uchc.edu/education/cardiogram/pdfs/cardiogram_summfall05.pdf
- http://heart.uchc.edu/education/cardiogram/pdfs/cardiogram_summfall06.pdf
- http://heart.uchc.edu/education/cardiogram/pdfs/cardiogram_winspr06.pdf
- http://heart.uchc.edu/education/cardiogram/pdfs/cardiogram_summfall07.pdf
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