

Bridging the Gap Between Consumer eHealth and Public Health Through a Diagnostic Decision Support System

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Abstract—For sound development of the consumer eHealth, the market needs to have proper connection to the public health authority. On the other hand, in public health, tracking of patients has been a bottleneck in the scientific process. To address the problems altogether, we propose an approach to automate the case registration through a diagnosis support system. In the proposed approach, we set up a diagnostic decision support system for physicians, coupled with a support system for patients, on the Internet. In this setting, symptomatic data of anonymized patients automatically accumulate from the physicians' search profile and the patients' reports. Then, researchers in need can find appropriate cases on the symptomatic database, to recruit them for further study. The paper illustrates the case registration model with decision support system, and discusses the pros and cons of the proposed model. The qualitative analysis suggests that the model can accumulate information of cases that cannot be collected at a reasonable cost using traditional approaches.

Keywords—Diagnostic decision support system; Patient registry; Patient diary

I. INTRODUCTION

Symptom checkers [1], [2] are considered to be embodiment of the consumer eHealth, which improves delivery of medical care in a novel and efficient way through information technology. They are a class of diagnostic decision support system, which can be used to guide patients to appropriate hospitals, or to clinics. It can also be used to suggest Over-the-counter (OTC) drugs, to avoid costly medical consultation for low income populations, which would contribute to save the rising costs for medical care in most countries. However, is it a truly reasonable way to take?

In the viewpoint of patients, convenience matters most, to find cheaper remedy, even without hospital visit, or to find doctors easily, who simply match their needs. However, the "consumers" are self-interested, and thus, just by meeting the needs of the consumers, the service would be detached from "public" health, which, in the long run, do harm the patients. They might decide not to visit a clinic, satisfied with the agreeable automated diagnosis, which could be an early symptom of fatal subarachnoid hemorrhage. If symptoms of a certain disorder do not impact the quality of life of the patients, they would not look for medical services, resulting in the poor understanding of such disease.

Accordingly, for further development of the consumer eHealth field, it would be crucial that the field satisfies patient's point of view, as well as more public point of view. This indicates that the consumer eHealth must be properly connected to public health authorities. The paper illustrates such a trial we made in Japan, a research for accumulation of unclassified disease profiles [3] through a diagnostic decision support system.

We first describe the motivation in Section II and illustrate the overview of the approach in Section III. These sections are followed by detailed description of our prototype in Section IV. We summarize the discussion for the proposed approach in Section V, and conclude the paper in Section VI.

II. MOTIVATION

In the heart of clinical research and public health lies "patient registry". However, it is not uncommon that the number of registered patients does not accumulate enough for statistical analysis in a given period. Indeed, it is the most laborious and time-consuming phase in clinical research, which annoys the steering committees of many research attempts.

The shortage of cases in clinical research might be ascribed to several factors. First of all, complicated registration process might serve as a barrier for clinicians to register their patients. Secondly, case registration would certainly be difficult for rare diseases, because of the scarcity of the qualified subjects. Third, it would be hard for researches to collect patients, if the case definition is vague. Indeed, there is a certain class of patients, who develop incomprehensible symptoms, which are called Medically Unexplained Symptoms (MUS). Most of these symptoms derive from psychosomatic disorder, but, they are also targets of modern medicine, as a task force of the US National Institutes of Health states; "Medically unexplained syndromes present the most common problems in medicine" [4].

Accordingly, the challenge for public health field is how to accumulate the information of patients, including vague symptoms, possibly from uncertain disorders. An approach for this goal is the Electric Health Records (EHRs) [5], in which all the data are digitally stored and exchanged through computer network [6], [7]. However, prevalence of such system is not at satisfactory level in most countries, including Japan, and

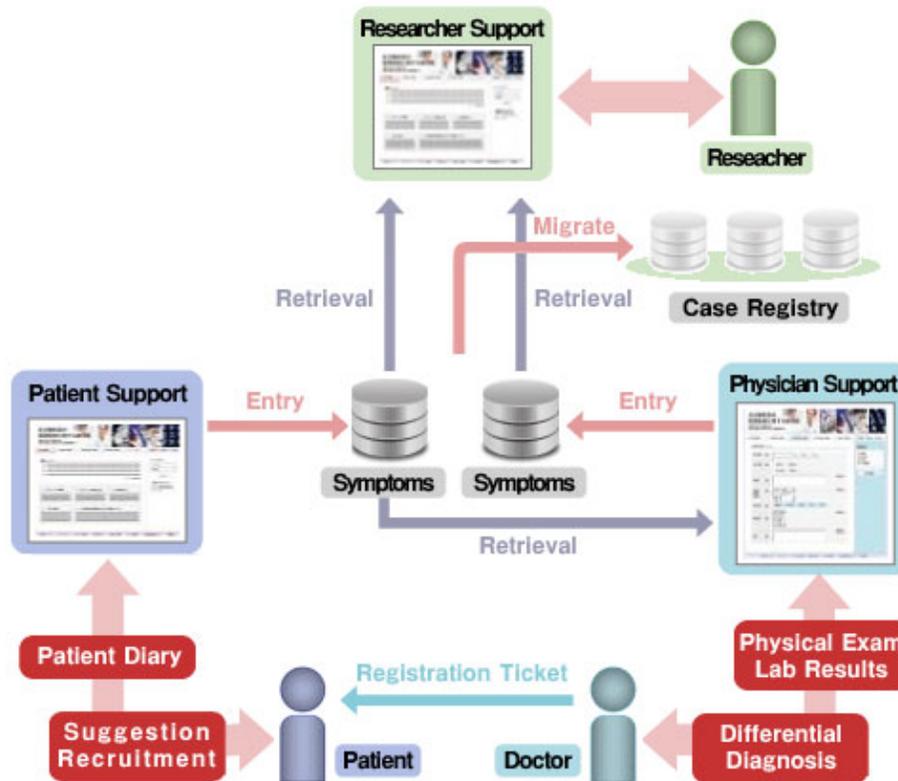


Fig. 1. Overview of the decision support system model for case registry

technology is not mature enough to comprehensively process the medical records written in natural languages.

Another approach that Google demonstrated is to harness the consumer behaviors to such a public health need. Google Flu-trend [8] utilizes Internet search trends to monitor prevalence of infectious agents, instead of gathering symptomatic data from medical institutions. This is based on an assumption that there is a strong correlation between search trends and prevalence of the disease in a region, inferred from the users' access profile. As the service suggests, careful design could bridge the consumer eHealth and public health. Next section illustrates such a model for case registry.

III. DIAGNOSIS SUPPORT MODEL FOR CASE REGISTRY

A simple approach for case registry is to store search profile of *symptom checkers* [1], [2]. In the same way as the Google flu-trend mechanism, the symptom checkers would be able to accumulate symptomatic information of patients, which might be useful for public health study. However, the straightforward approach is vulnerable to patients' biased self-assessment, and cannot accumulate objective information suitable for clinical research. It would be preferable that the data is qualified enough for epidemiological analysis. Further, the self-assessment model cannot accumulate lab results that can be obtained even at the smallest clinics.

Consequently, we propose a combined setting (Figure 1), in which the physician support system and the patient support system cooperate together, for collection of useful patient information. In the approach, the diagnosis support system for physicians takes symptomatic data, and returns a list of differential diagnosis. The system is built to support physicians, with features useful to make clinical decisions, and thus, physicians would willingly input their information for better patient care and to save their time.

For the patient part, the system issues a registration ticket for each patient, requested by a doctor. The ticket allows a patient to create an on-line account for an anonymous symptomatic diary system. The diary is reviewed by the physicians and by the researchers, who can send suggestions of diagnosis and recruitment messages for more detailed study to the patients. Because the patients with undiagnosed disease are highly motivated, they also willingly register their detailed symptoms and their history onto the system, expecting higher chances of diagnosis.

The registration ticket establishes the logical link, between the symptomatic data and the clinical findings, for anonymous patients. In this setting, subjective and objective data are independently collected and appropriately associated to each other, which serve as a virtual case registry for researchers.



Fig. 2. Diagnosis Support System (in Japanese) - The table provides an symptomatic input form in a clinically structured way



Fig. 3. Differential diagnosis list (in Japanese) - Each item in the list contains useful links to clinical references

IV. A PROTOTYPE SYSTEM

This registration model automatically accumulates the patient information, harnessing the motivation of physicians and patients into the case registry. To demonstrate the proposed scheme, we implemented a prototype in a research project for national registry of unclassified diseases [3]. The prototype comprises a physician support system, a patient support system, and a researcher support system, which will be outlined in this section.

A. Physician support system

The physician support system is an automatic diagnosis system [9], [10], [11], [12], which is designed to provide a variety of information useful for clinicians having trouble with difficult cases. The system takes chief complaints, physical examination, and laboratory results, as input (Figure 2). On the screen, selected symptoms are listed in the rightmost column. Then, when the diagnosis button is pressed, the system returns a list of differential diagnosis (Figure 3), calculating possibility of each disease utilizing a disease knowledge base. The physician support system also includes a Bulletin Board System and a Wiki system, to discuss difficult cases and other valuable topics. Further, we provided a feedback system, to efficiently collect various feedback and suggestions from the users, to continuously improve the system.

The symptomatic data, submitted to the system as a query, are anonymously stored in the system, and will be used for further analysis by researchers. Although the system does not have novelty as an automated diagnosis system, each item in the list has hyperlinks to related documents, such as review articles and other disease databases to further help the physicians. For the future revisions, we are planning to provide premium access service to commercial EBM (Evidence Based Medicine) resources, such as UpToDate [13] and DynaMed

[14], on the link list, to further motivate the clinicians to use the decision support system.

B. Patient support system

For difficult cases, physicians can issue an anonymous registration ticket, on the system. The ticket is passed to patients, to be used to create a patient account on the patient support system. The system comprises a patient diary, which is considered to be useful to support their life [15], and communication tools. The patient diary stores symptomatic data in the system, with logical links to the patient record for physicians, in an anonymized way (Figure 4). Because of the logical link, physicians can collect symptomatic information of the patient, without keeping privacy information of the patient, such as name, sex and data of birth. Downside of the setting is that, researchers cannot contact the patients via postal service or via telephone call, because their privacy information is stripped on the system. Accordingly, the system provides a messaging system, for study recruitment by researchers.

For the patients, it would be desirable that they can store and manage all the health information on the system, throughout their lives. Such an idea is called Personal Health Record (PHR), nowadays. However, PHR necessarily stores personal information, because there are many types of data that cannot be easily anonymized, such as medical images, which mostly contain personal names and other identification. Consequently, PHR service requires higher level of information security, which is beyond the focus of the prototype system. Thus, on our system, we simply provided a link to a third-party PHR service so that patients can allow researchers to access their detailed health records, for more proper diagnosis.



Fig. 4. Patient Support System (In Japanese) - Showing a symptomatic diary for a registered patient

C. Researcher support system

For researchers, the prototype includes a search engine of the case registry, to find cases who present a certain set of symptoms. Then, they can contact the patients by sending messages, if they need further investigation. The system also provides a BBS and a Wiki for researchers. Additionally, to study disorders that do not fall in a known category of human disease, researchers need a database of known diseases. For this purpose, we also implemented a disease knowledge base, integrated into the automated diagnosis system, which can store information of disease and its major symptoms, coupled with epidemiological profile.

Note that a patient record comprises more various and more detailed information, including demographic information, past medical history, family history, medications, etc. The registry, on the other hand, provides a very primitive symptomatic database, and thus, it could be insufficient for clinical research. Accordingly, we are planning to provide a *data migration tool* and a more flexible patient registry, coupled with patient recruiting tool, so that researchers can start up a survey for specific purposes at low cost, utilizing the data in the primitive registry as a basis.

V. DISCUSSION

An advantage of the proposed model is that the model can extensively accumulate data of patients at low cost, including hard-to-diagnose cases, rare cases, and MUS cases. This property also favors the model as an outbreak monitor of

unknown health hazard, because the public health authorities cannot afford detailed surveillance of every patient. They can continuously monitor the search trends, and can even detect unclassified disorder, by matching the symptom set with the known disease profiles.

There has been many types of Computer-assisted diagnostic decision support systems; for general diagnosis, for each specialty, and for specific category of medical images [9]. Most of the systems have been built as stand-alone systems, or integrated into clinical workstations in hospital information systems. The proposed model, on the other hand, behaves like an Internet search engine, which takes symptomatic data as input and returns a list of possible diagnosis with a variety of useful Web links, while keeping a log of the search queries as a patient symptomatic database. Indeed, this model instantiates another application area for computer-based decision support systems, which automatically accumulate useful information at low cost.

As a diagnosis support system, the prototype currently covers roughly 1600 diseases, which exceeds 650 entries in INTERNIST-1 [9], but, the quality of the knowledge base and the diagnosis algorithm are still premature. Accordingly, we are now improving the algorithm and trying to extend the coverage through automated generation of disease profile by text-mining technique on rare disease database such as Online Mendelian Inheritance in Man (OMIM) [16] and Orphanet [17].

High-quality EBM resources, such as UpToDate [13] and DynaMed [14] are focusing on major diseases and topics, and emphasis is on their quality of the articles, not on the coverage. On the other hand, rare disease databases such as OMIM and Orphanet covers thousands of minor disorders, but, common disorders are out of their focus. Accordingly, our attempt may bridge the gap, between the common and the rare, by providing integrated interface for disease databases, as a disease search engine, searchable by symptoms and findings.

VI. CONCLUDING REMARKS

Patient registries are key components in public health, but require substantial commitment by physicians. Accordingly, most of the budget and the time are spent on this part in clinical research. However, physicians can hardly benefit from the case registration, which tends to result in the shortage of registered cases.

In the proposed model, patient data are submitted separately by physicians and patients, motivated for their own goal. This setting brings a unique property to the model that the participants voluntarily turn in their data, driven by their own incentives, which realizes exceedingly cost-effective surveillance.

This model also possesses a unique property, in respect to information security. For protection of patient privacy, clinical information systems have higher security requirements, which tends to compromise the system usability [18]. Indeed, the HIPAA Privacy Rule decreased the number of patients available for clinical research [19]. On the other hand, our proposed approach separates the registration of patient data

into two parts, one for automated registration of anonymized symptomatic data by physicians, and the other for description of the illness by the patients. Because of the separation, the physician support system can be optimized for system usability, without worrying too much about the patient privacy. The more detailed information is voluntarily provided by the patients themselves, which also minimizes the privacy concern in the system.

Although there is ample room for further improvement in the current prototype, the model has the favorable properties for consumer eHealth and for public health. We will continue the investigation of the data acquisition model, and will shortly proceed to a proof-of-concept study to prove the efficacy of the proposed model.

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