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caREMOTE: The Design of a Cancer Reporting and Monitoring Telemedicine System for Domestic Care

Chihwen Cheng, *Student Member, IEEE,* Todd H. Stokes, *Member, IEEE*, May D. Wang, *Senior Member, IEEE*

***Abstract*—After receiving cancer treatment, patients often experience a decline of HRQoL (health-related quality of life). Physicians typically evaluate HRQoL during periodic clinical visits. However, out-patient reporting of vital signals between two visits could be used to interpret the decline of HRQoL. Considering that the vast majority of patients recovering from cancer are not in hospitals, it is often impractical for the care providers to collect these data. In this paper, we design and prototype caREMOTE, a cancer reporting and monitoring telemedicine system, which can be used in domestic cancer care. By extending a standard clinical trial informatics model, we build a prototype on cloud computing services that can be accessed by a mobile application. We aim to maximize the potential of caREMOTE to help medical practitioners efficiently monitor discharged patients' HRQoL and vital signals, and facilitate data reusability and system interoperability in future collaborative cancer research.**

I. INTRODUCTION

HEALTH-related quality of life (HRQoL) is a main concern during the recovery phase for patients, and physicians, after cancer treatment [1]. Some studies have shown strong association between patient HRQoL and length of survival in advanced disease settings [2]. Others have also shown that HRQoL factors have stronger prognostic value than the performance status of treatment, e.g., tumor size, in palliative care settings [3]. Thus, it is important for recovering cancer patients to report, and for their physicians/caregivers to monitor, HRQoL. In this paper, we address two key issues related to HRQoL monitoring in terms of: (a) frequency of data acquisition and (b) system interoperability.

In terms of frequency of data acquisition, the most convenient, and common, practice is to gather data during the patient consults with the medical team in a clinical setting. Such data include self-reported answers from patient questionnaires, i.e., patient-reported outcomes (PRO) to describe HRQoL, as well as supervised assessment in terms of mental and physical symptoms, e.g., depression and weight change. Because most cancer patients recover primarily in the home environment, i.e., out-patient with relatively few post-treatment consultations, consult-based data acquisition In other words, the frequency of consult-based data acquisition is insufficient and uninformative to monitor HRQoL.

Modern health information technology (IT), e.g., electronic PRO (ePRO), may help to overcome this problem of infrequent patient data acquisition to monitor HRQoL. However, there are two major limitations, in particular with regard to self-reported data. First, while mobile tools have been widely adopted to target out-patient symptom monitoring, e.g., HealthWeaver [4] and WHOMS [5], these tools use only patient questionnaires to measure health status. None of these tools allow patients to report vital signals with clear supervision from healthcare professionals. Second, out-patients tend to report adverse symptoms only when they feel the symptoms are relevant or significant. Some patients may not be sufficiently knowledgeable to report certain health issues on a regular basis [6], especially those that may be related to recovery, e.g., hypertension as a result of decreased metabolic load from tumor removal. As a result, even with ePRO solutions, the frequency of self-reported data still may not be adequate to monitor HRQoL accurately.

In terms of system interoperability, although the use of health IT systems has increased substantially within the past decade, it is still a challenge to integrate medical record systems with clinical trial systems [7]. Thus medical informatics standards, e.g., HL7 and DICOM, have been developed to facilitate data exchange. At the same time, several health IT tools were also developed to manage cancer-related data. Most of them facilitate health resources management and access, e.g., decision guides, discussion forums, and articles, such as WebChoice [8]. However, although some of these tools have been validated in real clinical setting, none were developed according to the medical informatics standards, which restricts these systems' interoperability.

In this paper, to address these two key issues, we propose and build a prototype of *caREMOTE*, a ***ca***ncer HRQoL ***re***porting and ***mo***nitoring ***te***lemedicine system, and aim to improve doctor-patient interaction for domestic cancer care. By following a standard clinical trial informatics model, *caREMOTE* is developed using cloud computing technology

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C. Cheng is with the Electrical and Computer Engineering Department of Georgia Institute of Technology, Atlanta, GA 30332 USA (e-mail:cwcheng83@gatech.edu)

T. H. Stokes and M. D. Wang are with the Bio-MIBLab (www.bio-miblab.org), the Wallace H. Coulter Department of Biomedical Engineeringt, Georgia Institute of Technology and Emory University, Atlanta, GA 30332 USA (e-mail:todd.stokes@bme.gatech.edu, maywang@bme.gatech.edu)

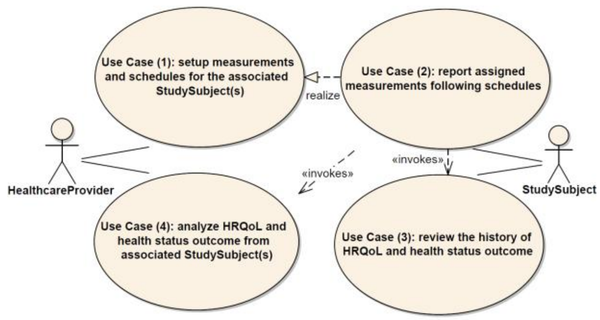


Fig. 1. Actors and use cases in caREMOTE with their relationships

for cost-effective data storage and communication. It allows caregivers to set up measurements with schedules to indicate to patients what data should be provided and when to report it. The system provides a mobile application that can access the cloud services to help caregivers efficiently manage patient profiles and outcomes, as well as allow patients to report, and review, their HRQoL and vital signals with less spatial and temporal restriction.

II. System Development Methods

A. Clinical Trial Informatics Standard

To enable the interoperability of caREMOTE, the system is established by extending the Biomedical Research Integrated Domain Group (BRIDG), which is a shared clinical trial standard model adopted by NCI, CDISC, and FDA [9].

Use cases and object models are represented using the Unified Modeling Language (UML) [10]. Two main roles in caREMOTE are defined to be (a) health caregiver and (b) out-patient who are `HealthcareProvider` and `Study-Subject` in BRIDG, respectively. Four main use cases of these two roles are shown in Figure 1: (1) to allow a caregiver to set up measurements and schedules for associated patients, (2) to allow a patient to report assigned measurements following the schedule set by his/her caregivers, (3) to allow a patient to review the history of HRQoL and vital signals, and (4) to allow a caregiver to analyze HRQoL and vital signals from associated patients.

Fig. 2 diagrammatically portrays the class model that supports the four use cases in caREMOTE. `Questionnaire-Score` and `VitalSignal` are patient data in terms of self-reported scores to questionnaires and bodily measurements acquired with medical devices. Both consist of a `Schedule` that indicates the reporting timelines. Based on these two objects, `QuestionnaireInterpretation` and `VitalSignalInterpretation` can be made. Afterwards, changes in patient HRQoL may be assessed as `HRQoLChangeInterpretation` by referring to the two interpretations.

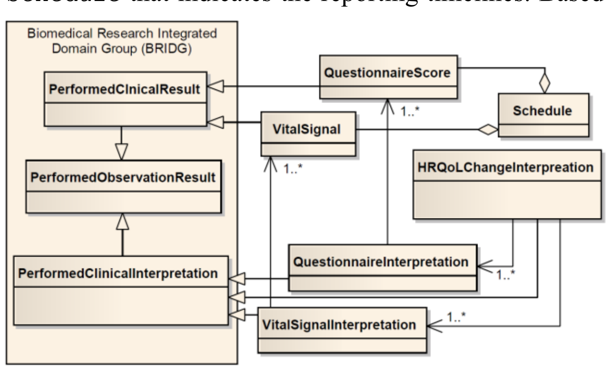


Fig. 2. The data model of caREMOTE and its relationship with the BRIDG model.

TABLE I
Questionnaires and Vital Signals Used in caREMOTE

Questionnaire	
Name	Usage
*QLQ-C30**	cancer-specific HRQoL and functional assessment instrument
FACT-G	
SF-36	generic HRQoL assessment instrument
CES-D	evaluate symptoms of depression
Vital-signal	
Name	Usage
Body Weight	track the change of weight
Blood Pressure	monitor the severity of hypertension
ZQ	summarize the sleep quality and quantity over the night

*copyright instrument

B. Questionnaires and Vital Signal Measurements

In order to measure different cancer HRQoL and health status aspects, four questionnaires and three vital signals were adopted in caREMOTE (Table I).

The *QLQ-C30* evaluation questionnaire, by the European Organization for Research and Treatment of Cancer (EORTC) [11], is the most widely employed scale which has been considered to have a high degree of reliability [12]. Academic permission was obtained from online registration [13]. *FACT-G* is another questionnaire to assess the functional status of cancer patients [14]. An example question in physical well-being group of FACT-G is: '*I am bothered by side effects of treatment*' with possible answer ranging from '*0: not at all*' to '*4: very much*'. Unlike cancer-specific QLQ-C30 and FACT-G questionnaires, *Short Form 36 (SF-36)* is a generic and multi-purpose health survey. It is comprised of 8 groups of 36 questions to assess both functional health and well-being status. In addition, *Center for Epidemiological Studies - Depression (CES-D)* scale was used to specifically test depression severity, which is a mental problem that is more common in cancer patients compared to the general population [15].

As for vital signals, weight change is a frequent health problem among people suffering cancer treatment, such as obesity, among women with breast cancer [16]. Obesity is also known as one of the risk factors associated with hypertension. When blood pressure is elevated over several months, damage to internal organs may occur as a result. Thus weight and blood pressure are two key vital signals to be monitored.

Sleep disorder is another prevalent observation among cancer patients, and can persist for months to years after cancer treatment. Although studies have shown a high relationship between fatigue and sleep disorders [17], data collection of these two signs are still passive and inefficient, e.g., via telephone surveys. To date, several commercial

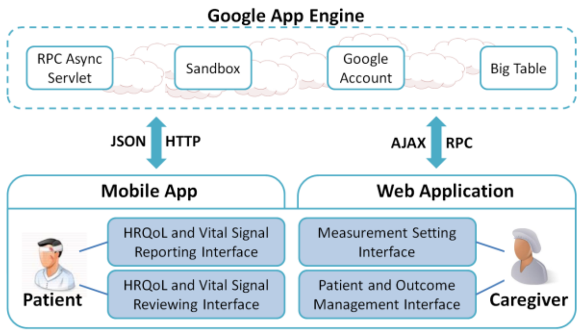


Fig. 3. System prototype, user interface and data communication between cloud service and mobile/web clients.

devices are available to analyze sleep quality. For example, Zeo (Zeo Inc., Boston, MA) is designed to help monitor sleep patterns by wearing a lightweight headband [18]. Zeo provides a ZQ, an overall score of the user's sleep over the night, which summarizes the sleep's quantity and quality by calculating a wide range of sleep patterns, such as time spent awake and asleep. Each morning, Zeo's bedside base unit calculates and displays the user's sleep patterns as well as ZQ. Therefore, ZQ was adopted by caREMOTE as a vital sign for monitoring sleep quality.

C. Technological Infrastructure Prototype

Figure 3 illustrates an overview of the system prototype and data communication in caREMOTE. The cloud infrastructure was built on the Google App Engine (GAE), the cloud computing business platform operated by Google [19]. Services on GAE are easy to build without unnecessary and routine maintenance. Data was stored in Google's Big Table technology. It contains powerful database query and transaction capabilities, and can automatically scale the database based on the needs of storage. It is quite suitable for healthcare system of discharged patients because their population is much higher and unpredictable than in-patients. Also, GAE applications can use Google Account service without extra account authentication and e-mail setup. Most importantly, GAE introduces Sandbox technology that isolates the caREMOTE database in its own secure, which protects sensitive personal health data from being violated.

Google Web Toolkit (GWT) is a development framework that was used to develop the web-based application of caREMOTE. It compiles Java code into JavaScript and HTML files that can be hosted on any web-based browser. Thus the client interface is more dynamic, without refreshing the whole page after each user action, by using Asynchronous JavaScript and XML (AJAX) and Remote Process Call (RPC) technologies [20].

Although the web-based application can be displayed by the native iPhone browser, i.e., *Safari*, the 3.5 inch screen size is not ideal for broader-scaled web content. Instead, we developed a new iPhone app to achieve a more ubiquitous monitoring and reporting platform. The mobile app not only has a better human-computer-interface (HCI) for users on move but also features the same functionality as the web-based application.

However, the iPhone OS (iOS) does not support direct RPC request to the GAE service. Thus the communication mechanism between the GAE services and iPhone app is using JavaScript Object Notation (JSON) technology via HTTP connections. It is a more lightweight data exchange format compared to traditional Extensible Markup Language (XML) format.

III. Results

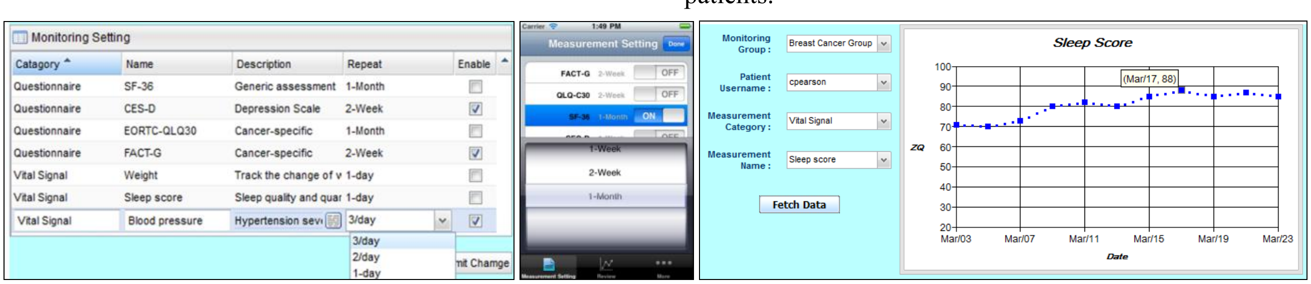
As shown in Fig. 3, user interfaces were developed to realize the four main use cases in caREMOTE. Interfaces of different roles, i.e., patients and caregivers, are independent of each other. Therefore the login page can re-direct the user to proper interface based on the account's role.

Measurement Setting Interface for Caregivers (Scenario 1): (Fig. 4a-4b) Based on the heterogeneity of care monitoring, an individual or groups would follow different measurement settings that are managed by the caregivers via this interface. Each setting tells which questionnaires and vital-signals are required for the patients to report as well as their reporting schedules. The frequency of each measurement can be set in a range between three times a day and once a month.

HRQoL and Vital Signal Reporting Interface for Patients (Scenario 2): (Fig. 5a-5d) Via this interface, the patient can know which measurements are currently pending to report and manually input, and submit their corresponding results. Because the interface synchronizes with the cloud, changes of measurement setting made by caregivers can update the pending reports here immediately.

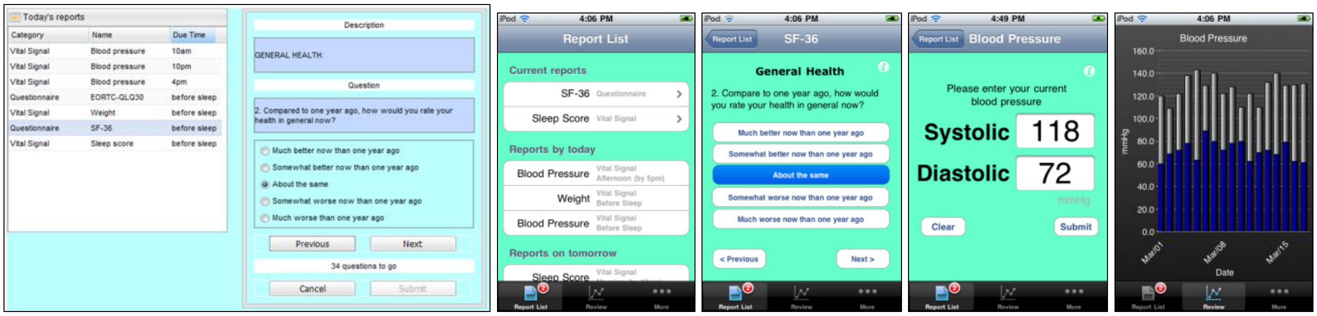
HRQoL and Vital Signal Reviewing Interface for Patients (Scenario 3): (Fig. 5e) This allows patients to review their history of HRQoL by specifying questionnaire or vital signal.

Patient and Outcome Management Interface for Caregivers (Scenario 4): (Fig 4c) This interface helps caregivers manage (i.e. create, modify, and remove) patient profile and review HRQoL history from one or a group of patients.



(a) (b) (c)

Fig. 4. User interfaces for caregivers. Web-based (a) and mobile-based (b) measurement setting interfaces. (c) Vital signal reviewing interface showing a trend of sleep score from one patient of one group.



(a) (b) (c) (d) (e)

Fig. 5. User interfaces for patients. (a) is the web-based reporting interface with the list of pending reports (left) and reporting form (right). From (b) to (e) are interfaces of the iPhone app. (b) is the list of pending reports which indicates the patient current (top-group) and the upcoming reports. (c) is the questionnaire answering form showing the second question of SF-36. (d-e) are blood pressure, i.e., vital signal, reporting and history reviewing interfaces.

IV. Conclusions and Future Work

In this paper, we propose the design and develop the prototype of caREMOTE to help medical practitioners efficiently monitor discharged patients' HRQoL and vital signals. In terms of improving the frequency of patient health data acquisition, caREMOTE is built on Google App Engine, a cloud computing platform, to achieve a more real-time reporting and monitoring environment. Furthermore, caREMOTE provides an iPhone application for caregivers and patients to report and/or retrieve health information with less spatial and temporal restriction. In terms of enabling the system's interoperability, patient data of HRQoL and vital signals is stored and accessed according to a standard clinical trial informatics model, which augments the reusability of healthcare data in future clinical cancer research.

In the near future, we may extend the current work in two primary directions: to improve the system and its security for cancer caregiver and patient users. First, to improve the system for users, we may investigate more possible correlations between HRQoL and recovery metrics, e.g., from surgery pathology reports. We will also try to incorporate wireless (e.g. Bluetooth) or even wearable devices for continuous data collection to augment data from vital signs monitoring. System usability, e.g., in terms of patient acceptance, completion rate, and completion time, will also be evaluated quantitatively in field tests. Second, although web-based applications of caREMOTE are currently protected by Google's Sandbox technology, these applications are not fully secured for mobile-based data communication, such as the JSON data format. Thus, to improve the system's security for users, we intend to implement the Advanced Encryption Standard (AES) [21], which is adopted by the United States federal government, to encrypt data transmitted via HTTP protocol.

In conclusion, we design caREMOTE to facilitate healthcare professionals in providing the majority of cancer patients, who are in domestic care settings, a similar level of patient-caregiver interaction that is more typical of patients who are monitored directly under clinical conditions, so as to realize the potential of telemedicine.

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