Using Personal Activity Diaries to Enhance Electronic Health Records

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Abstract
We posit that significant gains in patient-clinician communications can be made by helping clinicians to better understand a patient's life between their visits to the doctor. In this paper, we propose a mechanism for augmenting electronic health records with *personal activity diaries*, high-resolution records of a patient's daily life, derived automatically from personal activity sensors. These activity diaries establish a shared context for discussing the patient's lifestyle and condition.

Author Keywords
personal data, patient care, healthcare, information stores

ACM Classification Keywords
H.5.m [Information interfaces and presentation (e.g., HCI)]: Miscellaneous.

Introduction
A key goal in improving patient-clinician communication is establishing a common context for communication with which a shared understanding can be established. This understanding is bi-directional, in the sense that the patient needs to be able to effectively interpret what the clinician is trying to convey to him or her, but also that the clinician needs to be able to arrive at an accurate characterisation of the patient's situation and condition,

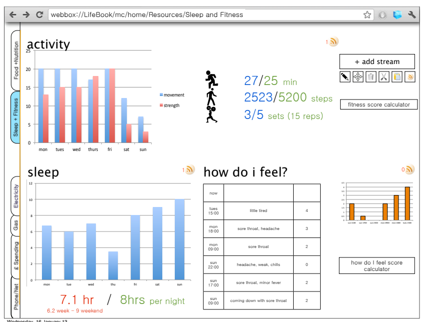

Figure 1: Mock-up of an activity diary dashboard, showing data from multiple devices.

as updated since the patient was last seen. This is often under time pressure and with limited access to information about how the patient has been in the interim.

One of the most promising technologies that has the potential to help provide such a common context is the patient-centric electronic health record (henceforth EHR) [2], a digital representation of the complete medical history of an individual as recorded by clinicians throughout a patient's life. The EHR has enabled both patients and their clinicians unfettered access to the patient's medical data, including diagnostics, reports, and history of interventions. This means that clinicians can more easily review a patient's long-term history even under time pressure and constraints. Moreover, since patients have access to their own medical histories, they can access the raw information that was the basis for a prognosis or decision.

Yet, so far, EHRs have primarily been limited to the storage of official diagnostic reports prepared by clinicians, technicians and nurses. These communications are both highly technical, making them difficult to interpret by end-user patients, but also highly limited in temporal resolution, reflecting only cases where a person was attended to and diagnostic-tested by a medical professional. Although this may be frequent for patients in inpatient care, those that come to see their clinician, say, once a month end up with extremely low-resolution samples of a patient's condition.

In this position paper, we look at the potential and problems of augmenting the next generation of EHRs with personal *activity diaries*, portraits of a person's dynamic condition captured at high temporal fidelity. Such activity diaries are intended, first and foremost, to supplement, rather than supplant the existing diagnostic reports performed by professionals, in order provide clinicians with a more complete picture of a patient's life throughout a period of care. We believe that such activity diaries could potentially also be beneficial to individuals as well, making people more aware of the evolution of their health.

Nonetheless, challenges abound. These primarily pertain to capturing these activity diaries, effectively storing these diaries, giving users easy-to-use access to these diaries, and privacy controls for giving patients the ability to disclose desired quantities of their diary to their clinicians. We discuss these, next.

Using Activity Diaries

We imagine integrated activity diaries to be used by both clinicians and patients in several ways. First, for nearly all types of conditions, monitoring a person's overall daily activity and sleep duration could easily indicate how much rest, exercise, and social exposure they might be getting. Moreover, longitudinal records of the time(s) that a person gets up, eats, works, exercises and relaxes can be analysed for irregular behaviours or habits that might be affecting his or her well-being. For more specific conditions, daily measurements of a person's blood pressure, blood oxidation, heart rate, breathing, weight, and galvanic skin response could be useful for tracking progress on a prescribed intervention, recovery from an illness, or onset of a new conditions, for example, or be used to pinpoint sources of prolonged stress.

Simply letting individuals see their own activity diaries could have direct effects on people's behaviour, motivation and perceived well-being, as well. For example, just as asking individuals to introspect and justify their opinions and feelings has been found to be both disruptive and reinforcing of their opinions [6], allowing people to reflect upon their historical activity records might help them realise or change their minds about how or why they feel particular ways. We feel that there is significant room for investigation here, and potential for research contributions pertaining to motivation and self-improvement.

product	measurement indices	price range (approx. USD)
FitBit	general activity (walking/jogging)	$50
Nike FuelBand	general activity (walking/jogging)	$199
WiThings WiFi Scale	weight	$200
WiThings BPM	blood pressure	$200
Zeo Pro	sleep duration & quality	$200
WakeMate	sleep duration	$50
Zensorium Tinké	heart rate variability, blood oxygenation, respiratory rate	$200
BodyMedia CORE 2	galvanic skin response, body temperature, sleep, respiratory rate, heart rate	(TBD)
Hapifork	eating time, rate, frequency	(TBD)

Table 1: *Consumer-grade activity sensors*: Activity and physiological measurement sensors with automatic data uplink to cloud services

Capturing activity diaries

The recent proliferation in personal wearable activity sensors and network- and storage- enabled digital health measurement devices has been driven by both the falling costs of embeddable electronics, and a surging public interest in "quantified-self"-style self-monitoring for self-improvement. Many of these sensors are lightweight, can be worn discreetly, measure several physiological statistics simultaneously, and most require little maintenance. Table 1 lists a sampling of the sensors currently available directly from retailers.

While few of these devices had initially been evaluated for accuracy or certified for clinical use, increasingly device manufacturers have begun to get independent certification. For example, BodyMedia advertises its device as "FDA-approved, clinically validated, most accurate wireless activity measurement". A separate study of activity-based sleep monitoring tools revealed that "low cost actigraphy-based approaches" correlated well with baseline (in-lab EEG-based measurements) for sleep duration, although less with sleep quality metrics [4].

Storing and Representing Activity Diaries

Currently, these devices are designed to upload measurements only to separate, dedicated web sites run by their manufacturers. Such sites are poorly suited for the long-term storage of people's activity data for several reasons. First, none of the sites provide long-term retention or access guarantees of user data (nor HIPAA security guarantees!). Second, it is difficult for a user to gain a unified understanding of their activity through the disparate interfaces provided, in part due of the widely different visual and interface representations. Finally, many of interfaces represent activity in arbitrary, "user-friendly" units, such as "Sleep score", "Fuel", "Zen level" etc., which are difficult or impossible for users to compare.

However, most of these sites have APIs providing programmatic access to raw sensor data. Our approach has been to leverage such APIs to retrieve a patient's information from all their devices, consolidating it into a uniform, common taxonomy and description logic, like those provided by SNOMED-CT [5] and ICD-10 [1]. The goal of such a formalisation is to provide a standard descriptive mechanism by which this data could be interpreted, such as by future clinical medical systems.

Since SNOMED-CT nor ICD-10 cover activity-related concepts, we devised a supplemental ontology called *Activity-SENSE*. This ontology encompasses patient activities, and standard units of measure with which activities measurements were taken, and concepts for describing sensors used. The intention is for records in Activity-SENSE, like those of SNOMED-CT, will be eventually translatable to dozens of different languages and mapped to similar activity ontologies, allowing international use and greater operability.

The WebBox EHR Platform

The high-resolution data collected by activity-sensing devices can result in a greater volume of data than current EHR platforms are designed to handle when accumulated over a patient's lifetime. To address this need, we have devised "WebBox" [3], a personal data platform optimised to handle the secure, long-term storage of large volumes of structured data. Thus far, WebBox has been used to archive clinician (hospital and GP-provided) data, including both raw structured data (such as clinical diagnostic results) and traditional reports prepared by clinicians. Being optimised for structured data capture and integration, our current work extends this platform to the aforementioned activity profiles, created from retrieving raw sensed data from digital health device APIs and translating such observations to the Activity-SENSE representation.

Biographies

Daniel A. Smith and *Max Van Kleek* are postdoctoral researchers on the SOCIAM project at the University of Southampton, and the principal architects of the WebBox personal information store. They have research interests in HCI, the Semantic Web and Personal Information Management.

Nigel Shadbolt (FBCS FREng) is Professor of Artificial Intelligence and Head of the Web and Internet Science Group, University of Southampton. As a member of the Public Sector Transparency Board, Chair of the UK Government's midata programme, and Chairman and Co-Founder of the Open Data Institute, Nigel has led the effort towards assisting the NHS to begin the continual release of health-care related datasets.

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