Editorial

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Health Avatar: An Informatics Platform for Personal and Private Big Data

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The Health Avatar project was started in 2010 with the goal of developing a software platform for personalized management of health information by the Systems Biomedical Informatics Research Center at Seoul National University College of Medicine, Seoul, Korea. The project was named 'Health Avatar', and it is expected to be completed 2017. All health related data about a person, healthy or diseased, was conceptualized as the person's Health Avatar, while data is defined as all forms of digitally coded results of observation or measurement. Therefore, the Health Avatar of a person is defined as all medical data obtained or obtainable from the person by all forms of observation and/or measurement.

The Health Avatar CCR Plus (CCR+) is a smartphone-enabled personal health record (PHR) system supporting ASTM CCR (Continuity of Care Record) and HL7 CCD (Continuity of Care Document) standards for the iOS and Android mobile environment. CCR+ has three layers of data integration, including personal genome data (or Foundation Self), PHR (or Physiomic Self), and personal lifelog (or Quantified Self), which are uniformly stored, accessed, and managed in the mobile smartphone environment. Personal genome data are stored as a slightly modified variant call format (VCF) file. Clinical data elements of CCR are individually created and registered to the Biomedical Metadata Standard for Health (BMeSH) server [1,2] supporting the ISO/IEC 11179 metadata registry (MDR) standard [3]. CCR+ was named after the enhanced extensibility and semantic interoperability of the CCR/CCD standard with the metadata technology. CCR+ functions as a (data) surrogate of a person in an integrated distributed intelligence platform or the Health Avatar Platform (HAP).

HAP is a run-time environment for distributed intelligence programming of health agents, which are expected to provide a variety of health services to CCR+ surrogates with privacy-controlled access to personal and private big data using open application programming interfaces (APIs). One can login with her/his own avatar to the platform, where individual avatars interact with distributed and healthcare-giving agents for real-time personalized medicine.

The platform provides open APIs for the developers of distributed agents, a broker to match individual avatars and agents, a secure communication channel for strict privacy control as well as (avatar and agent) profile registries, contract manager, and shared resources. The open APIs permit intelligent agents to have authorized (read and write) access to an avatar's clinical, genomic, and lifelog data. No storage of personal data is allowed in HAP, except for a very limited set of personal profiles, for privacy reasons; i.e., HAP is free from personal data centralization.

Recently, the semantic interoperability of CCR+ has been successfully demonstrated with secure PHR data exchange in a nation-wide pilot system of voluntary patients and five major healthcare institutions; Division of Biomedical Informatics, Seoul National University, Ajou University Hospital, Gachon Ghil Hospital, Pusan National University Hospital, and Chonnam National University Hospital [4]. It has been demonstrated that patients' access to their own health data from hospitals can be greatly benefited by the Health Avatar project, which in turn enables personalized health data management with personal smartphones.

This issue introduces some of the successful distributed agents that have been developed by using the open HAP APIs and providing healthcare services to users by accessing and analyzing clinical, genomic and lifelog data of their CCR+. Park et al. [5] further extended their MDR-based CCR+ data model and proposed a multi-layered validation method for the CCR+ XML files exchanged to improve syntactic and semantic interoperability. Kwon et al. [6] developed a very useful application for capturing and managing physical activity measurements obtained from the accelerometer and gyroscope of a smartphone at 50 Hz. One's physical activity patterns are analyzed and categorized into different states of walking, running, sitting, standing, and lying down periods with metabolic equivalent (MET)-based calorie consumption and then sent to the user's CCR+ through HAP API functionalities. Other HAP-based applications, such as drug similarity search based on genomic data and pathology data exchange, are also presented [7,8].

As Jeon et al. [9] has correctly pointed out, the personal health data managed by the current healthcare apps are not only poorly organized or even misleading; an additional issue is that they are not represented in a format that can be uniformly managed, accessed, or analyzed. The personal health data of each app is separately managed in silos. Managing personal health data is even harder than creating healthcare service apps for developers.

The conceptual framework of Health Avatar representing all health data about an individual that are personally and privately managed by the person in her/his smartphone provides a uniform way of storing, retrieving, and managing personal health data such that it accelerates the development of healthcare service apps (or agents). Data created by different agents, such as daily calorie consumption, glucose level, and environmental exposure, are uniformly captured as parts of the whole personal health data or avatars and can be reused by different agents. Not only the communication between avatars and agents is securely managed, but also the entire lifecycle of exchanged data is strictly controlled by the platform. The Health Avatar CCR+ and Platform empower patients for continuity of care and personal health promotion with improved privacy control over their own health information.

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