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## Towards Improving the Portability of Personal Healthcare Data

セディック, アデル, モハメド, アブドゥルラーマン, アルアッバシ

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氏 名: セディック アデル アルアッバシ

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## 論文内容の要旨

A Personal Health Record (PHR) is digitized and stored for efficient patient management in hospitals or clinics. At the patient side, the health records are not digitally stored.

Nowadays people move from one place to another more than before. However, the digitized past health records do not move with them. The digitized data belong to the hospitals and the patients do not have digital access to them. Past efforts produced standard medical record formats and information messaging protocols. These standards were focused to enable interoperability among organizations. The reality is that the standards are not widely deployed and many hospitals are using their own stand-alone systems. Therefore, it is technically difficult for an individual to digitally carry standard PHRs with him/her. Healthcare data portability for an individual remained a big issue.

This research aims to improve PHR portability for an individual. We introduce a new application; we call it a PHB (Personal Health Book). This application will allow an individual to import PHRs from different hospitals, store them and share with other parties. The PHB can sit on an individual storing device (e.g. USB drive or a smart card) or can be installed as a web application.

In this work, we focused on three technical challenges: (1) How to import PHRs from multiple heterogeneous sources efficiently (2) How to store the imported PHRs in an efficient manner in terms of capacity and accessibility, and (3) How to export viewable PHRs to other trusted parties.

In this research, we proposed three items to address the above three technical challenges: (1) developed an import algorithm to read PHRs from heterogeneous structured hospital healthcare applications without loosing or missing any data (2) designed a decomposed database to efficiently store the imported data consuming minimum capacity, and (3) developed an algorithm to export the data to trusted parties.

In order to prove our proposed concept and monitor the performance, we developed a simulation to find the most optimum database design for the PHB database. We compared long database design and decomposed design in terms of number of rows generated, number of unnecessary data repetition, database size growth, number of generated cells, and size of wasted memory. The simulation constitutes 10,000 records, in different 3 cases (12, 2 and 5 number of

hospitals), each case has different maximum number of unique items (up to 10, 0 and 5).

On an average the decomposed database design performed better than the long database design with 16.7% in number of rows generated, 88.9% in number of unnecessary data repetition, 40.29% in database size growth, 42.84% in number of generated cells and 79.87% in size of wasted memory.

The second part of the simulation was used to evaluate the designed database behavior in terms of data items storing and size. On an average (of first 10 records) the stored items were 106.28% less than the imported items from various PHRs, that is 984 bytes stored compared to 3,216 bytes imported.

Finally, we tested the above-mentioned algorithms and the database design of our proposed PHB application by importing PHRs from two different hospitals - one from our Portable Health Clinic (PHC) Project Database in Bangladesh and one from a Japanese hospital. The database structures of the hospitals are unknown to our PHB application. The imported PHRs were transferred to XML format manually. We set a schema with minimal restrictions to validate the XML documents. With the help of the proposed import algorithm, the imported PHRs were successfully stored into the PHB database. Then we exported the stored data and viewed them by using a web browser. We could read all the PHR data. However, the Japanese PHRs were manually translated and human bias was implied. The assumption was that the dictionary performed accurately. This can be treated as an ideal scenario.

The simulation environment we developed this time considered limited cases. This may not reflect the real time scenario. Healthcare data is very personal and thus sensitive. It is hard to test the portability of healthcare data by using real life data. The algorithms, and the database design need to be deployed for accurate evaluation. We have the plan to test the PHB in our current PHC Project running in Bangladesh.