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The Vision of Personally Managed Health Data: Barriers, Approaches and Roadmap for the Future

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Call for Papers

The Vision of Personally Managed Health Data: Barriers, Approaches and Roadmap for the Future

Due date for submissions: September 30, 2018

Advancements in healthcare practice, limitations of traditional healthcare processes, and the need for flexible access to health information have created an ever-growing demand for electronic health data systems. One element in this trend has been systems collecting and managing personal health data for individuals. Those systems provide citizens and patients with the ability to become more active in managing their own care, to combine data from multiple sources, and to assist individuals with the organization and interpretation of their own health and illness experiences. Through such systems, patients are able to provide daily life-status information, to maintain their own records of medical exams, and to define the access rights to their personal data, leveraging that access to improve their personal health and to manage any diseases that may affect them.

Despite their tangible benefits, existing systems collect and exploit only limited, fragmented information, not unveiling their real potential. Their uptake has been slow mainly due to the lack of usability, integration, and interoperability [1] as well as challenges related to ethical and security considerations and to the implementation of added-value services [2, 3]. Most of the developed systems are trying to cover either very limited or an extremely wide set of clinical parameters and health-related uses, failing to provide appropriately usable, clean, and simple interfaces, ignoring also the cognitive issues in the design and use of such systems [4, 5]. Ethical, security and data ownership issues have limited the integration with other service providers and electronic health records (EHRs) [6], and there are challenges related to acceptable methods for sharing information among patients, relatives, friends, physicians, and researchers [7, 8]. The lack of trust, the inefficient access control, and often inadequate security mechanisms on these systems complicate their adoption, whereas the benefit of added-value services that leverage the collected information is not always obvious [2, 3, 9].

There is, however, a growing interest in citizen/patient empowerment and an increasing availability of mature technologies for hosting extensible and secure health services. In addition, with the prevalence of mobile health applications [10], there is a robust interest by individuals regarding the use of personal health applications [7]. We accordingly are seeking special issue papers that explore in depth new methodological approaches for overcoming barriers to the adoption of personal health systems and other forms of patient-centered medical record systems.

Examples of potential topics for contributions to this issue include, but are not limited to, novel methodologies or approaches for tackling the following issues:

- Novel architectures and delivery platforms for personal health data
- Analyses of barriers to the adoption of systems collecting, managing and analyzing personal health data
- Scalability and performance, e.g., using cloud infrastructures

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