

Abstract

The aim of this research is to identify the role that identification plays in supporting identified stakeholders in the care and management of patients with the disorder Phenylketonuria. The research idea has come from the challenges identified with interoperability of information in electronic health record systems as identified in the paper by Chen et al, 2015.

The motivation for this research is improved patient safety and data quality. To obtain the highest standards of patient safety, data quality needs to be improved. Interoperability of the data is integral and needs to play a major role in the eHealth strategy. Furthermore, it should be incorporated into the development plans of future integrated healthcare information systems (HIS).

The research question is 'What role does identification play to support Metabolic Dieticians and Scientists for care and research of patients with Phenylketonuria (PKU) – An information modelling perspective'. The answer will focus on three key areas. Firstly, the role of identifiers in integrated healthcare and research using an EHR. Secondly, identifier issues focusing on modelling and quality. Finally, identifying uses carried out by dieticians and scientists using information for care and research of patients with PKU. These use cases were identified by conducting focus groups using the 1-2-4-all liberating technique (McCandless, 2010). From researching these key areas, there is an anticipation that the results gathered could influence future standards for EHR communication.

Strategies were introduced which highlighted the current state and plans for health care in the future. For successful execution of an eHealth strategy, research showed it to be dependent on fundamental enablers being present. The key themes presented were integration, interoperability, and standardisation. The literature review identified a gap where the importance of identifiers should be included for future research and work.

The research process consisted of 11 stages. The research question leads the topic to be reviewed in the literature. Ethical approval was received from Temple Street Children's university hospital and Trinity College Dublin. Focus groups were held with scientists, dieticians, and health informaticians. Results from these were categorised, illustrated and tabulated to display the results. The synthesis of the literature and practical work led to the creation of personas, a UML activity diagram, and use cases.

EURO-CAS, European and international standard organisations like CEN and ISO along with national strategies like the EHR persona project from eHealth Ireland together create a standards accreditation process. The positive is that stakeholders from the National, European and International forums influence the decision making. The benefit of having a wide decision-making base is that the process is rendered more robust and complete. The practical work completed will hopefully contribute to the standards process for EHR communication.

For the successful implementation of a patient-centric eHealth system, there needs to be a shift from reactive to proactive healthcare. The research represented in this dissertation concerns itself with the role of identities in this shift, through the management of patients with Phenylketonuria (PKU).