
CONFERENCE ABSTRACT**Patient Engagement in the development of a National Electronic Health
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The characteristics of health information and its flow throughout health and social care delivery and research is integral to quality integrated care. Electronic Health Record(EHR) systems can facilitate appropriate availability of quality, clinically sensible information to decision makers when and where required. Development of EHRs is very challenging due to the heterogeneity of information producers and consumers, the care, research, regulation and development environment and the range of current and future uses and use contexts for the record. There is also the complexity of the system itself to consider. EHRs are longitudinal and comprise many interdependent aspects e.g. architecture, data storage and user interfaces to suit use settings within care and research organisations as well as home or community environments.

Traditionally, patients have not been included in the development of such large scale, complex, national eHealth systems even though they and their carers are in a unique position to describe and comment on the characteristics of information flow across the entire system. In Ireland, the Office of the Chief Information Officer(OOCIO) has placed significant focus on our national EHR development. Some new groupings e.g. the council of clinical information officers (CCIO) have formed and relationships between existing stakeholders and patients are developing and strengthening. One of the more innovative, patient inclusive activities of the OOCIO involves development of personas that will be representative of potential users of our national EHR and will directly influence procurement of our national EHR.

The development process for EHR systems is complex with unstable user requirements, a variety of independent stakeholder groupings, interdependent components, essential flexibility and reliance on human skills and teamwork. These characteristics place EHRs squarely in the domain of what are called wicked systems(1). One crucial factor in successful development and adoption of wicked systems is stakeholder engagement with multiple engagement processes required, usually over a long period of time. Due to lengthy project timescales, support and resources it is not usually possible to get consistent, continual stakeholder engagement for the duration of development of a national EHR. So, care needs to be taken on engagement processes, opportunities and outputs.

The authors are collaborating with various stakeholders including the national standards authority of Ireland (NSAI), the health informatics society of Ireland(HISI), regulation authorities, the OOCIO, the CCIO, Higher education institutes, industry, patients and patient organisations. This paper will report on three aspects of this collaboration. Firstly, describing our national EHR development environment. Secondly, identifying how patients and their carers could potentially engage meaningfully alongside other stakeholders in the development and adoption of our National EHR. Finally, engagement work to date will be presented including patient persona development with the OOCIO, engagement with NSAI/HSE advisory panel to comment on information standards aspects for our national EHR, a patient focused workshop and feedback session at the HISI annual conference which captured views on and possible next steps for our national EHR development and on the educational front, inclusion of patients in participatory design classes on the MSc in Health Informatics in Trinity College Dublin.

References:

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