CONFERENCE ABSTRACT

# Information When and Where Needed for Safe and Effective Integrated Care

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**Introduction**: Clinical information when and where needed is a fundamental requirement to realising the promise integrated health services and care. Unco-ordinated patient care, conflicting advice, delays in diagnosis and treatment, and redundancy in the system with unnecessary repetition of information gathering and diagnostic investigation are the hallmark of a lack of shareable healthcare records. An integrated electronic patient record (EPR), stored centrally can diminish fragmentation as the same patient information is available to each discipline involved in patient care regardless of location, multiple users of the record can have simultaneous access to the record, and an electronic record is readily interrogated to support service monitoring and planning.

**Aim**: To improve integration of epilepsy care and services within and between healthcare agencies by incorporating a novel state-of-the-art secure web-based EPR into service delivery across Ireland.

**Methods**: Using mixed methods of ethnography, interviews, focus groups, surveys and audits, the role of shared information in facilitating integrated care was examined. This entailed engagement with people with epilepsy (PWE) and their carers, as well as healthcare providers from multiple health service: epileptologists, epilepsy specialist nurses, researchers, health service managers, general practitioners, general practice nurses, community nurses. This analysis of the epilepsy ecosystem in Ireland informed the requirements for the development of the National Epilepsy EPR. In an iterative process of design and development these requirements were translated by software engineers into the epilepsy EPR. Implementation of the system into clinical practice also occurred incrementally with associated workflow re-design.

**Results**: Over a 12year period, the National Epilepsy EPR in Ireland has grown from a concept to a system that contains the longitudinal healthcare records of approximately 7000 PWE. It

comprises functionality to capture and record information required for optimal patient care: e.g. epilepsy history, social history, medications, investigations, co-morbidities. The system is in daily use in 12 specialist epilepsy care sites across Ireland supporting range of tasks including out-patient services, epilepsy surgery care, epilepsy telephone advice line, outreach to intellectual disability sector and to obstetric care. It is providing timely access to clinical information, promoting better communication between clinicians and supporting clinical research.

**Conclusion**: Our innovative project is leading the way in Ireland in exploiting (ICT) to enhance quality and safety of chronic disease management while containing cost. While the clinical field of interest is epilepsy the learning is certainly applicable to the management of other similarly complex chronic conditions.  The National Epilepsy EPR has been designated a Lighthouse Project for eHealth Ireland to demonstrate the potential of technology to drive better-integrated care.

**Limitations**: Lack of interoperability between different electronic health record systems poses a challenge for the National Epilepsy EPR. However, this is currently being addressed by the wider Irish health service.

**Lessons learned**: Achieving success with an EPR requires courage and patience.  Engagement with clinicians and patients is key to understanding the ecosystem so that the appropriate and sustainable technical solution is put in place.

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