

CONFERENCE ABSTRACT

Co-designing Integrated Care Using Participatory Action Research [PAR]: The Epilepsy Partnership in Care [EPiC] Project

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Introduction: Concepts of “Co-design”, “Co-creation”, “Co-production” are currently used by those promoting innovation to improve integration of healthcare services. They each reflect a practice where both the consumer and the provider of a service/product work together, in partnership, to make something happen. In response to the fragmentation of traditional health services Integrated Care has become a core value of current and emerging health service reforms worldwide. Models of Integrated Care are promoting enhanced co-ordination of care for individuals, better continuity across organisational boundaries and healthcare sectors and improved efficiencies and use of limited health care resources.

While Integrated Care is high on the health reform agenda, this does not mean it is actually happening. Using epilepsy as a probe, the National Clinical Care Programme for Epilepsy in collaboration with academic partners from RCSI, Maynooth and Dublin City Universities is conducting a project entitled “Epilepsy Partnership in Care (EPiC)” to explore and advance the integration of care and services provided.

Aim: The EPiC Project aims to:

realise the promise of Integrated Care for people with epilepsy in Ireland.

develop a fine-grained understanding of the provision of services and the experience(s) of living with epilepsy.

identify and act on opportunities for promoting better integration of epilepsy services and care.

Methods: Ethnographic field work (in-depth interviews, observational field work and focus groups) initially explored Integrated Care in the Irish epilepsy domain. This involved engagement with people with epilepsy (PWE), families, carers, community resource officers, healthcare providers from multiple health services (epileptologists, epilepsy specialist nurses, health service managers, general practitioners, community nurses) at various sites across

Ireland ranging from the patient living room to the hospital ward. From this field work, four contexts for creating participatory action research (PAR) teams were identified.

Results: 32 people with epilepsy, 6 community resource officers, 4 consultant epileptologists, 13 epilepsy specialist nurses, 3 intellectual disability sector nurses, 3 general practitioners, 2 health service managers and 1 epilepsy service manager have participated in the project.

The exploration has elucidated the full range of actors involved in the epilepsy ecosystem, and the nature of their interactions with each other and their surroundings. Evidence of (expert epilepsy clinicians), gaps in (role confusion), and challenges to (competing priorities) integration of epilepsy care have emerged as have opportunities for advancing it through PAR research. Four PAR teams (Community Care; Education; Adolescent Transition; Telephone Advice) were formed into collaborative partnerships between people who receive and deliver epilepsy care and iteratively explored the meaning of Integrated Care while simultaneously identifying both opportunities for and challenges to achieving sustainable integrated care.

Conclusion: The EPiC project recognises people with epilepsy in the context of their whole lives not just their medical condition. It is collaboratively observing and cataloguing the diversity of needs, and experiences within the epilepsy care domain in Ireland from the day-to-day life of the person with epilepsy to the experiences of those who deliver services and care. EPiC will create the conditions for intelligently designing and implementing integrated care.

Keywords: integrated care; co-designing; participatory action research; patient centred care; healthcare reform
