

CONFERENCE ABSTRACT

The Patient Narrative Project - Phase One

17th International Conference on Integrated Care, Dublin, 08-10 May 2017

Derick Mitchell¹, Clare Hudson², Tomas Carroll³, Ava Battles⁴, John Church⁵, Anne Lawlor⁶, Jason Last⁷, Clare Duffy⁸, Anne McFarlane⁹, Claire Kinneavy⁵, Catherine Darker¹⁰, Gaye Stephens¹¹

1: Irish Platform for Patient Organisations, Science and Industry (IPPOSI) , Ireland;

2: Health Service Executive, Ireland;

3: Alpha One Foundation, Ireland;

4: Multiple Sclerosis Ireland, Ireland;

5: Arthritis, Ireland;

6: 22q11, Ireland;

7: School of Medicine & Medical Science, University College Dublin, Ireland;

8: Family Carers, Ireland;

9: Graduate Entry Medical School, University of Limerick, Ireland;

10: Department of Public Health & Primary Care, Trinity College Dublin, Ireland;

11: Centre for Health Informatics, Trinity College Dublin, Ireland

In 2012 the Irish Department of Health set the agenda[1] in Ireland for the creation of ‘a new integrated model of care that treats patients at the lowest level of complexity that is safe, timely, efficient, and as close to home as possible’. To enable the delivery of integrated models of care five Integrated Care Programmes are being established within the Irish Health Service Executive under the office of the Clinical Strategy and Programmes Division (CSPD)

Although ‘integrated care’ has many definitions, it is commonly agreed that its realisation has to result in better outcomes and experience of health services for the individuals who use them, whereby services are well co-ordinated around the needs of the user. In addition, discussions on the development and delivery of services must hold the voice of the user at its core and seek ‘to impose the patient perspective as the organising principle of service delivery’.[2]

The ‘Patient Narrative Project’ was initiated in late 2016 to, for the first time in the Republic of Ireland, deliver the patient / service user perspective on what should be expected from person-centred coordinated care and to guide the development of current and future services and strategy through the office of the CSPD.

The Irish Platform for Patients’ Organisations, Science & Industry (IPPOSI)[3], with their proven experience and expertise in harnessing a coherent and critical voice of service users has led the first of three phases of the project. This paper describes phase one of the project (which ends in April 2017) in which service users and their organisations will co-produce:

a set of generic descriptors for what person-centred co-ordinated care looks and feels like from the Irish service user perspective and

a definition for 'person-centred co-ordinated care' that is shared, understood and used by service users and staff at all levels of the health service in Ireland

IPPOSI has lead an evidence-based, narrative enquiry methodology to hear and collate experiences of service users and patients in Ireland who need care over time from multiple services, as well as their carers and families and the health staff relating to their experiences. The experiences will be translated into descriptors and a definition of person-centred co-ordinated care that will be written not just for the experts, but for patients, people, families and carers.

The goal is that the descriptors and definition of what good integrated care and support looks and feels like for people will be adopted nationally. They will be used to guide policy, strategy and design, and as a guide to what teams at local levels should be aiming to achieve practically, in their efforts to integrate services around patient, family and carer needs. Phase two of the project will use the generic descriptors to develop a standard process of engagement with service users that will allow a higher volume of their narratives and experiences to be heard and used to benchmark, guide and develop health services.

References:

1- Irish Department of Health. Future Health – A Strategic Framework for Reform of the Health Service 2012–2015. Dublin; 2012

2- Lloyd & Wait., Integrated Care; a guide for policymakers. London. Alliance for Health and the Future. 2005;7

3- Available from: www.ipposi.ie

Keywords: patient narrative; person-centred co-ordinated care
