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CONFERENCE ABSTRACT

Development of a national self management support framework for Ireland, for patients with Cardiovascular Disease, COPD, Asthma and Diabetes

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Introduction: This presentation describes the approach taken in development of the Irish national framework for self management support for the major cardiovascular and respiratory diseases and diabetes, and early implementation issues. The draft framework is currently going through a consultation and will be finalised later this year.

The health service executive (HSE) in Ireland provides health and social care. All health services except general practitioners (GPs) and practice nurses are provided by the HSE. There is also some private provision of mainly secondary care services. Sustainability of modern health services is a concern in Ireland as abroad. Reforms are based on integrating services, engaging patients to self care, and leveraging e-health technology

Self management support is cited as a key component of the chronic care model, although the least developed, and includes the provision of information, education and other supportive interventions to improve individuals' confidence and skills in managing their health conditions.

Activities of health services to support self-management can be categorised along a continuum, with passive information provision about healthy behaviours and other 'technical' interventions at one end of the scale and initiatives that more actively seek to support behaviour change and increase self-efficacy at the other.

Research indicates that support for self management for people with chronic conditions is lacking in Ireland, and was identified as a priority for patient groups in the National Patient Consultative Forum in 2012.

The Health Services Executive national service plan 2015, included development of a national framework for self care for patients with cardiovascular disease, chronic respiratory diseases and Diabetes. Implementation of the framework is a national priority (Healthy Ireland in the Health Services. National Implementation Plan 2015-2017).

Population: All adult patients in the Republic of Ireland, diagnosed with - or at high risk for development of- cardiovascular diseases, chronic respiratory diseases and Diabetes.

Key stakeholders: Patients; patient representative organisations; Health services senior management, clinical strategy and programme leads, primary care and acute hospitals divisions; clinical, nursing and allied health professionals.

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Key Findings: Development of the national framework involved the following key stages and tasks

• Scoping and planning of the project involved informal consultation with selected key stakeholders – a wide range of stakeholders was identified and strong interest from within the voluntary sector and patient advocacy groups.

• A Health Technology Assessment (HTA) of self management supports was commissioned to examine the efficacy and cost effectiveness of generic and disease specific interventions and applicability in the Irish setting. This identified strong evidence for disease specific interventions such as pulmonary rehabilitation and cardiac rehabilitation; asthma education and action plans; diabetes structured education and stroke rehabilitation; less strong evidence for generic supports. Other evidence, particularly on implementation internationally, was referenced in the framework

• A survey was carried out across the regional Community Health Organisations (there are 9 in Ireland) to identify self management supports and programmes already available for each of these disease groups. This together with other sources identified under-provision of evidence based self management supports. Provision is inadequate due to various factors e.g. lack of resources for chronic disease management in primary care; reduction of level of services due to economic recession.

• Patient consultation carried out in 2012 on the subject of long term conditions management was reviewed to inform the development of this framework – support for self management; better provision of information; the voluntary sector as important partners emerged as themes.

• The HTA, data from consultations, survey results, and information from Irish research and international practice, informed the draft framework. An advisory group of clinicians and key stakeholders has been invited to come together to agree the draft framework (April 2016).

• An external provider will be involved in broader consultations on the framework, prior to finalisation (September 2016).

Highlights: Whole system support will be necessary to implement this framework which proposes greater involvement of GPs in supporting self management and also greater partnership working with the voluntary sector. National management will be required to ensure implementation and coordination of all aspects of the framework: working with the HSE and primary care; building partnerships with the voluntary sector; and linking with regional health care structures.

Provision of evidence based self management support interventions needs to be expanded. Generic supports such as provision of information on long term conditions; supports for behaviour change and medication adherence also need to be developed, taking in to account the requirements of people with multiple conditions.

Patient empowerment should be prioritised, including the necessary fundamental transformation of the patient–caregiver relationship into a collaborative partnership, as advocated by the European Patients Forum's campaign for Patient Empowerment.

The framework proposes that this partnership should be utilised to produce a self management plan to jointly identify and help meet the individual patient's self management needs.

Health care workers need to be equipped with the necessary skills and knowledge to support self management.

Self management support is often poorly understood as a concept by health care providers. This is confounded by interchangeable use of a number of terms e.g. self care and patient centred care. The National Framework will adopt core definitions of self management and self management support. This is central to increasing all stakeholders' understanding of SMS within the Irish healthcare system.

Innovation should be supported with dedicated funding, and evaluation of new programmes built in from the start.

Conclusions: Continuing clinical, organisational and system support will be necessary to implement support for self management and the voice of the patient must be included in new and ongoing provision.

Keywords: chronic disease; self management support; health services