



# Living Well with a Chronic Condition: Framework for Self-management Support

National Framework and Implementation Plan for Self-management Support for  
Chronic Conditions: COPD, Asthma, Diabetes and Cardiovascular disease



**Self-management  
Support**



This framework and implementation plan was developed by a Health Service Executive (HSE) working group, under the leadership of Dr. Orlaith O'Reilly National Clinical Advisor and Programme Lead Health and Wellbeing, with the support of an advisory group. Membership of the working group is listed below and membership of the advisory group is listed in Appendix 1.

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**Self-management  
Support**

**National Framework and  
Implementation Plan for  
Self-management Support  
for Chronic Conditions:  
COPD, Asthma, Diabetes and  
Cardiovascular Disease**

# Foreword

Healthcare provided by professionals represents just the ‘tip of the ice-berg’ in supporting patients with chronic conditions. The majority of care for chronic conditions is provided by the person themselves. The majority of people over 65 years have two or more chronic conditions. Our population aged 65 years and over is growing by approximately 20,000 each year, and with it the numbers living with chronic conditions. Enabling our health services to cope with the increased number of people living with chronic conditions, will depend on the extent to which people engage with their own health and health conditions. Supporting and empowering people in managing their conditions as well as possible can improve quality of life and reduce the impact on health and the likelihood of complications, hospitalizations and deaths from these conditions.

The National Self-management Support Framework for Chronic Conditions: COPD, Asthma, Diabetes and Cardiovascular disease, sets out how we in the health services, and working with patients and our partners across the wider system, want to support patients to engage with and manage their conditions, through collaborative relationships and supportive interventions.

Supporting self-management is inseparable from high quality care for people with long term conditions and is a priority for patients. Organisational and clinical leadership will be essential to support the culture change necessary in moving from reactive to more pro-active and person-centred care, with the patient an active partner in their own healthcare.

Self-management support is a critical element of our journey toward building a sustainable health service. This Framework, focusing on people living with chronic conditions, supports the implementation of *Healthy Ireland* throughout the health services and beyond. The concept of self-management is one that cuts across the prevention spectrum (primary, secondary and tertiary prevention) by establishing a pattern for health early in life and providing strategies for mitigating illness and managing it in later life. The Framework and the approach set out, lays the foundations for the work that is required over the

months and years ahead. This work, when fully implemented over a number of phases, will re-shape and re-direct our focus toward the patient, their lived experiences coping with and managing their health and their condition. It will support a collective shift in emphasis toward creating enabling, supportive and transformative environments that put the patient first, realising the value of active participation and effective collaborative interactions between patients and healthcare staff.

Finally, this Framework and the work ongoing to implement it, will support a shared, common, evidence-based understanding of how particular models of care can better support patients and reduce the pressure on healthcare services into the future. We look forward to building support and increasing resources for the implementation of this framework nationally, regionally and locally in collaboration with Community Healthcare Organisations and Hospital Groups; in collaboration with our patients and with partners in the wider health system, including general practice, academia, voluntary groups and communities. Above all, we look forward to the positive impacts on the health and wellbeing of our patients and their families that will ensue.

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# Introduction

Every day, people with long-term health conditions, their family members and carers will make decisions, take actions and manage a broad range of factors that contribute to their health. Self-management support acknowledges this and supports people to develop the knowledge, confidence and skills they need to make the optimal decisions and take the best actions for their health. Evidence of positive outcomes highlights the benefit of supporting people to manage their own health as effectively as possible. These benefits can be felt by people with long-term health conditions, health professionals, and the health services<sup>1</sup>.

Chronic diseases are recognised as a major component of health service activity and expenditure, as well as a major contributor to mortality and ill-health. Thirty eight percent of Irish people over 50 years have one chronic condition, 11% have two or more of eight chronic conditions<sup>2</sup> and 65% of adults over 65 years have two or more chronic conditions<sup>3</sup>. The prevalence of diabetes, cardiovascular and respiratory disease continues to increase due to our ageing population and prevalence of risk factors<sup>3</sup>. People with chronic diseases presently utilise around 70% of health services resources<sup>4</sup>. They are more likely to attend their GP, to present at Emergency Departments, to be admitted as inpatients and to spend more time in hospital, than people without such conditions. Approximately 80% of GP consultations and 76% of hospital bed days used are related to chronic diseases and their complications<sup>5,6</sup>. It has been estimated that in Ireland approximately 1 million people suffer from heart disease, diabetes or respiratory disease<sup>7</sup>. For all chronic conditions the prevalence is significantly higher in people with lower levels of education and in lower socio-economic groups<sup>6</sup>.

Supporting people to self-manage their health conditions through systematic provision of education and supportive interventions increases their skills and confidence and improves outcomes for patients – ranging from quality of life and clinical outcomes, to reduced healthcare utilisation including hospitalisation<sup>8</sup>. Reported costs vary according to

the intensity of the intervention, but are typically low relative to the overall cost of care for the chronic condition in question and in some instances, can result in cost savings through reductions or shifts in healthcare utilisation<sup>8,9</sup>.

Self-management support is an important aspect of the Integrated Care Programme for the Prevention and Management of Chronic Disease, and is key to delivering person-centred care, in which patients are empowered to actively participate in the management of their condition.

It is closely aligned with the HSE goal of promoting health and wellbeing as part of everything we do so that people will be healthier<sup>10</sup>.

Self-management support interventions are any interventions that help patients to manage portions of their chronic condition or conditions through education, training and support<sup>8</sup>. The most effective self-management support interventions are multifaceted; tailored to the individual (their culture and beliefs) and tailored to specific conditions. They are underpinned by a collaborative relationship with a healthcare professional within a healthcare organisation that actively promotes self-management<sup>11</sup>.

This framework sets out what the health services must do to support people with chronic conditions in managing their conditions. The provision of interventions at patient level is not enough. International evidence indicates that we must also take action at the levels of healthcare professionals – education and training; the organisation – including resourcing and coordination; and the wider system through working in partnership with GPs, academia and voluntary organisations, and patients themselves, in order to successfully support self-management.

## **Dr. Orlaith O'Reilly,**

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# Executive Summary

## Introduction

Chronic diseases are recognised as a major component of health service activity and expenditure in Ireland, as well as a major contributor to mortality and ill-health. Every day, people with chronic health conditions, their family members and carers will make decisions, take actions and manage a broad range of factors that contribute to their health. Self-management support acknowledges this and supports people to develop the knowledge, confidence and skills they need to make decisions and take actions in relation to their health conditions.

This framework provides an overview of self-management support and offers recommendations for implementation of self-management support in Ireland, along with a plan for implementation and priorities for early implementation.

The development of this framework was guided by a national advisory group and was informed by Irish and international evidence, including a Health Technology Assessment conducted by the Health Information and Quality Authority (HIQA). An extensive consultation was carried out which included healthcare professionals within and outside the HSE; patients and carers; representatives from the voluntary and community sector; and the department of health.

## What is Self-management Support?

Self-management support is the systematic provision of education and supportive interventions, to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support. It is an important element of person-centred care, acknowledging patients as partners in their own care, supporting them in developing the knowledge, skills and confidence to make informed decisions.

## Rationale and Mandate

Healthcare provided by professionals represents the 'tip of the ice-berg' in supporting patients with chronic conditions. The majority of care for chronic conditions is provided and coordinated by the person themselves, with the support of family members and carers, at home and in the community. For example, a person with diabetes has on average 3 hours contact a year with their healthcare team. They self-manage their condition for the remaining 8757 hours in the year – dealing with symptoms; the effects of treatment; remembering to take medications; trying to change behaviour; dealing with the effects on emotions and relationships; and on the activities of daily living. There is good evidence that certain interventions which support self-management, improve outcomes for patients – ranging from quality of life and clinical outcomes, to reduced healthcare utilisation including hospitalisation. The Patients' Consultative Forum in 2011 identified self-management support as an integral part of clinical care for people living with chronic conditions. Support for patient self-management is a key element of person-centred care, one of the four domains of quality in Irish healthcare.

The ageing population and prevalence of risk factors in the population means that the prevalence of these chronic conditions will continue to increase year on year. *Healthy Ireland in the Health Services - National Implementation Plan* includes actions to develop a national framework for self-management support and development of services accordingly; and to increase the proportion of patients utilising self-care and self-management supports. Self-management support is a work stream of the Integrated Care Programme for the Prevention and Management of Chronic Disease.



## Principles of the Self-management Support Framework

There are four overarching, evidence-based principles of self-management support which underpin this framework:

1. Patients should be seen as active partners in their healthcare
2. Supporting self-management is inseparable from high-quality care for people with long term conditions
3. Investment should be prioritised in those interventions for which there is good evidence of clinical effectiveness, and
4. A whole system approach to implementation of self-management support should be taken.

## Self-management Support Interventions

These are any interventions which help patients to manage portions of their chronic conditions through education, training and support. The most effective self-management support interventions are those which are multifaceted, tailored to the individual and tailored to specific conditions; and are underpinned by a collaborative relationship with a healthcare professional within a healthcare organisation that actively promotes self-management.

Core components of these interventions include education; psychological strategies; practical support for physical care; action plans for use in deterioration in conditions subject to exacerbations; and social support.

Evidence from a patient survey indicates a lack of support for self-management in areas such as information about their condition and provision of care plans. A survey of Community Healthcare Organisations (CHOs) found that a range of supports are being provided but with wide variation in provision. This survey may form the baseline for the development of local directories of available self-management supports. Self-management support is better developed in Donegal than other areas. Needs assessments have indicated that provision of some key self-management supports which are supported by the strongest evidence of effectiveness (including cardiac rehabilitation, diabetes structured patient education and pulmonary rehabilitation) are well below required levels.

Regular clinical review and care planning, which can enable proactive management of chronic disease, are not currently facilitated in General Practice in Ireland.

## Whole System Model for Self-management Support for Chronic Conditions

A whole system approach to implementation is recommended to support self-management of chronic conditions. Within the whole system model, key actions are required at the levels of the patient, the professional, the organisation and the wider system.

**Individual** - Patients should have access to disease specific interventions which support their self-management e.g. cardiac and pulmonary rehabilitation, diabetes structured patient education, provision of asthma action plans. Generic interventions should also be provided including regular clinical review, care and support planning, provision of information, health behaviour change support, peer and social support, generic self-management education, and carer support.

**Healthcare professionals** - Healthcare professionals should be provided with the skills and information they need in supporting self-management, including adopting a person-centred approach and encouraging patient engagement.

**Organisation** - The healthcare organisation should provide policy support; financial support and resources; coordination of delivery; technology supports; quality assurance and evaluation.

**Wider system** - Wider system support is provided through partnership with non-HSE healthcare staff such as General Practitioners (GPs), practice nurses and pharmacists; voluntary organisations and service users; community organisations; and academia.

Effective self-management support should be underpinned by a collaborative, communicative relationship between the patient and a trusted healthcare professional. A self-management plan should be jointly agreed, through a process of personalised care planning, between the patient and a trusted healthcare professional.

## Implementation

Following on from the recommendations, are the actions in the high level implementation plan (Section 7). Some recommendations have been prioritised for early implementation based on likelihood of maximum beneficial impact, and strongest evidence. These are:

- Standardise and increase provision of cardiac rehabilitation
- Standardise and increase provision of pulmonary rehabilitation
- Increase provision of standardised diabetes structured patient education
- Increase provision of care planning, initially focusing on practice nurse training on asthma management, including skills training and asthma action plans
- Include self-management support for chronic conditions as part of the undergraduate curriculum for health and social care professionals to ensure they have the knowledge, skills and confidence to embed self-management support (including person-centred care) into their professional practice
- Recruit self-management support co-ordinators for each CHO to ensure implementation of the self-management support framework, including mapping current self-management support provision; creation of local directories of self-management support services; and development of self-management support plans for each CHO
- Develop a patient guide to self-management support to engage patients and carers, and to promote self-management of chronic conditions.

## Monitoring and Implementation of the Framework

Key performance indicators and other measurement tools will be developed. Use of existing datasets where appropriate will avoid duplication of effort. Outcome measures will include clinical, healthcare utilisation and patient experience measures.

## Framework Recommendations

### Individual Level - Disease Specific Self-management Support

1. Implement the National Clinical Programmes' recommendations on self-management support as per the Models of Care for COPD, asthma, diabetes, heart failure, acute coronary syndromes and stroke, across clinical settings
2. Implement the National Clinical Guidance on Stroke and Transient Ischaemic Attack (TIA) in relation to self-management support, across clinical settings
3. Provision of and access to standardised diabetes structured patient education should be increased. Specific self-management support programmes of proven benefit e.g. the DAFNE programme should be available for patients with diabetes type I
4. Structured exercise based programmes such as cardiac and pulmonary rehabilitation, should be standardised nationally and provision and access increased
5. Implement support for self-management of hypertension, including self-monitoring of blood pressure, and information and support for health behaviour change, in conjunction with improved diagnosis and treatment of hypertension
6. Future development of national disease specific guidelines should include evidence-based recommendations on supporting self-management

### Individual level - Generic Supports to Self-management

7. Put in place regular clinical review incorporating care planning – including self-management plan - for patients diagnosed with these chronic conditions (COPD, asthma, diabetes & cardiovascular disease), supported by appropriate resources and training for healthcare professionals - to enable integration of self-management support into routine clinical care
8. Identify patients' and carers' needs and preferences for information, including health literacy needs, when developing resources

9. Promote the development and co-ordination of consistent information resources, informed by patients and carers needs and preferences, across care settings
10. Ensure that self-management skills are incorporated into disease specific patient education and training (e.g. problem solving, goal setting)
11. A range of health behaviour change interventions should be available to patients including support from their regular healthcare professional and referral to other services e.g. smoking cessation, exercise interventions - based on the individual's self-management support needs
12. Support the implementation of the "Making Every Contact Count" framework for health behaviour change
13. Ensure a range of interventions are provided to promote adherence to medications and support for dietary behaviour change, including those provided by Pharmacists and Nurses, and dietetic services
14. Provide generic chronic disease self-management education programmes as part of a range of available self-management supports and targeted to those most likely to benefit (younger patients, those lacking confidence, and those coping poorly with their condition(s))
15. Healthcare professionals, and others involved with the care of those with chronic conditions, should link people with non-medical sources of social and peer support within the community, appropriate to their needs, through signposting and /or social prescribing
16. Social Prescribing should be developed to enable social and peer support, targeted at identified 'high need' groups
17. Social and peer supports should be included in local CHO self-management support directories
18. Spouses, family or carers should be included in patient education and other self-management support interventions where possible and appropriate
19. Support the development of effective self-management support programmes for people with multiple chronic conditions

## Healthcare Professional Level

20. Work in collaboration with third level institutions and professional organisations to develop undergraduate and postgraduate curricula for healthcare professionals in self-management support for chronic conditions
21. Training should be provided to frontline healthcare professionals to provide self-management support, including personalised care planning
22. Ensure adequate resourcing at CHO and Hospital Group level for delivery of self-management support; including release for staff training
23. Promote engagement of healthcare professionals through digital and other means, to increase knowledge, awareness and practice of self-management support

## Organisational Level

24. A National SMS programme lead will be assigned to coordinate the roll-out, implementation, phasing and further development of the plan. Implementation will be overseen by a National Oversight Group, with internal, external and patient representation to advise and guide the work as it develops.
25. Specific implementation supports will be put in place in relation to the national strategy and planning function; operations support; and clinical supports.
26. The supports outlined above will form a national SMS programme team which will also include nine self-management support coordinators, one for each CHO.
27. There should be named leads at CHO and HG levels to ensure implementation of the SMS framework including governance, co-ordination, quality assurance, communication and evaluation

28. Each CHO and Hospital Group should have a local plan for self-management support led by the Health and Wellbeing leads (CHO) and Healthy Ireland leads (Hospital Groups (HG)). These plans should include mapping of local services which support self-management for signposting to patients, identification of service gaps where they exist, considering in particular the needs of 'hard to reach' groups, and mechanisms for quality assurance and evaluation of local programmes
29. Promote understanding of the value of self-management support and its role in person-centred, integrated care, to ensure its recognition and incorporation in service development
30. Ensure adequate resourcing of primary care teams to facilitate the provision of self-management support, addressing the issue of fragmented and inadequate services at community level
31. Provide resources for education and training of healthcare professionals and facilitate release of staff for training
32. Ensure the development of evidence informed self-management support interventions for patients within the HSE and through external providers
33. Ensure existing and future national ICT systems including electronic health records; Healthlink; and other initiatives, are used to support the implementation of SMS, including information sharing and continuity across services and care settings, and performance management
34. Support the implementation of self-management support elements of the clinical programmes models of care and this framework through financial means - via the GP contract; through Grant Agreements with voluntary and community organisations; and through HSE services:
  - Create budgets for SMS implementation at national and CHO/HG level
  - Make available Innovation funding to encourage development of evidence-informed self-management support programmes and initiatives e.g. in providing SMS to 'hard to reach', or marginalised groups
35. Interventions should be standardised at national level and subject to routine and ongoing evaluation
36. Continue to develop a central referral, coordination and evaluation system for structured programmes (commenced in 2015 for diabetes structured patient education) to help to facilitate standardisation, and ongoing audit and evaluation
37. Quality assurance, and routine and ongoing evaluation of programmes should be undertaken including patient outcomes and experience of care provided
38. Key Performance Indicators (KPIs) and reporting systems should be developed to monitor achievements
39. Technological supports, telehealth and telephonic health coaching should be considered where evidence supports them, as a mode of delivery for self-management support, or as one element of more complex interventions. As technological developments and population requirements evolve over time, appropriate recommendations should be made accordingly. Cost and evaluation must be considered as some telehealth interventions can be high cost.

## Wider System

40. Develop the roles of GPs and practice nurses in relation to care planning and signposting to supports, as an essential part of the delivery of care
41. Develop partnerships with the community and voluntary sectors which support self-management
42. Engage with providers such as community pharmacists to maximise their ability to support self-management
43. Engage with professional and regulatory bodies regarding the role of Continuous Professional Development (CPD) in developing and maintaining relevant self-management support skills
44. Develop partnerships with academia to ensure gaps in the evidence are addressed including effective self-management support for patients with multiple chronic conditions

# 1. Background

Chronic diseases are recognised as a major component of health service activity and expenditure, as well as a major contributor to mortality and ill-health. Thirty eight percent of Irish people over 50 years have one chronic condition, 11% have two or more of eight chronic conditions (heart attack, angina, stroke, diabetes, asthma, COPD, musculoskeletal pain and cancer)<sup>2</sup>, and 65% of adults over 65 years have two or more chronic conditions<sup>3</sup>.

It has been estimated that in Ireland approximately 1 million adults have cardiovascular or respiratory disease or diabetes<sup>7</sup>. Over the age of fifty, it has been estimated that 625,000 people suffer from cardiovascular disease, respiratory disease or diabetes<sup>\*12</sup>. For all chronic conditions the prevalence is significantly higher in people with lower levels of education and in lower socio-economic groups<sup>6</sup>.

The prevalence of these diseases continues to increase due to our ageing population and prevalence of risk factors<sup>3</sup>. People with chronic diseases presently utilise around 70% of health services resources<sup>4</sup>.

They are more likely to attend their GP, to present at Emergency Departments, to be admitted as inpatients and to spend more time in hospital, than people without such conditions. Approximately 80% of GP consultations and 76% of hospital bed days used are related to chronic diseases and their complications<sup>5,6</sup>.

Every day, people with chronic health conditions, their family members and carers will make decisions, take actions and manage a broad range of factors that contribute to their health. Self-management support acknowledges this and supports people to develop the knowledge, confidence and skills they need to make the optimal decisions and take the best actions for their health. Evidence of positive outcomes highlights the benefit of supporting people to manage their own health as effectively as possible. These benefits can be felt by people with chronic health conditions, health professionals, and the health services<sup>1</sup>.

## 1.1 Aims of the Framework

The aims of this framework are to:

- Provide an overview of self-management support
- Provide recommendations on how self-management support for four major chronic conditions – chronic obstructive pulmonary disease (COPD), asthma, diabetes and cardiovascular disease - should be implemented in the Irish health system
- Inform a plan for the implementation of the self-management support framework
- Guide prioritisation of investment in self-management support initiatives according to the evidence base.

## 1.2 Methods

The following methods were used in developing this framework:

- A Health Technology Assessment (HTA) was carried out by the Health Information and Quality Authority (HIQA) in 2015 at the request of the HSE to examine the clinical and cost-effectiveness of generic self-management support interventions for chronic diseases and disease-specific interventions for COPD, asthma, cardiovascular disease and diabetes<sup>8</sup>.
- Other key literature – including reviews of implementation evidence on self-management support published in 2014 (PRISMS<sup>11</sup> and RECURSIVE<sup>9</sup> studies) – and international policy documents were reviewed; together with the relevant National Clinical Programmes models of care and supporting documents.
- A survey was carried out to identify existing self-management support provision in Ireland<sup>13</sup>
- Other evidence on provision in the Irish health system was reviewed. (See Section 3.1)

\* This estimate was made using TILDA data and includes: CHD, Heart failure, stroke, TIA, diabetes, COPD, Asthma, Atrial Fibrillation and Hypertension<sup>12</sup>. See acknowledgements in reference section.



- The findings of consultations carried out with the Patients' Consultative Forum in 2011 were reviewed, together with the 'Framework for Self-management Support, Long-Term Conditions'<sup>14</sup> which followed on from those consultations<sup>15</sup>. The Patients' Consultative Forum was established in January 2011 to facilitate communication and consultation with regards to the design, delivery and evaluation of the national clinical programmes.
- A national advisory group (Appendix 1) was set up in 2016 to assist with development and finalisation of the framework.
- An initial draft of the framework was further refined through a national consultation in 2016. This consultation included focus groups with healthcare professionals both within and outside the HSE, patients and representatives of patient organisations; and interviews with HSE senior management, and ICGP and Department of Health representatives<sup>16</sup>.
- The national consultation also informed the development of the high level implementation plan for the framework.

### 1.3 What is Self-management Support?

**Self-management** is defined as the tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their condition<sup>17</sup>.

#### Examples of self-management tasks:

- Monitoring symptoms and signs e.g. weight gain (in heart failure), peak flow rate (asthma), blood glucose levels (diabetes), knowing when to seek medical assistance and from whom
- Remembering to take medications - at the correct dosage and time, adjusting if appropriate
- Changing health behaviours e.g. level of physical activity, stopping smoking, healthy eating
- Dealing with the effects of the condition on activities of daily living –adjusting to living with disability e.g. for people who have had a stroke, dealing with effects on employment
- Dealing with the effect of the condition on emotions and relationships e.g. with spouse or family; managing symptoms of anxiety or depression resulting from or co-existing with the condition

The following characteristics describe someone who is able to self-manage their long term condition:<sup>18</sup>

#### The person

- Knows about their condition
- Follows a treatment plan (care plan) agreed with their health professionals
- Actively shares in decision-making with health professionals
- Monitors and manages signs and symptoms of their condition
- Knows how to respond to a deterioration in their condition
- Manages the impact of the condition on their physical, emotional and social life
- Adopts lifestyles that promote health
- Has access to support services and has the confidence and ability to use them.

**Self-management support is defined as the systematic provision of education and supportive interventions, to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support (Adapted from Institute of Medicine, 2003)<sup>17</sup>.**

**Person-centred care and support** is the first theme of "National Standards for Safer Better Healthcare", the national healthcare standards<sup>19</sup>. Self-management support is an important element of **person-centred care** for people with chronic conditions<sup>8</sup>, acknowledging patients as partners in their own care, and supporting them in developing knowledge, skills and confidence to make informed decisions<sup>20</sup>.

Self-management is the responsibility of individuals, however, this does not mean people doing it alone. Successful self-management relies on people having access to the right information, education, support and services. It also depends on professionals understanding and embracing a person-centred, empowering approach in which the individual is the leading partner in managing their own life and condition(s)<sup>21</sup>.

Many self-management support interventions focus on increasing **self-efficacy** i.e. increasing an individual's confidence in their ability to carry out a certain task or behaviour, thereby empowering the individual to self-manage (HIQA 2015)<sup>8</sup>.

**Self-care** is defined as the actions people take to care for themselves, their children and their families to stay fit and well. This includes: staying fit and healthy, both physically and mentally; taking action to prevent illness and accidents; correct use of medicines; treatment of minor, self-limiting illnesses and better care of long-term conditions. Self-care is understood to include the self-management of chronic conditions<sup>22</sup>.

## 1.4 Rationale and Mandate for Self-management Support

Healthcare provided by professionals represents just the ‘tip of the ice-berg’ in supporting patients with chronic conditions. The majority of care for chronic conditions is provided by and coordinated by the person themselves with the support of family members and carers, at home and in the community.

*“A person with diabetes has on average **3 hours** contact a year with their healthcare team. They self-manage their condition for the remaining **8757 hours** in the year”<sup>23</sup>*

The Patients’ Consultative Forum in 2011 identified self-management support as an integral part of clinical care for people living with chronic conditions<sup>15</sup>. The 2012 framework which followed, recommended a ‘whole systems approach’ in implementing high quality self-management support within the Irish healthcare system. It identified three strategic actions as central to this:

- empowering patients
- enabling healthcare professionals to support self-management
- and improving access to self-management supports<sup>14</sup>.

Self-management and self-management support are core elements of high quality, evidence based care for people with chronic health conditions<sup>11</sup>. The Chronic Care Model makes clear the role of self-management support in the management of chronic conditions<sup>24</sup>. This model has broad international acceptance as a framework to provide guidance on shifting from our current model of care which is predominantly acute and episodic care, to a lifelong model of health promotion, prevention, early intervention and chronic care.

Self-management support interventions can improve outcomes for patients – ranging from quality of life and clinical outcomes, to reduced healthcare utilisation including hospitalisation<sup>8</sup>. International evidence suggests that most self-management support interventions are relatively inexpensive to implement. Reported costs vary according to the intensity of the intervention, but are typically low relative to the overall cost of care for the chronic condition in question and in some instances, can result in modest cost savings through reductions or shifts in healthcare utilisation<sup>8,9</sup>.

Supporting self-management is considered critical by the World Health Organization (WHO) for “countries where ageing populations and the growing burden of non-communicable disease means that there is ever greater demand for health services”<sup>25</sup>.

In Ireland, a significant increase in the older population (aged 65 years and over) is predicted, from 532,000 in 2011 to over 734,000 in 2021, and over 1.4 million by 2046<sup>23</sup>. This increase, together with the prevalence of risk factors, will give rise to a continuing increase in chronic diseases with the consequent burden on individuals and the healthcare system.

### Policy Context

Supporting people with chronic conditions to manage their health conditions, enabling them to live as well as possible, aligns with the HSE goal of promoting health and wellbeing as part of everything we do so that people will be healthier<sup>10</sup>. It is an important element of person-centred care which is a key domain of quality in Irish healthcare<sup>19,20</sup> and supported under legislation in the Health Act 2007.

National policies recommend that patients should be encouraged and empowered to self-manage their conditions: *Tackling Chronic Disease – A Policy Framework for the Management of Chronic Diseases*<sup>5</sup> (2008), states that “patients should actively participate in the management of their condition”. *Future Health*<sup>3</sup> (2012) recommends “programmes of self-care for patients to encourage better self-monitoring and treatment of chronic disease”.

*Healthy Ireland: A Framework for Improved Health and Wellbeing 2013 – 2025*<sup>27</sup> (2013), recognises the need to implement a model for the prevention and management of chronic illnesses, empowering people and communities, with an emphasis on partnership and cross-sectoral work to increase the proportion of people who are healthy at all stages of life. *Healthy Ireland in the Health Services - National Implementation Plan*<sup>28</sup> (2015), addresses this through actions to develop and implement a national framework for self-care for the major cardiovascular, respiratory diseases and diabetes and to develop services accordingly (Actions 26 and 43) and to increase the proportion of patients utilising self-care and self-management supports (Action 44).

The self-management support framework for is a work stream of the Integrated Care Programme for the Prevention and Management of Chronic Disease.

Other actions arising from the Healthy Ireland implementation plan address modifiable risk factors and take a life course perspective on chronic conditions including supporting self-management, so are strongly linked with the self-management support framework. These include the ‘Making Every Contact Count’ framework for health behaviour change<sup>29</sup>; and the National Policy Priority Programmes: Alcohol; Tobacco Free Ireland; Healthy Eating and Active Living; Positive Ageing; Wellbeing and Mental Health; and Healthy Childhood.

# 2. Principles of the Self-management Support framework

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The following evidence based principles of self-management support underpin this framework:

- **Patients should be seen as active partners in their healthcare.** Self-management support is key to empowering patients. This means providing patients with the opportunities and the environment to develop the skills, confidence and knowledge to move from being passive recipients of care to being active partners in their healthcare<sup>30</sup>.
  - **Supporting self-management is inseparable from high-quality care for people with long term conditions.** This was the key theme from combined qualitative and quantitative meta-reviews and an implementation systematic review published in 2014. Health services should consider how they can promote a culture of actively supporting self-management as a normal, expected, monitored and rewarded aspect of the provision of care<sup>11</sup>.
  - **Investment should be prioritised in those interventions for which there is good evidence of clinical effectiveness.** Where chronic disease self-management support interventions are provided, it is critical that an agreed definition of self-management support interventions is developed and the implementation and delivery of the interventions are standardised at a national level and subject to routine and ongoing evaluation<sup>9</sup>.
- **A whole system approach to implementation of self-management support should be taken.** Key actions are required at the levels of:
    - The patient
    - The healthcare professional
    - The organisation
    - The wider system.

The healthcare organisation is responsible for providing the means (both training and time/material resources) to enable professionals to implement self-management support and to enable patients to benefit from self-management support, regularly evaluating self-management support processes and clinical outcomes<sup>1, 11</sup>.



# 3. Self-management Support Interventions

Self-management support interventions are any interventions that help patients to manage portions of their chronic condition or conditions through education, training and support<sup>8</sup>. The most effective self-management support interventions are multifaceted; tailored to the individual (their culture and beliefs) and tailored to specific conditions. They are underpinned by a collaborative relationship with a healthcare professional within a healthcare organisation that actively promotes self-management<sup>11</sup>.

## The core components of self-management support interventions include:<sup>11</sup>

- Education - provision of knowledge and information about the long term condition
- Psychological strategies to support people adjusting to life with a long term condition
- Practical support for physical care tailored to the specific long term condition including
  - Coping with activities of daily living for people with disabling conditions
  - Action plans to advise on prompt appropriate action in the event of deterioration, in conditions subject to marked exacerbations
  - Intensive disease-specific training to enable self-management of specific clinical tasks
- Social support as appropriate
- Other potentially effective components include self-monitoring with feedback and practical support with adherence strategies tailored to the individual.

No one component has been shown to be more important than any other, or effective in isolation.

## Examples of self-management support interventions:

- Asthma education supported by written action plan and skills training
- Structured education programmes incorporating self-management skills (e.g. diabetes structured patient education)
- Cardiac rehabilitation programmes; pulmonary rehabilitation programmes
- Regular clinical review incorporating care planning, and self-management plan
- Health coaching
- Support for health behaviour change e.g. smoking cessation support; exercise interventions; dietetic consultations and support
- Provision of high quality consistent information appropriate to the needs of the individual
- Peer support e.g. support groups – face to face, telephone, internet based
- Community based supports e.g. walking groups.

## 3.1 Current Provision of Self-management Support in Ireland

The surveys of patients and clinical stakeholders by Darker *et al.*<sup>31</sup> published in 2015, provide Irish evidence of the importance of self-management support to patients, and the current lack of support in key areas such as information about their condition and provision of care plans. Patients rated the importance of good knowledge of their condition as 'extremely important', however only a minority of patients reported receiving written information on how to manage their chronic condition at home. Only one in four patients received a written care plan, and only a minority were asked about their ideas or goals when making a treatment plan.

The HSE carried out a survey of Community Healthcare Organisations (CHOs) in 2015 to identify existing self-management supports<sup>13</sup>. The survey report was supplemented by other information to provide as complete a picture as possible and may form a baseline for the development of local directories of available self-management supports. The services and programmes available in all CHOs were: cardiac rehabilitation, pulmonary rehabilitation, structured patient education for diabetes and smoking cessation services. Stroke support groups are found throughout the country, but stroke rehabilitation programmes are not available everywhere.

Generic chronic disease self-management programmes based on the Stanford model are run in a number of acute hospitals, CHOs, and by voluntary organisations.

Community based programmes (e.g. smoking cessation) and supports (e.g. walking groups, stroke support groups, community cooking programmes) are provided to varying extents in different areas. While some areas reported a number of wider community supports available, others reported very few of these. One possible reason for the variation is differing levels of knowledge among healthcare professionals responding. The survey did not provide information about the numbers of patients taking any of these programmes, waiting lists, or whether provision is adequate to meet need.

CHO1 has implemented coordination of self-management support as part of its long-term conditions work in Donegal, and developed social prescribing to direct high needs patients to appropriate social and peer supports.

Personalised care planning, a process which encourages healthcare professionals and people with chronic conditions, and their carers, to proactively manage their conditions, including identifying and directing them to supports needed by them to self-manage, is not currently facilitated in primary care.

Other sources indicate that provision of some key self-management supports, including those which are supported by the strongest evidence of effectiveness, are well below required levels:

- A national needs assessment for cardiac rehabilitation carried out in 2016 found that there was capacity to meet only 39% of need. Need was assessed for patients with coronary heart disease or heart failure. When broader referral criteria were included, the capacity was even lower<sup>32</sup>.
- A national needs assessment for pulmonary rehabilitation carried out in 2016 found that there was capacity to provide only 11% of need<sup>33</sup>.
- An audit of diabetes structured patient education indicated that in 2014, structured patient education courses for type II diabetes were completed by 2755 people<sup>34</sup>. Estimates of annual increase in number of cases suggest an additional 4,000 cases per year in adults over 45 alone<sup>35</sup>. It is estimated that 190,000 people in Ireland have diabetes (90% type II), and the prevalence is increasing every year, in line with global trends<sup>36</sup>, highlighting the need to improve access to and provision of structured education.
- A 2015 audit of stroke services found that general rehabilitation services for stroke patients are lacking in the acute setting and indicated very little provision of community rehabilitation services<sup>37</sup>.

# 4. Whole System Model for Self-management Support for Chronic Conditions

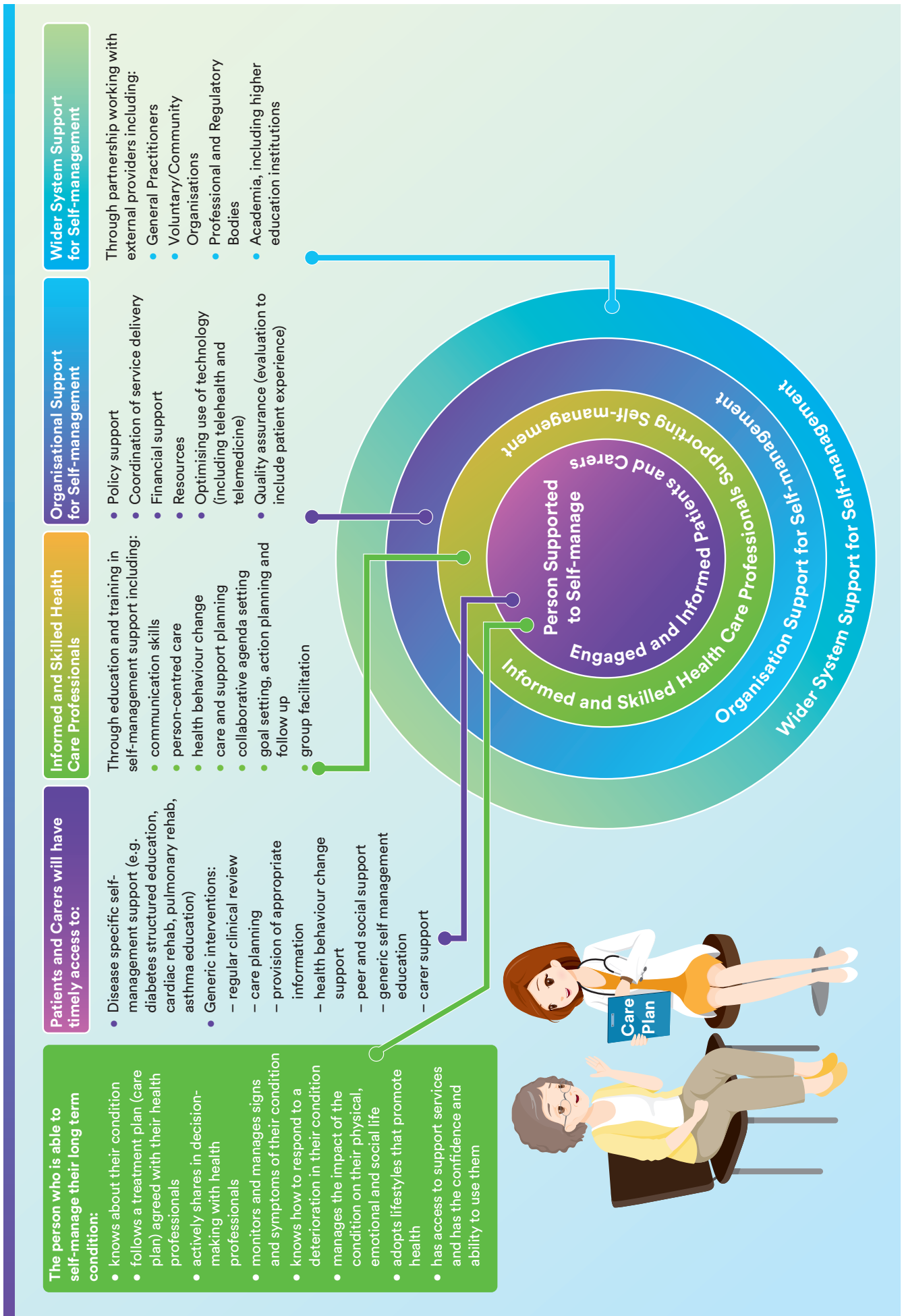
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A whole system approach to implementation is recommended to support self-management<sup>11</sup>. Within the healthcare system, patient self-management can be supported by interventions provided at different levels:<sup>11</sup>

- 1. The individual** – interventions aimed at enabling patients and carers to be engaged and informed **which are provided directly to patients and carers include**
  - Disease specific interventions
    - By individual disease area – COPD, asthma, diabetes, cardiovascular disease
  - Generic interventions
    - Regular clinical review
    - Care and support planning
    - Provision of information
    - Health behaviour change support
    - Peer and social support
    - Generic self-management education
    - Carer support
- 2. Healthcare professionals** - interventions such as training and education, which provide healthcare professionals with the skills and information they need in supporting self-management, including adopting a person-centred approach and encouraging patient engagement
- 3. Organisation** – interventions which support patient self-management through policy support; financial support and resources; provision of information; promotion of peer support; coordination of delivery; optimising use of technology; quality assurance and evaluation
- 4. Wider system support** e.g. through partnerships with voluntary organisations; developing the role of GPs and practice nurses; partnerships with service user and voluntary organisations; promoting research and innovation.

This approach is illustrated in Figure 1. Detailed recommendations at each of the four levels are given in Section 5.

Figure 1: Whole System Model for Support for Self-management for Chronic Conditions



## 4.1 Care Planning and Self-management Support

Effective self-management support should be underpinned by a collaborative / communicative relationship between the patient and a trusted healthcare professional<sup>31</sup>. A self-management plan should be jointly agreed, through a process of personalised care planning, between the patient and a trusted healthcare professional (e.g. GP/practice nurse/ case manager)<sup>38</sup>.

Personalised care planning encourages healthcare professionals and people with chronic conditions, and their carers, to work together to clarify and understand what is important to that individual (see Figure 2). They agree goals, identify support needs, develop and implement action plans, and monitor progress. This is a planned and continuous process, not a one-off event<sup>39</sup>.

The plan should identify the patient's particular self-management support needs – for instance, these may include help with health behaviour change; need for social support or peer support or support for (or from) a family member; or with disease specific education or training. The healthcare professional should be part

of the provision and coordination of self-management support including negotiating the referral or signposting the patient to other self-management support interventions with the patient's collaboration.

The healthcare professional should have knowledge of available self-management support resources (including a directory of local community resources) to refer or signpost the patient to services and activities which support self-management.

*Social prescribing* is one mechanism for linking people with non-medical sources of support within the community to improve physical, emotional and mental wellbeing.

The self-management plan should be reviewed regularly in a structured way along with the patient's overall care plan as their need for support changes. It should be integrated into the patient's care over time and across care settings. Training and support for frontline health professionals to provide self-management support is essential.

Figure 3 shows an example of what self-management support might look like in action from the perspective of a person with a chronic condition, giving examples of supports coming from various sources both within and outside the HSE.

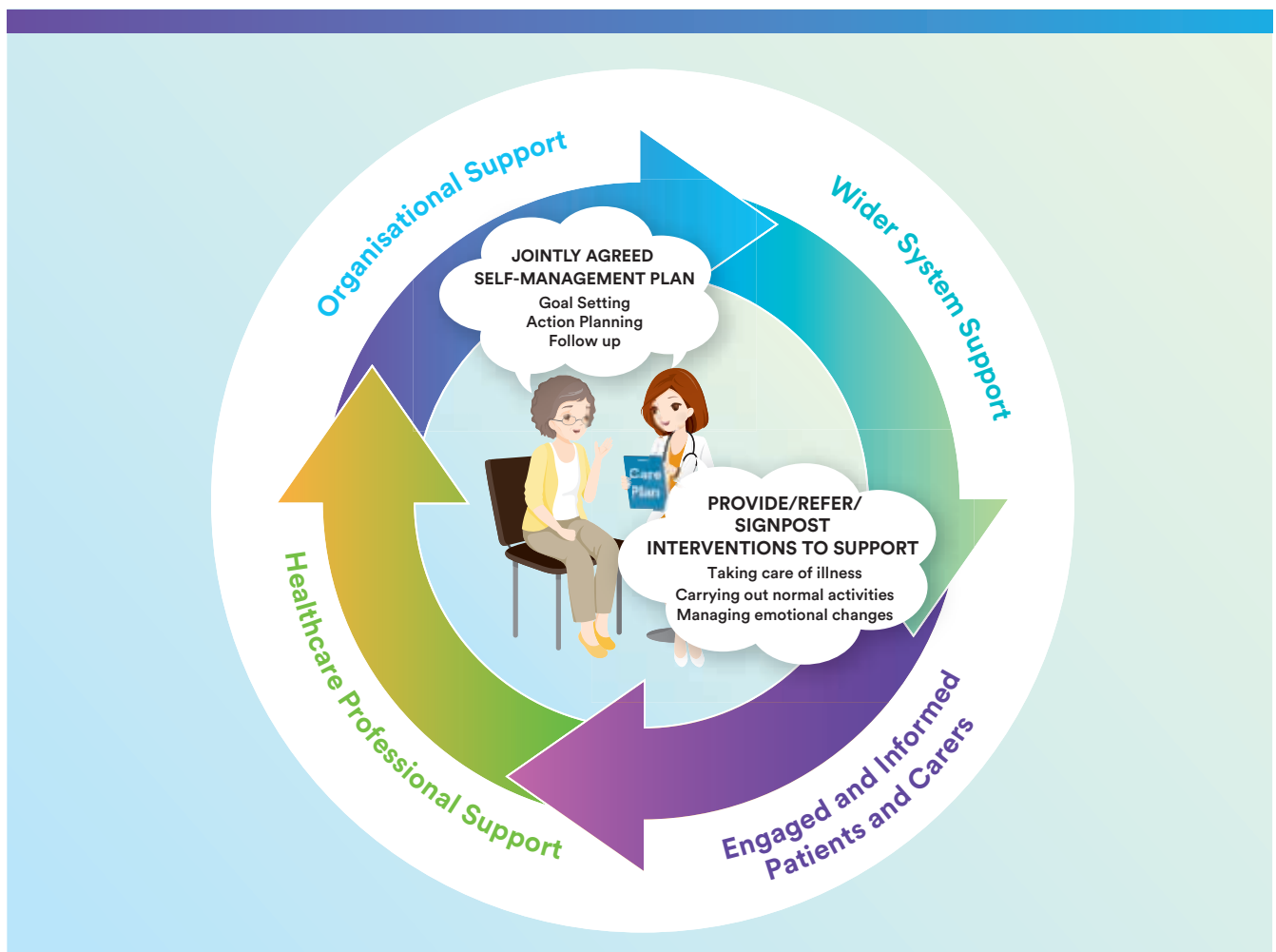
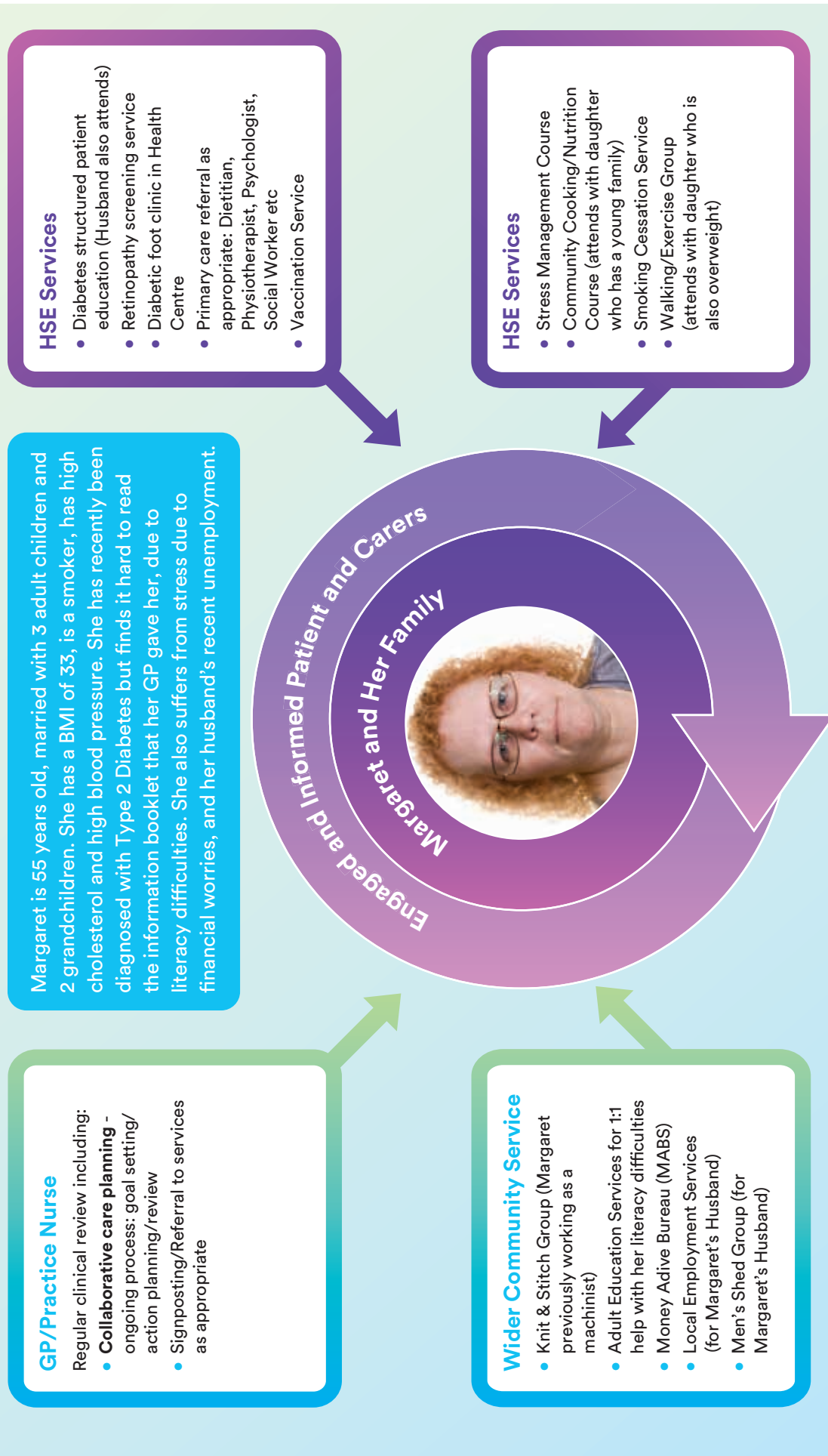


Figure 2: Care Planning to Support Self-management



Figure 3: What Does Self-management Support Look Like In Action?



# 5. Recommendations

The framework recommendations are laid out according to the levels of the whole system model described in Section 4: i.e. the individual (disease specific and generic interventions), healthcare professionals, organisation, and wider system levels.

## 5.1 Individual Level - Disease Specific Self-management Support

Disease specific interventions such as diabetes structured patient education and cardiac rehabilitation help people build knowledge, skills and confidence. The most strongly evidence based interventions identified in the health technology assessment on self-management support for chronic disease<sup>8</sup> are represented within the National Clinical Programmes models of care which have brought together evidence and expertise on these disease areas. The recommendations from the models of care, where available, for each condition are summarised below, but the individual models of care where relevant should be referred to for further details.

*Generic self-management support interventions*, which may apply to a wider number of disease areas, and are key to implementation of the disease specific recommendations (e.g. regular clinical review), are dealt with separately in Section 5.2.

### Chronic Obstructive Pulmonary Disease (COPD)

The national COPD model of care describes self-management support as a component of routine care and describes what this should entail. It highlights the need for support with health behaviour change and for recognition and management of depression and anxiety. Its recommendations on self-management support include:<sup>40</sup>

- Clinicians should provide information to patients on COPD in a format appropriate to the patient

- All patients should be made aware of supports and resources available via the national patient support organisation, COPD Support Ireland, their nearest local support group and also resources such as [www.hse.ie](http://www.hse.ie), Citizens Information Centres etc
- There should be a collaborative partnership approach between the healthcare professional and patient, to define problems, identify priorities and goals, create treatment plans, and solve problems
- All patients starting on an inhaler should have a formal training session on inhaler technique by an appropriately trained healthcare professional. Inhaler technique should be checked at each healthcare review
- All patients with COPD should have an agreed written self-management plan. Review of the self-management plan should be part of each patient review
- Pulmonary rehabilitation should be an integral part of the management of people with COPD. Those patients not suitable for formal pulmonary rehabilitation programmes should have access to exercise training programmes.

### Asthma

The National Clinical Programme for Asthma's model for implementation of guideline-based management of asthma recommends:<sup>41</sup>

- Guided self-management education, including self-monitoring of peak expiratory flow and/or symptoms
- Regular medical review supported by a written asthma action plan
- All patients should be made aware of supports and resources available via the national patient support organisation - Asthma Society of Ireland, local specialist services and also information resources such as [www.hse.ie](http://www.hse.ie)
- All patients starting on an inhaler should have a formal training session on inhaler technique by

an appropriately trained healthcare professional. Inhaler technique should be checked if possible at each healthcare review.

Central to implementation is the annual, at minimum, asthma clinical review which includes support with adherence to medication and inhaler technique and support with health behaviour change.

## Diabetes Types I and II

One of the main priorities of the national clinical programme for diabetes is that everyone with diabetes should access a structured programme of care incorporating all aspects of diabetes care. Education, including self-management support, is addressed specifically in the current ICGP national guidelines<sup>36</sup> which were updated in conjunction with the National Clinical Programme for diabetes in 2016. As well as outlining the recommended content of self-management education and the key components of programmes, the guidelines highlight the following key points on self-management education:

- Patient education is recognised as an integral part of management
- Education at all stages of the integrated care pathway should involve collaborative goal setting, patient empowerment and self-management support
- Regular clinical review should include self-management support and education
- Co-existing chronic conditions including depression or dependency can impact on capacity for diabetes self-management
- Membership of diabetic associations and support groups are encouraged.

Recommendations in relation to patient self-management are also made in the national model of care for the diabetic foot<sup>42</sup>.

Provision of type I diabetes structured patient education programmes is recommended in international guidelines<sup>43</sup>.

## Ischaemic Heart Disease

The national model of care for acute coronary syndromes<sup>44</sup> deals with myocardial infarction (heart attack) and unstable angina. While focusing on the acute services, this model of care recommends:

- Prompt and robust referral to cardiac rehabilitation services; ensure that all patients have access to services

- Access to health and social care professionals for multi-disciplinary care - particularly cardiac rehabilitation, smoking cessation counsellors, and dietitians
- Patient information should be available for all patients admitted with acute coronary syndrome.

## Heart Failure

The heart failure model of care<sup>45</sup> describes self-care as a vital part of the management of heart failure in the community and recommends:

- Patient education initiated during hospital stay, helping patients and their families understand their diagnosis, disease management and care in dealing with a chronic illness
- Education and training on self-care should also be provided on Out Patient Department (OPD) visits by a specialist heart failure nurse
- GPs, practice nurses and public health nurses have an important role in continuing this education while reinforcing, supporting and encouraging self-care behaviours
- Rehabilitation programmes for patients with heart failure require an existing heart failure structured programme as outlined in the model of care
- Patients attending general practice and Primary Care Teams (PCT) have access to interventions for prevention of cardiovascular disease, including lifestyle advice and education
- Home care services, including education and advice; promotion of self-care and monitoring treatment; and provision of essential enabling equipment to facilitate independence in activities of daily living
- Multidisciplinary care for elderly patients with heart failure in long-term residential care and access to heart failure education for staff working in these areas should be provided
- Community and specialist palliative care services should receive patients with heart failure according to agreed criteria
- Shared guidelines and care pathways, agreed with the GP clinical director and ICGP, for the prevention, diagnosis and management of heart failure patients in primary care
- Patient information on self-care for heart failure should be available in written form and through the internet
- Access to psychological support and a social worker should be available through the hospital multidisciplinary team.



## Stroke

The national clinical guidelines and recommendations for the care of people with stroke and transient ischaemic attack<sup>46</sup> make the following points in relation to self-management support:

- Emphasises the need for information, and encouragement of patients to take maximum responsibility for their own recovery
- Recognises the need for practical supports for self-management, for instance, equipment required on discharge to the community setting
- Provides detailed recommendations on post-stroke education and self-management support – including reference to generic and stroke specific self-management programmes, and recognising how social contexts and relationships may affect behaviour
- Multidisciplinary rehabilitation, both acute and non-acute and community based, are recognised as components of stroke care.

The National Clinical Programme for stroke model of care<sup>47</sup> advocates the need for continued rehabilitation close to home as soon as medical intervention is no longer necessary.

## Hypertension

Hypertension is not represented by a national clinical programme or model of care. However, evidence indicates that self-management support, including self-monitoring of blood pressure where appropriate, is effective in the management of hypertension. Patient education and community pharmacist interventions can also be effective<sup>8</sup>. International guidelines highlight the importance of lifestyle changes in the prevention and management of hypertension, including health behaviour change – physical activity, weight reduction, salt intake reduction, smoking cessation<sup>48</sup>. Management of hypertension is itself key to prevention of other conditions including heart failure, stroke and acute coronary syndrome. The heart failure model of care in particular refers to ‘self care’ in relation to prevention – through management of hypertension.

However, evidence indicates a high level of undetected hypertension and poor control of hypertension in Ireland<sup>49</sup> which must be a key focus for improvement.

### Recommendations

- 1. Implement the national clinical programmes’ recommendations on self-management support as per the models of care for COPD, asthma, diabetes, heart failure, acute coronary syndrome and stroke, across clinical settings**  
– *Implementation action 7.19*
- 2. Implement the national clinical guidance on stroke and transient ischaemic attack in relation to self-management support, across clinical settings**  
– *Implementation action 7.19(e)*
- 3. Provision of and access to standardised diabetes structured patient education should be increased. Specific self-management support programmes of proven benefit e.g. the DAFNE programme<sup>50</sup> should be available for patients with diabetes type I**  
– *Implementation action 7.19(b)*
- 4. Structured exercise based programmes such as cardiac and pulmonary rehabilitation, should be standardised nationally and provision and access increased**  
– *Implementation actions 7.19(a), 7.19(c)*
- 5. Implement support for self-management of hypertension, including self-monitoring of blood pressure, and information and support for health behaviour change, in conjunction with improved diagnosis and treatment of hypertension**  
– *Implementation action 7.19(f)*
- 6. Future development of national disease specific guidelines should include evidence-based recommendations on supporting self-management<sup>8</sup>**  
– *Implementation actions 7.19(g), 7.19(h), 7.19(i)*

## 5.2 Individual Level - Generic Supports to Self-management

Generic supports such as regular clinical review, peer and social support, and health behaviour change supports, are recommended for people with specific conditions, depending on the needs of the individual. These and other generic self-management supports can be tailored for people with more than one chronic condition.

### Regular Clinical Review

Review at regular intervals enables support for self-management by healthcare professionals and is recommended in the clinical programmes models of care<sup>36, 40, 41, 45</sup>. This proactive approach facilitates care planning, identifying self-management supports needed, and initiating, reinforcing, signposting or referring to those supports. Care planning includes patient-centred joint goal setting. There is also evidence that personalised care planning reduces depression in patients with chronic conditions<sup>8</sup>.

#### Example: House of Care (UK)

The *House of Care* approach to care planning used in the UK is an example of care and support planning. It is a systematic process that enables the person living with one or more long term conditions to have more collaborative and productive conversations with their healthcare professionals. Using this approach, traditional clinical issues are discussed. In addition, there is a discussion about support for self-management and what the patient can do to stay well, focussing on the person's life goals and what matters to them. There may also be discussion on decisions about care at the end of life where applicable. The healthcare professional may also signpost activities and social services within a community. The patient is given time to prepare for conversations and a care plan template is often used to document the conversations<sup>39, 51</sup>.

#### Recommendation

7. **Put in place regular clinical review incorporating care planning – including self-management plan - for patients diagnosed with these chronic conditions, supported by appropriate resources and training for healthcare professionals - to enable integration of self-management support into routine clinical care**

– Implementation actions 7.4, 7.10, 7.12, 7.13, 7.14, 7.15, 7.19, 7.23

### Provision of Information

Being able to effectively obtain and use health information is an essential element of empowering and supporting patients to self-manage their chronic conditions<sup>52</sup>. People with chronic conditions, and their carers, need a variety of information at different times, depending on their personal situation and the stage of their condition. However, there are a number of key stages where people need specific health information and advice: <sup>21, 53, 54</sup>

- *Diagnosis*: understanding the condition (impact and prognosis), medication and treatment options, and contact details of relevant support services and networks
- *Living with the condition*: adapting to the impact of the condition on social roles and daily activities, learning how to manage the condition, using their medication, accessing appropriate vaccination and understanding when and how to access further help and support
- *Progression of the condition and changes in life circumstances*
- *Transitions in the condition and care: moving between care settings*
- *End of life*

Information can be either disease specific, or generic (e.g. how to most effectively liaise with healthcare professionals, or information on relaxation techniques).

Since people with chronic conditions, and their carers, learn in different ways, information should be available in a variety of formats that can be personalised to meet individuals needs and understanding. The impact of information provided is greater when written information is targeted, personalised and reinforced by verbal communication from healthcare staff<sup>55</sup>. It is important to identify patients and carers with poor levels of **health literacy** and this needs to be taken into account when designing and imparting information and care planning for best use of resources<sup>56</sup>.

### Recommendations

- 8. Identify patients' and carers' needs and preferences for information, including health literacy needs, when developing resources**  
– Implementation actions 7.5, 7.7, 7.8, 7.24
- 9. Promote the development and co-ordination of consistent information resources, informed by patients and carers needs and preferences, across care settings**  
– Implementation actions 7.5, 7.7, 7.8, 7.23, 7.24

## Health Behaviour Change Support

This is a component of various established self-management programmes including cardiac and pulmonary rehabilitation, stroke rehabilitation programmes and diabetes structured patient education<sup>8</sup>. Healthcare professionals dealing with patients with chronic conditions should be skilled in supporting health behaviour change, and health behaviour change interventions should be available locally to patients e.g. smoking cessation services and exercise interventions. Motivational interviewing in particular is supported by good evidence of effectiveness in supporting health behaviour change<sup>8</sup>. Health coaching as defined by Kivela et al incorporates motivational interviewing techniques<sup>57</sup>.

*Making Every Contact Count*, a framework and implementation plan for health behaviour change for the health service outlines lifestyle behaviour change as a key tool in supporting self-management for people with chronic conditions<sup>29</sup>. *Making Every Contact Count* aims to have all health professionals make each routine contact with every patient count in terms of supporting lifestyle behaviour change. Specifically for patients with chronic conditions, *Making Every Contact Count* supports lifestyle behaviour change through more intensive support in their efforts to make lifestyle changes and in managing their existing chronic conditions. This intensive support will use reflective listening and motivational interviewing to support individuals with making lifestyle and behavioural changes in relation to risk factors.

### Recommendations

- 10. Ensure that self-management skills are incorporated into disease specific patient education and training (e.g. problem solving, goal setting)**  
– Implementation action 7.19(h)

- 11. A range of health behaviour change interventions should be available to patients including support from their regular healthcare professional and referral to other services e.g. smoking cessation, exercise interventions - based on the individual's self-management support needs**  
– Implementation actions 7.17, 7.18, 7.19, 7.20, 7.21, 7.22, 7.25, 7.28, 7.30, 7.35
- 12. Support the implementation of the Making Every Contact Count framework**  
– Implementation action 7.25

## Support with Adherence to Medication and Dietary Changes

Nurse-led interventions using the information-motivation-behavioural skills model can lead to improvements in medication adherence. In addition, a range of generic self-management support interventions (e.g. telephone follow-up, video, contract, feedback and nutritional tools) can lead to improvements in adherence to dietary advice<sup>8</sup>.

The role of the pharmacist in supporting self-management is recognised in the National Clinical Programmes' models of care and the breadth of the potential contribution of pharmacists in supporting patients in the management of chronic diseases is outlined in *Future Pharmacy Practice in Ireland*<sup>58</sup>.

HSE dietetic services have a key role in supporting patients to make changes relating to dietary behaviours.

### Recommendation

- 13. Ensure a range of interventions are provided to promote adherence to medications and support for dietary behaviour change, including those provided by pharmacists and nurses, and dietetic services**  
– Implementation actions 7.4, 7.6, 7.1

## Generic Chronic Disease Self-management Education Programmes

These programmes seek to empower patients with the skills and confidence to better manage chronic conditions and interact with the healthcare system, but are not disease specific. Examples include the Stanford model, Expert Patient Programme, and the Flinders model<sup>8</sup>.

### Example: Stanford Programme

This is based on the concept of self-efficacy within social learning theory. It was originally developed by Stanford University in the US. It uses peer educators to build self-efficacy in a group setting. The Stanford chronic disease self-management programme is a generic programme, that is, it can be used for patients with a range of chronic diseases. It is based on the fact that people with chronic disease have similar concerns and, with specific skills and training, can effectively manage aspects of their own conditions. The programme consists of two and a half hour workshops once a week for six weeks, and while generally administered in community settings, is also available online<sup>8</sup>.

There is some evidence of short-term improvements in self-efficacy, health behaviour (exercise) and health outcomes (pain, disability, fatigue and depression) for the Stanford model generic chronic disease self-management programme, although no evidence of a decrease in healthcare utilisation<sup>8</sup>. Evidence from the evaluation of the Expert Patient Programme in the UK (a derivative of the Stanford model) shows that younger people benefited substantially more than older people from participation in this programme. Those with low self-efficacy and health related quality of life at baseline were more likely to benefit. It was concluded that it may be worthwhile encouraging younger patients, those lacking confidence, and those coping poorly with their condition to attend generic chronic disease self-management programmes<sup>59</sup>.

### Recommendation

**14. Provide generic chronic disease self-management education programmes as part of a range of available self-management supports and targeted to those most likely to benefit (younger patients, those lacking confidence, and those coping poorly with their condition(s))**

– Implementation action 7.34

## Peer and Social Support

*Peer support* is defined as support from a person who has experiential knowledge of a specific behaviour, condition or situation<sup>60</sup>. Peer support includes the following:

- Health professional-led groups which facilitate the exchange of peer-support
- Peer-led face-to-face self-management programmes e.g. Stanford programme
- Peer coaches
- Community health workers e.g. within the traveller community
- Support groups e.g. stroke support groups, COPD Ireland support groups
- Telephone-based peer support
- Internet and email based support
- Joint peer and healthcare professional led programmes

Without ongoing support, people's knowledge, skills and confidence to self-manage decline over time<sup>61</sup>. Many programmes therefore include ways for people to connect with peers and other forms of ongoing support after the programme is completed. For example, the Irish pulmonary rehabilitation model of care recommends that "on completion of a programme all patients should be provided with information regarding existing voluntary groups/networks which they can contact for ongoing support and social interaction. Patients also need information on local venues where they can continue to exercise, links with community centres, and other community resources including local gyms may be beneficial"<sup>62</sup>. Contact details for local community services and voluntary organisations should be coordinated locally and regionally, in a shared online location for use across care settings.

Poor *social support* is a risk factor that is associated with poorer self-care behaviours and increased mortality and morbidity for people with chronic conditions<sup>63</sup>. Social support groups have been identified in qualitative research as helpful to people with diabetes, and stroke survivors 'where once physical improvement had plateaued the stroke survivor could be left with the challenge of returning to society with a significant disability'<sup>11</sup>.

**Social prescribing:** This is a mechanism for linking people with non-medical sources of support within the community to improve physical, emotional and mental wellbeing. The healthcare professional and patient identify together the type of activities that will be of benefit, with the professional writing a '*prescription*' directly to a service or '*referring*' the individual to an intermediary, such as a link worker,



with whom a package of services can be constructed<sup>1</sup>. This approach has recently been tested and evaluated successfully in a social prescribing programme in Donegal where the various options taken up by participants include books for health, exercise initiatives, stress control workshops, creative and green activities, and volunteering<sup>64</sup>.

**Signposting:** This is informing people of available community and voluntary supports and resources. It acts as a bridge between healthcare professionals and the social activities and supports available locally and can be done by a variety of people including health trainers, wellbeing coaches, navigators, and voluntary community services networks e.g. directories of local services and supports<sup>1</sup>.

While many of these supports and services are provided outside of a traditional consultation between a healthcare professional and a person with a chronic health condition, all of these types of support are strengthened when backed up by professionals' use of skills such as motivational interviewing, goal setting and problem solving in consultations<sup>1</sup>.

#### Recommendations

**15. Healthcare professionals, and others involved with the care of those with chronic conditions, should link people with non-medical sources of social and peer support within the community, appropriate to their needs, through signposting and /or social prescribing**

– Implementation actions 7.7, 7.8, 7.11, 7.21, 7.22, 7.26

**16. Social prescribing should be developed to enable social and peer support, targeted at identified 'high need' groups<sup>64</sup>**

– Implementation actions 7.13, 7.14, 7.20

**17. Social and peer supports should be included in local Community Healthcare Organisation self-management support directories**

– Implementation action 7.22

## Carer Support

The HSE National Patient Forum<sup>15</sup> identified that patients and their carers want to be more involved in their care and treatment. This view is also expressed in the National Carer's Strategy which states that "carers should be involved, as appropriate, as partners in care planning and provision by health and personal social service providers and particularly by the primary care team"<sup>65</sup>.

#### Recommendation

**18. Spouses, family or carers should be included in patient education and other self-management support interventions where possible and appropriate**

– Implementation actions 7.5, 7.8

## Multimorbidity

Most of the interventions identified in the health technology assessment are disease specific, and these have the strongest evidence of clinical and cost effectiveness. However, a significant proportion of the population experience multimorbidity, whereby patients have multiple chronic conditions, a number of which may be amenable to self-management<sup>8</sup>. Providing a single disease-specific intervention may not be the best way to enable successful self-management among this population. Equally, exposure to numerous interventions may be counterproductive, placing an unsustainable burden on the individual. Consideration should be given to patients' age, their level of ill health and any existing treatment burden e.g. attending multiple providers for a range of complex treatments.

For people with multimorbidity a coherent evidence-based approach that acknowledges their conditions and how they interact is essential. Some reviews suggest that self-management support should be tailored to a specific disease, as a patient's knowledge of their own disease is believed to be an essential component of self-management. However, it has been highlighted that interventions that are targeted at either specific combinations of common conditions, or at specific risk factors or functional difficulties for patients with multiple conditions may be more effective<sup>8</sup>. Programmes such as this are in development e.g. OPTIMAL programme<sup>66</sup> and the evidence base is still developing. Further research in this area should be supported to develop the evidence base for self-management support programmes for patients with multimorbidity in the Irish context. It should be recognised that some existing disease specific programmes such as cardiac rehabilitation and diabetes structured patient education address issues of relevance to patients with multiple conditions. Lifestyle factors such as smoking, physical activity, healthy eating and stress management, are common to many chronic conditions.

#### Recommendation

**19. Support the development of effective self-management support programmes for people with multiple chronic conditions**

– Implementation actions 7.2, 7.34, 7.36

## 5.3 Healthcare Professional Level

Self-management support interventions should be underpinned by a collaborative / communicative relationship between the patient and a trusted healthcare professional<sup>8</sup>.

### Workforce Development

**Resourcing:** The consultation process for this framework document carried out in 2016 identified inadequate and fragmented resourcing – inadequate staff capacity to deliver self-management support programmes and initiatives, and to deliver primary care services - as a significant barrier to providing self-management supports.

**Knowledge and Skills Required:** Self-management support involves a cultural shift in how we understand the roles, responsibilities and relationship between people living with chronic conditions and the health and social care professionals and others who support them. For health professionals it means not only providing clinical care, but helping people to think about their strengths and abilities, identifying their information needs and goals, and the changes they can make in their lives to take control, reach their goals and maintain their physical and mental health and wellbeing.

The tools that provide a structure to achieve this are:<sup>1</sup>

- **Collaborative agenda setting:** At the start of the consultation, the practitioner and the person talk about and agree the health issues to explore and the problems to work on
- **Care and support planning:** Helps people set their own aims and goals, then plan the support and care needed to achieve them
- **Recognising and exploring ambivalence:** Practitioners can explore people's readiness to change, then respond accordingly
- **Goal setting, action planning and follow up:** The practitioner supports the person to identify a goal they want to achieve and break this down in to small achievable actions. There should be a written, jointly agreed plan. Following up goals later involves developing problem-solving skills and exploring solutions to barriers, as well as positive affirmation of progress and effort.

All of these approaches are underpinned by the use of core communication skills that build relationships of trust and rapport. These skills include: open-ended questioning; reflection; empathy; affirmation

and normalisation; summarising; signposting; active listening and non-verbal communication. Approaches can be adapted to reflect each person's level of knowledge, skills and confidence around managing their health condition<sup>1</sup>. In addition, group facilitation skills may also be required e.g. for those delivering structured patient education. Healthcare professionals also require knowledge of locally available supports, and how to access them.

**Training and support:** Organisations have an important role in supporting their practitioners to develop and use these skills and embed them into practice. This means providing training and ongoing support, and adapting systems and processes. For example, elements of self-management support could become part of revalidation criteria for doctors as in the UK<sup>67</sup>. Training whole teams or workforce groups together is key to ensuring common understanding of self-management support and core tools and techniques, creating a common language and culture; and a critical mass of trained practitioners within a team or service to put the skills into practice across a service or organisation. This improves the ease with which self-management support can be tested and adopted and enables practitioners to support each other through training and later when using the skills in practice. A combination of face-to-face, role modelling and e-learning teaching methods can be used<sup>1</sup>.

### Recommendations

- 20. Work in collaboration with third level institutions and professional organisations to develop undergraduate and postgraduate curricula for healthcare professionals in self-management support for chronic conditions.**  
– Implementation action 7.10
- 21. Training should be provided to frontline healthcare professionals to provide self-management support, including personalised care planning**  
– Implementation actions 7.10, 7.12, 7.13, 7.14, 7.15
- 22. Ensure adequate resourcing at Community Healthcare Organisation and Hospital Group level for delivery of self-management support; including release for staff training**  
– Implementation actions 7.16, 7.17, 7.18, 7.22
- 23. Promote engagement of healthcare professionals through digital and other means, to increase knowledge, awareness and practice of self-management support**  
– Implementation actions 7.2, 7.11, 7.13, 7.14, 7.15, 7.21, 7.26,

## 5.4 Organisational Level

The ‘pivotal role of organisational support’ has been identified as key to implementing self-management support. While there are areas such as CHO 1 (Donegal) which have forged ahead in promoting self-management support, the level of acknowledgement of its importance is at an early stage in Ireland. A concerted effort will be required to prioritise this approach to ensure support at the highest levels of leadership, including clinical leadership, and management.

### Governance

Self-management support is a critical element of our journey toward building a sustainable health service. This Framework and the approach set out within it lay the foundations for the work that is required over the months and years ahead. This work, when fully implemented over a number of phases, will re-shape and re-direct our focus from acute hospital services to the patient, their experiences and their journey with their illness. It will direct our gaze to creating enabling, supportive and transformative environments that put the patient first and support those living with long term conditions, their families and friends.

This Framework will be supported and led by three new senior roles being created within the health service – the Deputy Director General Strategy and Planning, Deputy Director General Operations and Chief Clinical Officer. Self-management support is a cross-cutting priority, essential to the success of all three posts as it relates to prevention, healthcare sustainability, efficiency, empowerment and efficacy. A lead will be assigned to coordinate the roll-out, implementation, phasing and further development of the plan.

Specific implementation supports will be put in place to

- a) ensure that the new National Strategy and Planning function has a ‘driving’ role in setting this agenda and articulating the way in which the services need to develop and outcomes expected
- b) provide operations support to ensure that the model of care is being delivered in practice by Hospital Groups and Community Healthcare Organisations, according to pre-defined standards and requirements and
- c) provide clinical supports to ensure patient experience is the cornerstone underpinning the approach and design, and that implementation is based on best clinical evidence and is tightly monitored to fully evaluate the extent to which outcomes are being achieved.

Implementation will be overseen by a National Oversight Group, with internal, external and patient representation to advise and guide the work as it develops.

The success of this Framework is dependent on:

- Working with investments already made in this area to do a better job regarding the kinds of advice, care and signposting offered to patients and professionals: standardising the programmes and services offered; creating better efficiencies where possible; developing better indicators and KPIs to enable monitoring of the impacts of existing investments and creation of a more robust platform to assess the impact of any future investments
- Building synergies between those programmes in which there has already been investment via the clinical programmes, Healthy Ireland, National Policy Priority Programmes, the Making Every Contact Count framework for health behavior change, and campaigns to support people to make healthier choices
- Building synergies between what has already been invested in with external partners and agencies and community groups to harness the value of our partnerships, relationships and investments at national, regional and local levels, – to create healthier environments (for people to live happier healthier lives, free from disease or symptoms of disease, to cope with their illness and thrive to the best degree possible) and tangible supports for those living with long term conditions
- Making significant efforts to focus carefully on where additional resources are required and to expand services and invest in prevention and self-management support so as to deliver a more cost effective model of service delivery in the medium to longer term, aligned to a set of output and outcome indicators.

### Recommendations

#### 24. A National Self-management support

**programme lead will be assigned** to coordinate the roll-out, implementation, phasing and further development of the plan. Implementation will be overseen by a National Oversight Group, with internal, external and patient representation to advise and guide the work as it develops.

– *Implementation action 7.1*

#### 25. Specific implementation supports will be

**put in place** in relation to the national strategy and planning function; operations support; and clinical supports.

– *Implementation action 7.1*

**26. The supports outlined above will form a national self-management support programme team which will also include nine self-management support coordinators, one for each CHO.**

– *Implementation action 7.3*

**27. There should be named leads at Community Healthcare Organisation and Hospital Group levels to ensure implementation of the self-management support framework, including governance, co-ordination, quality assurance, communication and evaluation**

– *Implementation action 7.2*

**28. Each Community Healthcare Organisation and Hospital Group should have a local plan for self-management support led by the Health and Wellbeing (CHO) and Healthy Ireland leads (Hospital Groups). These plans should include mapping of local services which support self-management support for signposting to patients, identification of service gaps where they exist, considering in particular the needs of ‘hard to reach’ groups, and mechanisms for quality assurance and evaluation of local programmes**

– *Implementation actions 7.17, 7.22, 7.37*

## HSE Senior Management

### Recommendations

**29. Promote understanding of the value of self-management support and its place in person-centred, integrated care, to ensure its recognition and incorporation in service development**

– *Implementation action 7.1, 7.3, 7.25,*

**30. Ensure adequate resourcing of primary care teams to facilitate the provision of self-management support, addressing the issue of fragmented and inadequate services at community level**

– *Implementation action 7.18*

**31. Provide resources for education and training of healthcare professionals and facilitate release of staff for training**

– *Implementation action 7.12*

**32. Ensure the development of evidence informed self-management support interventions for patients within the HSE and through external providers**

– *Implementation action 7.7, 7.20*

**33. Ensure existing and future national ICT systems including electronic health records; Healthlink; and other initiatives, are used to support the implementation of self-management support, including information sharing and continuity across services and care settings, and performance management**

– *Implementation action 7.27*

## Financial Support and Incentives

### Recommendation

**34. Build the case, using evidence based arguments, for investment in the self-management support elements of the clinical programmes models of care and this framework - via the GP contract; through grant agreements with voluntary and community organisations; and through HSE services:**

**Create budgets for self-management support implementation at national and Community Healthcare Organisation/Hospital Group level**

– *Implementation actions 7.4, 7.17*

**Make available innovation funding to encourage development of evidence-informed self-management support programmes and initiatives e.g. in providing self-management support to ‘hard to reach’ or marginalised groups**

– *Implementation actions 7.17, 7.18, 7.20, 7.35*



## Quality Assurance, Evaluation and Monitoring

Evaluation of self-management support interventions will help to ensure that they are delivering benefits to patients, and allow the content and format of the interventions to be refined ensuring value for money in investing in these services. Evaluation should aim to provide a longer-term perspective not currently available in the literature, and will support decisions about the optimal delivery of such interventions<sup>8</sup>.

Evaluation should be carried out at individual patient level, at service and organisational level, and at commissioning and planning level. This should include patient involvement, and measures of patient experience, to support self-management as effectively and efficiently as possible<sup>1</sup>. At individual patient level, evaluation should harness existing HSE initiatives such as the National Patient Experience Survey and the Patient Narrative Project led by HSE Clinical Strategy and Programmes division. Key performance indicators (KPIs) and reporting systems should be developed to monitor achievements.

### Recommendations

- 35. Interventions should be standardised at national level and subject to routine and ongoing evaluation<sup>8</sup>**  
 – *Implementation actions 7.19, 7.36*
- 36. Continue to develop a central referral, coordination and evaluation system for structured programmes (commenced in 2015 for diabetes structured patient education) to help to facilitate standardisation, and ongoing audit and evaluation**  
 – *Implementation actions 7.21, 7.27*
- 37. Quality assurance, and routine and ongoing evaluation of programmes should be undertaken including patient outcomes and experience of care provided**  
 – *Implementation actions 7.25, 7.27, 7.31, 7.36, 7.37*
- 38. Key performance indicators (KPIs) and reporting systems should be developed to monitor achievements**  
 – *Implementation action 7.27, 7.30, 7.31*

## Technological Supports and Telehealth

Technological supports, telehealth and telephonic health coaching should be considered where evidence supports it as a mode of delivery for self-management support. Mobile devices offer great promise for improving the health of the population. However, the pace of science in evaluating mobile applications is incongruent with the business and industry sectors and the consumer demands. To date, mobile technologies have generally been evaluated in motivated individuals and in selected settings. These idealised conditions will lead to exaggerations of the typical effectiveness that might be seen had the product been evaluated in general community practice, or among diverse or underserved populations. Perhaps most challenging, studies to-date have almost uniformly evaluated a single technology compared with standard care, and there have been almost no head-to-head studies comparing various technologies with each other<sup>68</sup>.

### Recommendation

- 39. Technological supports, telehealth and telephonic health coaching should be considered where evidence supports them, as a mode of delivery for self-management support, or as one element of more complex interventions<sup>8</sup>. As technological developments and population requirements evolve over time, appropriate recommendations should be made accordingly. Cost and evaluation must be considered as some telehealth interventions can be high cost**  
 – *Implementation action 7.28*

## 5.5 Wider System

A whole system approach for self-management support should be promoted. In addition to the preceding recommendations many of which impact on the wider health system, the following are recommended.

### Recommendations

**40. Develop the roles of GPs and practice nurses in relation to care planning and signposting to supports, as an essential part of the delivery of care**

– *Implementation actions 7.4, 7.13, 7.14*

**41. Develop partnerships with the community and voluntary sectors which support self-management**

– *Implementation actions 7.2, 7.7*

**42. Engage with providers such as community pharmacists to maximise their ability to support self-management**

– *Implementation action 7.6*

**43. Engage with professional and regulatory bodies regarding the role of continuous professional development (CPD) in developing and maintaining relevant self-management support skills**

– *Implementation action 7.15*

**44. Develop partnerships with academia to ensure gaps in the evidence are addressed including effective self-management support for patients with multiple chronic conditions**

– *Implementation action 7.36*

# 6. Priorities for Initial Implementation

Implementation of all of the recommendations will be required in order to successfully progress the implementation of the self-management support framework, through Hospital Groups and CHOs, as part of the Integrated Care Programme for the Prevention and Management of Chronic disease. However, given the breadth of the recommendations, and the finite resources available for implementation, a pragmatic, and evidence based approach has been taken to prioritise implementation of recommendations which will have maximum impact, and for which there is the strongest evidence.

Within phase 1 of implementation - as detailed in section 7.1 - the following key actions have been prioritised:

1. Standardise and increase provision of cardiac rehabilitation  
**Recommendation 4, implementation action 7.19(a)**
2. Standardise and increase provision of pulmonary rehabilitation  
**Recommendation 4, implementation action 7.19(c)**
3. Increase provision of standardised diabetes structured patient education  
**Recommendation 3, implementation action 7.19(b)**
4. Increase provision of care planning, initially focussing on practice nurse training on asthma management including skills training and asthma action plans  
**Recommendations 1 and 7, implementation action 7.4, 7.19(d)**
5. Include self-management support for chronic conditions as part of the undergraduate curriculum for health and social care professionals to ensure they have knowledge, skills and confidence to embed self-management support (including person-centred care) into their professional practice  
**Recommendation 20, implementation action 7.10**
6. Recruit self-management support co-ordinators for each CHO to ensure implementation of the self-management support framework - including mapping current self-management support provision, creation of self-management support directories and development of self-management support plans for each CHO  
**Recommendations 17, 26 and 28 implementation actions, 7.17, 7.2 and 7.22**
7. Develop a patient guide to self-management support to engage patients and carers, and to promote self-management of chronic conditions  
**Recommendations 8 and 9, implementation action 7.5**

# 7. Self-management Support Implementation Plan

## 7.1 Phase 1 2018-2021

The implementation plan presented in Table 1 represents the first phase of implementation. Progress, including governance, will be reviewed after two years to inform the second phase of implementation (Section 7.2).

**Table 1**

No	Actions	Lead	Partners	Start date	Comp date
<b>Governance and Policy</b>					
7.1	Assign a national lead for SMS to coordinate the roll-out, implementation, phasing and further development of the plan, with supports from strategy and planning, operations and clinical functions.  Appoint a National Oversight Group, with internal, external and patient representation to advise and guide the work as it develops.	National Director of Health & Wellbeing	CHOs; HGs; NCAGL H&W CSP; PPP Leads, HI lead, SMS team; External partners	Q4 2017	Q4 2018
7.2	Appoint self-management support co-ordinators at CHO level, and identify named leads at Hospital Group level to implement SMS: including governance, co-ordination, quality assurance, communication and evaluation.	CHO& HGs	SMS national working group; NCAGL H&W CSP;	Q1 2017	Q1 2018
7.3	A national SMS programme team will be established	National SMS lead	National SMS oversight group	Q42017	Q2 2018
<b>Partnerships</b>					
7.4	Include the delivery of SMS, including regular clinical review and care-planning into the negotiations of the GP contract, including building a robust case for investment in SMS.	HSE GP contract negotiation steering group	National SMS lead; ICPCD	2017	2018
7.5	Develop a patient/carer friendly guide to SMS incorporating a plain English definition of SMS, taking account of cultural and language differences, and varying levels of health literacy.	National SMS programme team	CHO SMS co-ordinators & HG HI leads; NALA; patients/ carers; patient representative organisations/ Voluntary organisations; Communications	Q1 2018	Q4 2018

No	Actions	Lead	Partners	Start date	Comp date
7.6	Engage with pharmacists to scope and develop the role of community pharmacists in supporting self-management.	National SMS programme team	PSI; CHO SMS co-ordinators & HG HI leads; PCRS; Primary care division; DOH	2018	2019
7.7	Work with voluntary organisations both nationally and locally, to ensure provision of peer support to patients and carers (identifying and filling gaps in services) building on existing initiatives and promoting public awareness of peer support.	CHO SMS co-ordinators & HG SMS leads; National SMS programme team	Voluntary organisations, patients, ICPCD; NCPs; SMS team	2018	2021
7.8	Work with voluntary organisations, and patients/carers directly, to ensure patient involvement in the development of SMS activities and resource development – e.g. staff training, service development and evaluation (including patient outcome measures) and increasing public awareness of SMS.	CHO SMS co-ordinators SMS programme team;	Patients and patient and carer organisations; NALA; Communications; NCP;	2018	2021
7.9	Develop a method of quality assurance for community based HSE funded programmes e.g. stress management programmes, community cooking programmes which support self-management.	National SMS programme team	CHO SMS co-ordinators; SMS team; Voluntary organisations; Community groups; PPPs; relevant HSE divisions	2018	2021
<b>Training and Staff Engagement</b>					
7.10	Collaborate with Higher Education Institutions in Ireland to include SMS education and skills training in the Standard Curriculum for Chronic disease prevention and management for relevant undergraduate and training and development for Health and Social Care Professionals.	National SMS programme team	ICPCD; HEIs, MECC Team	Q1 2017	Q2 2018
7.11	Engage with and promote awareness of SMS with HSCPs serving the CHO population, including HGs, to promote and support delivery of SMS to patients with chronic conditions, and in order to optimise the delivery of SMS within current capacity.	CHO SMS co-ordinators & HG SMS leads	National SMS programme team; Communications	Q1 2018	2021

No	Actions	Lead	Partners	Start date	Comp date
7.12	Develop a training plan for SMS for Health and Social Care Professionals to include training requirements (including post graduate training) and identification of priority staff. Include non-HSE staff such as pharmacists, GPs, and practice nurses in HSE training and education initiatives.	National SMS programme team	CHO SMS co-ordinators & HG HI leads; ICGP; Professional organisations; IPNA; QID	2018	2021
7.13	Engage with GP's through the ICGP in relation to professional development and training to ensure that GP's have the knowledge, skills and confidence to implement SMS and care planning and including understanding of the role of social prescribing.	National SMS programme team	ICGP; HEIs; CHO SMS co-ordinators & HG HI leads	2018	2021
7.14	Engage with Practice Nurses in relation to professional development and training to ensure that Practice Nurses have the knowledge, skills and confidence to implement SMS and care planning focussing initially on asthma education, skills training and asthma action plans	National SMS programme team	HEIs, IPNA, CHO PN co-ordinators; CHO SMS co-ordinators & HG HI leads	2018	2021
7.15	Work with national training bodies for healthcare professional groups to develop post graduate training in SMS, to ensure that SMS training, including health behaviour change skills and care-planning are included as part of Continuous Professional Development.	National SMS programme team	national training bodies for healthcare professional groups	2018	2021
<b>Operational Planning and Resources</b>					
7.16	Address identified gaps in generic and disease specific provision of SMS through the service planning process, in particular focusing on the priority recommendations identified in the SMS framework.	CHOs & HGs	SMS programme team; NCPs; Primary Care division; Acute Hospital division	2018	2019
7.17	Develop plans for SMS implementation within CHO and Hospital Groups.	CHO SMS co-ordinators & HG SMS leads	HSE Divisions; SMS team; HI oversight group	Q4 2017	2019
7.18	Build robust business cases for adequate resourcing and agree sustainable and effective approaches to increasing access and scaling effective programmes at CHO (including resourcing of primary care teams) and HG level, including the input of recommended disciplines (physiotherapy, psychology, dietetics etc) to disease specific rehabilitation and education programmes.	Primary care division; Acute hospital division	CHO SMS co-ordinators & HG HI leads; ICPCD	Q4 2017	2021

No	Actions	Lead	Partners	Start date	Comp date
7.19	Implement the relevant National Clinical Programmes models of care, recommendations on self-management support including in particular:	Primary care and Acute divisions	HGs; CHOs; SMS team; GPs and practice nurses; CROI; National Clinical Programmes	Q1 2017	2019
	a) Build a robust business case for adequate resourcing and agree sustainable and effective approach to increasing access, scaling and standardisation of cardiac rehabilitation – including for heart failure patients - through development of cardiac rehab services nationally, including alternative methods of delivery where evidence supports this.	National SMS programme team, SPHM lead for CVD	Croi, NCP; CSP; ICPCD; H&W; CHO SMS co-ordinators & HG HI leads, HGs	2018	2019
	b) Build a robust business case for adequate resourcing and agree sustainable and effective approach to increasing access, scaling and standardisation of diabetes structured patient education.	National HSE diabetes SPE Co-ordinator	Primary care division; Acute hospital division; NCPs; Voluntary organisation; SMS coordinator	2018	2019
	c) Build a robust business case for adequate resourcing and agree sustainable and effective approach to increasing access, scaling, and standardisation of pulmonary rehabilitation.	National SMS programme team, HGs & CHOs	NCP; CSP; ICPCD; H&W; SMS team; CHO SMS co-ordinators & HG HI leads	2018	2021
	d) Build a robust business case for adequate resourcing and agree sustainable and effective approach to increasing access, scaling, and standardisation of asthma education supported by written action plan and skills training to be available to all asthma patients.	National SMS programme team, Primary care division; Acute hospital division	NCP; CSP; ICPCD; H&W; SMS team; CHO SMS co-ordinators & HG HI leads; HGs; CHOs; Voluntary organisations	2018	2021

No	Actions	Lead	Partners	Start date	Comp date
	e) Work with colleagues and other stakeholders to support robust planning for development of other areas of SMS including increasing access to general rehabilitation therapy, information provision and peer support for people with stroke.	HGs; CHOs; Primary care division; Acute hospital division	Voluntary organisations; CHO SMS co-ordinators & HG HI leads	2019	Phase 2
	f) Build a robust business case for adequate resourcing and improved diagnosis and treatment of hypertension, and self-management support through the ongoing development and implementation of the GP contract.	Primary care division	NCP; CSP; ICPCD; H&W; SMS team; CHO SMS co-ordinators & HG HI leads; Voluntary organisations	2018	2019
	g) Support the implementation of self-management support through the integrated care demonstration projects and ongoing development of the ICPCD.	CHOs & HGs	SMS team; CHO SMS co-ordinators & HG HI leads; NCPs	2018	2019
	h) Ensure that self-management skills are incorporated into disease specific patient education and training (e.g. problem solving, goal setting).	National SMS programme team	Voluntary organisations; NCPs	2018	2020
	i) Establish the governance of the disease specific programmes across all settings.	National director Health and Wellbeing	NCP; SMS team; CHO SMS co-ordinators & HG HI leads; Voluntary organisations	2020	2021
7.20	Build the evidence base for SMS, including building the case to support the development of innovative, evidence-informed self-management support programmes and initiatives (including provision of innovation funding), building on existing examples of good practice e.g. social prescribing.	National SMS programme team; CHOs & HG	CHO SMS co-ordinators & HG HI leads; HEIs; Voluntary organisations	2018	2021



No	Actions	Lead	Partners	Start date	Comp date
7.21	Develop digital information hub for SMS in collaboration with MECC, National Health and Wellbeing Policy Priority Programmes and relevant National Clinical Programmes for patients, carers, health and social care professionals and the general public, to include information, resources and signposting and links to training resources and central registration for disease specific SMS initiatives and programmes such as structured patient education programmes.	AND HP&I	National SMS programme Team, H&W PPP's, NCPs; MECC Team; Communications; Voluntary organisations; ICPCD, ICT, SMS co-ordinators	2018	2021
7.22	Map the current provision of SMS programmes and supports (including peer and social supports) within each CHO and Hospital Group, and identify and quantify any resource gaps in capacity.  Produce and regularly update a directory of available SMS programmes and supports to facilitate signposting.	CHO SMS co-ordinators & HG SMS leads	National SMS programme team, Voluntary organisations, Community organisations; relevant HSE services	Q1 2018  2018	Q4 2018  2021
7.23	Collaborate with key stakeholders to collate and develop toolkits for implementation of SMS to include care plan templates and other resources, building on resources already developed, and ensuring continuity across settings.	National SMS programme team (including SMS coordinators)	HG HI leads; ICGP; ICPCD; IPNA; Pharmacists; Therapy Professions; CHOs; Mental health division; Voluntary organisations	Q3 2017	2021
7.24	Ensure provision of health information resources taking account of health literacy and adhering to the 'communicating in plain English' guidelines.	HSE - Primary care division; Acute hospitals division	National SMS programme team National clinical programmes; Communications; CHO SMS co-ordinators & HG HI leads; ICPCD; Patients, NALA, Voluntary organisations	Q1 2018	2021

No	Actions	Lead	Partners	Start date	Comp date
<b>Cross-divisional and Wider System Working</b>					
7.25	Ensure SMS is incorporated appropriately into all relevant HSE programmes, and that synergies with SMS are explored and exploited, including ICPs, and Healthy Ireland implementation plans, National Clinical Programmes, Policy Priority Programmes and Making Every Contact Count, health literacy initiatives, mental health initiatives; patient narrative project; patient experience survey; QID patient centredness framework	National SMS programme team	ICPs; H&W; PPP leads, QID, CHO, HGs, MECC, Mental Health division, CSP; QID, SMS team	2018	2021
7.26	Develop an SMS communication plan to convey the vision for SMS including key messages, via development of print, online and social media resources, vignettes and SMS branding. The plan should target patients, carers, healthcare workers, HSE managers, the wider system and the general public, and include a plan for dissemination of examples of good practice and information on progress of SMS implementation.  Identify clinical champions from among GPs, hospital specialist and health & social care professionals to promote and endorse the SMS framework.	National SMS programme team Communications	ICT; PPP leads; ICPCD; HP&I; MECC team; NCP leads; Professional colleges; Voluntary organisations; NALA	Q3 2017	Q2 2018
7.27	Ensure existing and future national ICT systems including electronic health records; Healthlink etc, are used to support the implementation of SMS, including information sharing and continuity across services and care settings, and performance management. This is a multi-phase element of the programme, which will take place over a number of years. Progress has commenced on some aspects.	National ICT	National SMS programme team ICPCD; ICGP; CHO; HGs; H&W; National diabetes SPE coordinator	2018	Phase 2

No	Actions	Lead	Partners	Start date	Comp date
7.28	Support the use of technological supports, telehealth and telephonic health coaching - where evidence and cost benefit supports it as a mode of delivery for SMS, - as technological developments, and population requirements evolve over the longer term implementation of this framework, and make recommendations as appropriate.	CIO	National SMS programme team; HIQA; ICPCD; NCPLs; NCPs; Primary care division; Acute hospitals division	2019	2021
<b>Monitoring and Evaluation</b>					
7.29	Develop a plan to ensure regular update and dissemination of Irish and International evidence on SMS, through academic and other partners to support SMS implementation and continuous quality improvement.	National SMS programme team	ICPCD; NCPs, HEIs, International Integrated Care interest groups, HRB; Communications; HIQA, SMS co-ordinators	2018	2021
7.30	Develop and agree KPI's and other measurement tools, and integrate into existing performance management reporting systems, to support the implementation of SMS at Hospital Group and CHO level.	National SMS programme team	H&W; HSE divisions; ICT	Q1 2018	Q4 2018
7.31	Ensure inclusion of appropriate SMS data in agreed GP chronic disease management data set.	Primary care division	ICGP; National SMS programme team; DOH; ICPCD	Q1 2017	2018
7.32	Commence planning for Phase 2 of implementation of the SMS framework considering points for development outlined in Table 2	National SMS programme team	ICPCD; NCPs, H&W	2020	2021

## 7.2 Phase 2

Planning for development in Phase 2 of implementation will consider the actions outlined in Table 2 below.

**Table 2**

Number	Actions	Lead	Partners
7.33	Establish costs for SMS interventions	National SMS programme team	HEI; Health economics support; Finance; CSP; Primary care division; Acute hospital division; Voluntary organisations
7.34	Target generic Chronic Disease Self-management Programmes (based on the Stanford Model) to those most likely to benefit (younger patients, those lacking confidence and those coping poorly with their condition(s)).	CHO SMS co-ordinators & HG SMS leads;	SMS team; Voluntary organisations; relevant HSE disciplines
7.35	Promote the inclusion of evidence based SMS including peer support, information provision and structured patient education into Grant Agreements with service providers as appropriate	Procurement; H&W	All HSE divisions; SMS team, CHO SMS co-ordinators & HG HI leads; Primary care division; Acute hospitals division; Mental health division; Voluntary organisations, Patient organisations
7.36	Support partnerships with Academia and other partners to ensure gaps in the evidence are addressed, and to support ongoing evaluation of interventions, developing the Irish evidence-base.	H&W	ICPCD; HEIs; HIQA; National SMS programme team; TILDA; HRB; NCPs; ICGP; RCSI; RCPI; Professional organisations; Voluntary organisations, SMS co-ordinators
7.37	Scope the development or adaptation of a system for self-registration and quality assurance of community and voluntary resources that would support SMS across the CHOs and Hospital Groups.	National SMS programme team and CHO SMS co-ordinators	HG HI leads; Local councils; Community organisations; Voluntary organisations; CHOs; HGs

# 8. Monitoring Implementation of the Framework

Key performance indicators (KPIs) and other measurement tools will be developed and agreed to measure the implementation and outcomes of the framework at Hospital Group and CHO level (*Implementation action 7.30*). A number of existing and planned KPIs and datasets within the system (e.g. acute hospitals metadata, the planned outcomes framework for the Healthy Ireland implementation plan, and the GP diabetes cycle of care dataset) may potentially be among those used for this purpose. Use of existing datasets, where these enable monitoring of self-management support implementation, will help avoid duplication of effort and minimise the administrative burden on front-line staff in the collection of the data.

In the interim, a number of process indicators will be put in place to monitor the initial phase of implementation of the self-management support framework using available datasets.

## 8.1 Measuring Initial Phase of Implementation

The following process measures will be reported directly by the self-management support team from Q4 2017 onwards to monitor the initial phase of implementation of the framework as described in Section 6:

### **Support for implementation of the framework within the Community Healthcare Organisations (CHOs) and Hospital Groups**

- Number of CHOs with self-management support coordinators in post
- Number of CHOs with self-management support directories developed
- Number of CHOs with self-management support plans developed

### **Service provision**

- Number of patients enrolled into newly developed community cardiac rehabilitation programme
- Number of patients with newly diagnosed type 2 diabetes who received a structured patient education programme

### **Increasing patient understanding and awareness of self-management support**

- Patient guide to self-management support developed and disseminated

### **Education of health and social care professionals on self-management support**

- Undergraduate curriculum for self-management support with Higher Education Institutes developed.

## Further KPI Development

Further process and outcome measures relevant to self-management support will be developed and reported via the Integrated Care Programme for the Prevention and Management of Chronic disease, including; the national structured patient education management system, cardiac and pulmonary rehabilitation programmes audit data sets, clinical nurse specialist data sets and the GP chronic disease dataset as they are agreed and finalised during 2018 and onwards:

### **Process Measures**

- Measurement of uptake of disease specific programmes: cardiac rehabilitation, pulmonary rehabilitation, diabetes structured patient education
- Number of practice nurses who have completed the e-learning programme and the practical training module in asthma management
- Number of patients with asthma action plans and inhaler technique training completed

### **Outcome Measures**

- Clinical outcomes
- Healthcare utilisation measures
- Patient experience measures

# 9. References

1. Health Foundation. A practical guide to self-management support: Key components for successful implementation. London: Health Foundation, 2015
2. Savva G, Hanly M, McDaid O, Richardson K, Kenny RA, Kee F. Multimorbidity in the older population: why multiple chronic conditions matter. Briefing paper. Dublin: Centre for Ageing Research and Development in Ireland (CARDI), 2011.
3. Health Service Executive. Planning for health – trends and priorities to inform health service planning. HSE, 2016.
4. Department of Health. Future Health: a strategic framework for reform of the health service 2012 - 2015. Dublin: Department of Health, 2012.
5. Department of Health and Children. Tackling chronic disease: a policy framework for the management of chronic diseases. Dublin: Department of Health and Children, 2008.
6. Health Service Executive. Preventing chronic disease: defining the problem. Dublin: Health Service Executive, 2014.
7. HSE, A proposal for the Prevention and Management of Chronic Disease by General Practitioners. HSE 2016
8. Health Information and Quality Authority. Health Technology Assessment of chronic disease self-management support interventions. Dublin: HIQA, 2015.
9. Panagioti M, Richardson G, Murray E, et al. Reducing care utilisation through self-management interventions (RECURSIVE): a systematic review and meta-analysis. Health Services and Delivery Research. 2014; 2(54).
10. Health Service Executive Corporate Plan 2015-2017. HSE, 2015
11. Taylor SJC, Pinnock H, Epiphaniou E, Pearce G, Parke HL, Schwappach A, et al. A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – Practical systematic Review of Self-management Support for long-term conditions. Health Services and Delivery Research 2014; 2(53).
12. TILDA data - Acknowledgements: The author would like to thank TILDA, the original data creators for making the data available. HSE acknowledges that those who carried out the original collection of the data bear no responsibility for the further analysis or interpretation of it. TILDA data was accessed via the Irish Social Science Data Archive - [www.ucd.ie/issda](http://www.ucd.ie/issda) for the purposes of this report. TILDA is co-funded by the Government of Ireland through the Office of the Minister for Health and Children, by Atlantic Philanthropies, and by Irish Life. TILDA data have been collected under the Statistics Act, 1993, of the Central Statistics Office. The project has been designed and implemented by the TILDA Study Team and Department of Health and Children. Copyright and all other intellectual property rights relating to the data are vested in TILDA.]
13. Cianci C, Mullaney C, Petty-Saphon N. Survey of self-management support for chronic disease. Health Service Executive, 2016.
14. Health Service Executive. Framework for self-management support, long-term health conditions. Naas: National Advocacy Unit, HSE, 2012.
15. Health Service Executive National Patient Forum. A framework for self-management: a position paper/scoping document. Self-management working group / HSE National Patient Forum, 2011.
16. McMurray A and Crimmins J. National consultation on a framework for self-management support. 2016.



17. Institute of Medicine. Priority areas for national action: transforming healthcare quality. Adams K, Corrigan JM, eds. Washington (DC): National Academies Press (US), 2003.
18. Flinders University. The Flinders program information paper. Flinders Program, 2017.
19. Health Information and Quality Authority. National healthcare standards for safer better healthcare. Dublin: HIQA, 2012.
20. Health Service Executive. Framework for improving quality in our health service, part 1. HSE, 2016.
21. Long-Term Conditions Alliance Scotland. "Gau Yersel" The self-management strategy for long term conditions in Scotland. Glasgow: LTCAS, 2008.
22. Department of Health. Supporting people with long term conditions to self care. A guide to developing local strategies and good practice. London: Department of Health, UK, 2006.
23. Department of Health. Self care – a real choice. London: Department of Health, UK, 2005.
24. Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: translating evidence into action. *Health Aff (Millwood)*. 2001; 20(6), 64-78.
25. World Health Organization. WHO global strategy on people-centred and integrated health services. Geneva: World Health Organization, 2015.
26. Central Statistics Office. Population and labour force projections 2016-2046. Dublin: Central Statistics Office, 2013.
27. Department of Health. Healthy Ireland: a framework for improved health and wellbeing 2013 – 2025. Dublin: Department of Health, 2013.
28. Health Service Executive. Healthy Ireland in the health services. National implementation plan 2015 – 2017. Dublin: Health Service Executive, 2015.
29. Health Service Executive. Making Every Contact Count. A health behaviour change framework and implementation plan for health professionals in the Irish health service. HSE, 2016.
30. European Network on Patient Empowerment. Patient empowerment - living with chronic disease: a series of short discussion topics on different aspects of self-management and patient empowerment for the 1st European conference on patient empowerment. 2012.
31. Darker C, Whiston L, O'Shea B. Chronic disease management in Ireland: perspectives from patients and clinical stakeholders – implications and recommendations for the Irish healthcare system. Dublin: Trinity College Dublin, 2015.
32. Petty-Saphon N. A needs assessment of cardiac rehabilitation services in Ireland – Draft. HSE, 2016.
33. Petty-Saphon N. An audit and needs assessment of pulmonary rehabilitation services in the Republic of Ireland – Draft. HSE, 2016.
34. Humphreys M. National lead for structured patient education. Personal communication, 2016.
35. Institute of Public Health. Diabetes briefing. 2012.
36. Irish College of General Practitioners, Health Service Executive, Irish Endocrine Society, Department of Health and Children. A practical guide to integrated type 2 diabetes care. 2016.
37. Irish Heart Foundation and Health Service Executive. National stroke audit 2015. IHF/HSE, 2015.
38. Royal College of General Practitioners. Care planning, improving the lives of people with long term conditions. Clinical Innovation and Research Centre RCGP, 2011.
39. NHS England and Coalition for Collaborative Care. Personalised care and support planning handbook: the journey to person-centred care. Leeds: NHS England and Coalition for Collaborative Care, 2015.
40. Health Service Executive National Clinical Programme for COPD. COPD Model of Care - Draft. HSE, 2016.
41. Health Service Executive National Clinical Programme for Asthma. Asthma Model of Care. HSE, 2014.
42. Health Service Executive National Clinical Programme for Diabetes. Model of Care for the Diabetic Foot. HSE, 2011.
43. National Institute for Health and Care Excellence. Type 1 diabetes in adult: diagnosis and management. NICE, 2015.
44. Health Service Executive National Clinical Programme for ACS. Acute Coronary Syndrome Model of Care. HSE, 2012.
45. Health Service Executive National Clinical Programme for Heart Failure. Heart Failure Model of Care. HSE, 2012.

46. Irish Heart Foundation. National clinical guidelines and recommendations for the care of people with stroke and transient ischaemic attack. IHF, 2010.
47. Health Service Executive National Clinical Programme for Stroke. Stroke Model of Care. HSE, 2012.
48. Mancia G, Fagard R, Narkiewicz K, Redon J, Zanchetti A, Bohm M, et al. 2013 ESH/ESC guidelines for the management of arterial hypertension. *Journal of Hypertension*. 2013; 31, 1281-357.
49. Murphy CM, Kearney PM, Shelley EB, Fahey T, Dooley C, Kenny RA. Hypertension prevalence, awareness, treatment and control in the over 50s in Ireland: evidence from The Irish Longitudinal Study on Ageing. *Journal of Public Health*. 2016; 38(3), 450-8.
50. DAFNE Study Group. Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: dose adjustment for normal eating (DAFNE) randomised controlled trial. *British Medical Journal*. 2002; 325:746.
51. Coulter A, Entwistle VA, Eccles A, Ryan S, Shepperd S, Perera R. Personalised care planning for adults with chronic or long-term health conditions. *Cochrane Database of Systematic Reviews* 2015; Issue 3. Art. No.: CD010523. DOI: 10.1002/14651858.CD010523.pub2
52. Coulter A and Ellins J. Patient-focused interventions: a review of the evidence. London: The Health Foundation and Picker Institute Europe, 2006.
53. European Patients Forum. EMPATHIE: empowering patients in the management of chronic diseases. 2014.
54. Department of Health. A guide to personalised care planning for people with long-term conditions. London: Department of Health, UK, 2011.
55. Coulter A. and Ellins J. Effectiveness of strategies for informing, educating and involving patients. *British Medical Journal*. 2007; 335(7609), 24-7.
56. National Adult Literacy Agency. Literacy audit for healthcare settings. Dublin: NALA and HSE, 2009.
57. Kivela K, Elo S, Kyngas H, Kaariainen M. The effects of health coaching on adult patients with chronic diseases: a systematic review. *Patient Education and Counseling*. 2014; 97(2), 147-57.
58. Pharmaceutical Society of Ireland. Future pharmacy practice in Ireland: meeting patients' needs. Dublin: PSI, 2016.
59. Reeves D et al. Predicting who will benefit from an Expert Patients Programme self-management course. *British Journal of General Practice*. 2008; 58(548), 198-203.
60. Dennis CL. Peer support with a healthcare context: a concept analysis. *International Journal of Nursing Studies*. 2003; 40(3), 321-32.
61. Heisler M. Building peer support programmes to manage chronic disease. Seven models for success. California Health Care Foundation, 2006.
62. Health Service Executive National Clinical Programme for COPD. Pulmonary Rehabilitation Model of Care. HSE, 2010.
63. Tay L, Tan K, Diener E, and Gonzalez E. Social relations, health behaviors, and health outcomes: a survey and synthesis. *Applied Psychology: Health and Well-Being*. 2013; 5(1), 28-78.
64. Health Service Executive. Donegal social prescribing for health and wellbeing. Evaluation report. HSE Social Inclusion Office, 2015.
65. Department of Health. The national carers' strategy: recognised, supported, empowered. Dublin: Department of Health, 2012.
66. Garvey J, Connolly D, Boland F, Smith SM. OPTIMAL, an occupational therapy led self-management support programme for people with multimorbidity in primary care: a randomized controlled trial. *BMC Family Practice*. 2015; 16:59.
67. General Medical Council. The good medical practice framework for appraisal and revalidation. Manchester: GMC, 2013.
68. Burke LE et al. Current science on consumer use of mobile health for cardiovascular disease prevention. A scientific statement from the American Health Association. *Circulation*. 2015; 132(12), 1157-213.
69. Holohan J, Manning P, Nolan D. Asthma control in general practice. Adapted from the GINA global strategy for asthma management and prevention. ICGP. 2nd Edition, 2013.

70. Hickam DH, Weiss JW, Guise J-M, Buckley D, Motu'apuaka M, Graham E, Wasson N, Saha S. Outpatient case management for adults with medical illness and complex care needs. Comparative Effectiveness Review No. 99. (Prepared by the Oregon Evidence based Practice Center under Contract No. 290-2007-10057-I.) AHRQ Publication No.13-EHC031-EF. Rockville, MD: Agency for Healthcare Research and Quality, 2013.
71. Nolte E and McKee M. Caring for people with chronic conditions: a health systems perspective. WHO European Observatory on Health Systems and Policy Series. Open University Press, 2008.
72. Global Initiative for Chronic Obstructive Lung Disease. Pocket guide to COPD diagnosis, management, and prevention. A guide for healthcare professionals. 2011.
73. World Health Organization. Diabetes fact sheet N° 312. Geneva: World Health Organization, 2015.
74. Disease Management Association of America. Disease management program evaluation guide. Including principles for assessing disease management programs. 1st Ed. Washington DC: DMAA , 2004.
75. Dickstein K, Cohen-Solal A, Filippatos G, McMurray JJ, Ponikowski P, Poole-Wilson PA, et al. ESC guidelines for the diagnosis and treatment of acute and chronic heart failure 2008: the Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2008 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association of the ESC (HFA) and endorsed by the European Society of Intensive Care Medicine (ESICM). *European Heart Journal*. 2008; 29(19), 2388-442.
76. Repper J and Carter T. A review of the literature on peer support in mental health services. *Journal of Mental Health*. 2011; 20(4), 392-411.
77. Nesta and Health Foundation. At the heart of health: realising the value of people and communities. 2016.
78. Bodenheimer T, MacGregor K, Sharifi C. Helping patients manage their chronic conditions. Oakland: California HealthCare Foundation, 2005.
79. University of York, Centre for Reviews and Dissemination. Evidence to inform the commissioning of social prescribing. York: Centre for Reviews and Dissemination, 2015.
80. World Health Organization. A health telematics policy in support of WHO's Health-For-All strategy for global health development: report of the WHO group consultation on health telematics, 11–16 December, Geneva, 1997. Geneva: World Health Organization, 1998.

# 9. Abbreviations

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AND HP&I	Assistant National Director Health Promotion and Improvement
CDSMP	Chronic Disease Self-management Programmes
CHO	Community Health Organisation
COPD	Chronic Obstructive Pulmonary Disease
CORU	Health & Social Care Professionals Council
Croi	The West of Ireland Cardiac Foundation
CSP	Clinical Strategy and Programmes
CVD	Cardiovascular Disease
DOH	Department of Health
GP	General Practitioner
HEI	Higher Education Institute
HG	Hospital Group
HI	Healthy Ireland
HIQA	Health Information and Quality Authority
HRB	Health Research Board
HSCPs	Health and Social Care Professionals
HSE	Health Service Executive
HTA	Health Technology Assessment
H&W	Health and Wellbeing
ICGP	Irish College of General Practitioners
ICPCD	Integrated Care Programme for the Prevention and Management of Chronic Disease
ICT	Information and Communication Technologies
IPA	Irish Pharmacist Association
IPNA	Irish Practice Nurses Association
KPI	Key Performance Indicator
MECC	Making Every Contact Count
MI	Motivational Interviewing
MOC	Model of Care
NALA	National Adult Literacy Agency
NCAGL	National Clinical Advisor and Group Programme Lead
NCP	National Clinical Programme
NHS	National Health Service
NMBI	Nursing and Midwifery Board of Ireland
PNA	Practice Nurse Association
PSI	Pharmaceutical Society of Ireland
PPP	HSE Policy Priority Programme
QID	Quality Improvement Division
RCPI	Royal College of Physicians Ireland
RCSI	Royal College of Surgeons Ireland
SMS	Self-management Support

# 10. Glossary of Terms

<b>Asthma</b>	Asthma is a chronic inflammatory condition of the airways characterised by recurrent episodes of wheezing, breathlessness, chest tightness and coughing <sup>69</sup> .
<b>Carer</b>	A carer is defined as a person who provides regular unpaid personal help for a friend or a family member with a long-term illness, health problem or a disability <sup>65</sup> .
<b>Case Manager</b>	<p>The central role of the case manager is the comprehensive co-ordination of a patient's care. The coordinating functions performed by a case manager include helping patients navigate the healthcare systems, connecting them with community resources, orchestrating multiple facets of healthcare delivery and assisting with administrative and logistical tasks. These coordinating functions are distinct from clinical function. Both the clinical and coordinating functions may be performed by the same healthcare professional e.g. practice nurse.</p> <p>Case managers are often utilised for patients who have complex needs and can be seen as an agent of the patient, taking the 'whole person' approach to care, and serving as a bridge between the patient, the practice team, the health system, and community resources<sup>70</sup>.</p>
<b>Chronic Care Model</b>	The Chronic Care Model (CCM) is an internationally recognised evidence-based model which identifies the essential components of a healthcare system that supports the provision of high quality care for chronic illness <sup>24</sup> .
<b>Chronic Condition</b>	The term chronic condition encompasses a broad range of disabilities, illnesses and diseases that people may live with over extended periods of time (more than six months). Chronic conditions are non-communicable and usually involve some functional impairment or disability and 'can be cared for but not cured'. Chronic conditions are also referred to as long-term conditions <sup>71</sup> .
<b>Chronic Obstructive Pulmonary Disease</b>	Chronic Obstructive Pulmonary Disease (COPD) is a common, preventable and treatable disease that is characterised by persistent respiratory symptoms and airflow limitation that is due to airway and/or alveolar abnormalities usually caused by significant exposure to noxious particles or gases <sup>72</sup> .
<b>Diabetes</b>	Diabetes is characterised by deficient insulin production and requires daily administration of insulin. Type 2 diabetes (formerly called non-insulin dependent or adult-onset diabetes) results from the body's ineffective use of insulin <sup>73</sup> .
<b>Disease Management</b>	Disease management is a system of coordinated healthcare interventions and communications for populations with conditions in which patient self-care efforts are significant <sup>74</sup> .
<b>Health Coaching</b>	Health coaching is the practice of health education and health promotion within a coaching context, to enhance the wellbeing of individuals and to facilitate the achievement of goals that enhance the quality of their lives and improve their health. The role involves listening, understanding, and facilitating, applauding, supporting, motivating and providing feedback to the patients. The concept of health coaching emerged from the motivational interviewing concept originated by Miller and Rollnick <sup>57</sup> .

<b>Health Literacy</b>	Health literacy refers to how people understand information about their health and healthcare and how they apply that information to their lives and use it to make decisions and act on it. Health literacy is not simply a matter of being able to read and make sense of health information; it is also an essential patient empowerment strategy <sup>52</sup> .
<b>Heart Failure</b>	Heart failure is a syndrome in which the patients should have the following features: symptoms of heart failure, typically shortness of breath at rest or during exertion, and/or fatigue; signs of fluid retention such as pulmonary congestion or ankle swelling; and objective evidence of an abnormality of the structure or function of the heart at rest <sup>75</sup> .
<b>Hypertension</b>	Hypertension is defined as readings on separate occasions consistently showing blood pressure to be $\geq 140$ mmHg systolic blood pressure (SBP) and/or $\geq 90$ mmHg diastolic blood pressure (DBP) <sup>48</sup> .
<b>Ischaemic Heart Disease</b>	Ischaemic heart disease is characterised by narrowing and hardening of the arteries that supply blood to the heart muscle. Restriction of blood supply to the heart can result in angina or myocardial infarction <sup>8</sup> .
<b>Patient Empowerment</b>	Empowering patients' means providing them with the opportunities and the environment to develop the skills, confidence and knowledge to move from being a passive recipient of care to an active partner in their healthcare <sup>30</sup> .
<b>Peer Support (including Social Support)</b>	Peer support is defined as support from a person who has experiential knowledge of a specific condition or behaviour as the target population <sup>60</sup> . Peer support in healthcare encompasses a range of approaches through which people with similar long-term conditions or health experiences support each other in order to better understand the condition and aid recovery or self-management. It can be delivered on a one-to-one basis, which may be in person, or through telephone support, or through a peer support group. Peer support can be offered across a wide range of conditions, including diabetes and coronary heart disease, but the largest body of research relates to peer-support for people with mental health conditions <sup>76</sup> .
<b>Person-Centred Care</b>	Person-centred care and support places service users at the centre of all that the service does. It does this by advocating for the needs of service users, protecting their rights, respecting their values, preferences and diversity and actively involving them in the provision of care. Person-centred care and support promotes kindness, consideration and respect for service users' dignity, privacy and autonomy. By considering service users' needs and preferences in the planning, design and delivery of care and support services, better service user satisfaction can be achieved. This, in turn, can lead to improved outcomes for service users including better health and wellbeing. Person-centred care supports equitable access for all service users so that they have access to the right care and support at the right time, based on their assessed needs. This is best achieved through an organisation-wide culture that is focused on what is most important from the service users' perspective <sup>19</sup> .
<b>Personalised Care-Planning</b>	Personalised care planning is defined as an anticipatory (forward-looking), negotiated discussion or series of discussions between a patient and a health professional (perhaps with other professional or family members present) to clarify goals, options and preferences and develop an agreed plan of action based on this mutual understanding <sup>51</sup> .
<b>Self-Care</b>	Self-care is defined as the actions people take to care for themselves, their children and their families to stay fit and well; this includes: staying fit and healthy, both physically and mentally; taking action to prevent illness and accidents; the better use of medicines; treatment of minor illnesses and better care of long-term conditions. The term self-care is understood to include the self-management of chronic conditions <sup>22</sup> .



<b>Self-Efficacy</b>	Self-efficacy, one of the core concepts of social cognitive theory, focuses on increasing an individual's confidence in their ability to carry out a certain task or behaviour, thereby empowering the individual to self-manage <sup>11</sup> .
<b>Self-Management</b>	Self-management is defined as the tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their conditions <sup>17</sup> .
<b>Self-Management Education</b>	Self-management education includes any form of formal education or training for people with chronic conditions which focuses on helping people to develop the knowledge, skills and confidence to effectively manage their own health and care. The content of self-management education programmes varies depending on the specific condition and individuals' information and support needs <sup>77</sup> .
<b>Self-Management Support</b>	<p>Self-management support is defined as the systematic provision of education and supportive interventions by healthcare staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support<sup>17</sup>.</p> <p>It may be viewed in two-ways:</p> <ul style="list-style-type: none"> <li>i) as a portfolio of tools and techniques which includes the provision of information, education and other supportive interventions to increase the person's knowledge, skills and confidence in managing their condition and</li> <li>ii) as a fundamental transformation of the traditional patient-health professional / caregiver relationship into a collaborative ongoing partnership, that includes care-planning, goal-setting and problem solving strategies<sup>78</sup>.</li> </ul> <p>Self-management support interventions are any interventions that help patients to manage portions of their chronic disease or diseases through education, training and support. Many self-management support interventions focus on self-efficacy<sup>8</sup>.</p>
<b>Social Prescribing</b>	Social prescribing is a way of linking patients in primary care with sources of support within the community. It provides GPs with a non-medical referral option that can operate alongside existing treatments to improve health and well-being. While there is no widely agreed definition of social prescribing, or 'community referrals', reports on social prescribing include an extensive range of prescribed interventions and activities <sup>79</sup> .
<b>Stroke</b>	Stroke is the neurological condition that results from brain damage caused by either blockage or rupture of a blood vessel in the brain <sup>8</sup> .
<b>Telemedicine</b>	<p>Telemedicine refers to the delivery of healthcare services, where distance is a critical factor, by all healthcare professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and for the continuing education of healthcare providers, all in the interests of advancing the health of individuals and their communities<sup>80</sup>.</p> <p>Telemedicine interventions typically comprised of four major elements:<sup>8</sup></p> <ul style="list-style-type: none"> <li>i. supply of medical care</li> <li>ii. use of technology</li> <li>iii. mitigation of issues of distance</li> <li>iv. provision of benefits</li> </ul>

# Appendix 1: Self-management Support Advisory Group

## Membership of Self-management Support Advisory Group

Name	Title
Dr. Carmel Mullaney	Lead for development of National Self-management Support Framework (Chair), Specialist in Public Health Medicine, National Health and Wellbeing Division
Prof. Pat Manning	Consultant Respiratory Physician, National Clinical Lead, National Clinical Programme for Asthma
Prof. Tim McDonnell	Consultant Respiratory Physician, National Clinical Lead, National Clinical Programme for Chronic Obstructive Pulmonary Disease (COPD)
Dr. Ronan Canavan (from April – August 2016)	Consultant Endocrinologist, National Clinical Lead, National Clinical Programme for Diabetes
Prof. Sean Dineen (from Sept 2016 onwards)	Consultant Endocrinologist, National clinical lead, National Clinical Programme for Diabetes
Dr. Siobhan Jennings	Specialist in Public Health Medicine, National Clinical Programme for Acute Coronary Syndrome
Prof. Ken McDonald	Consultant Cardiologist, National Clinical Lead, National Clinical Programme for Heart Failure
Prof. Joe Harbison	Consultant Physician, National Clinical Lead, National Clinical Programme for Stroke
Valerie Twomey	Senior Programme Manager, Integrated Care Programme for Chronic Disease Prevention & Management (April 2016 meeting only)
PJ Harnett	Senior Programme Manager, Integrated Care Programme for Older Persons
Marian Wyrer	Lead Nurse, National Clinical Programmes for Asthma and COPD
Dr. Andree Rochfort	GP and member of the Irish College of General Practitioners
Dr. Louise Doherty	Specialist in Public Health Medicine, Department of Public Health, HSE North West
Brid Kennedy	Donegal Long Term Conditions Programme Manager
Lynn Stoddart	Assistant Director of Public Health Nursing, Sligo

Name	Title
June Boulger	Lead for Public & Patient Participation Acute Hospital Division
Dr. David Hanlon	GP and National Clinical Advisor, HSE Primary Care Division
Margaret Humphreys	National Lead for Structured patient Education
Dr. Anna Clarke	Education and Research Development Lead, Diabetes Ireland
Sharon Cosgrove	CEO Asthma Society of Ireland
Patricia Hall	Irish Heart Foundation
Damien Peelo	Executive Director COPD Support Ireland
Michael Drohan	Patient representative, and COPD Support Ireland peer support group leader
Kate Gajewska	Patient representative, and Member of Diabetes Ireland
Dr. Miriam Owens	Specialist in Public Health Medicine, Department of Health
Grainne O'Leary	Arthritis Ireland
Geraldine Quinn	Health Promotion and Improvement / Quality Improvement Division, HSE
Dr. Maria O'Brien	Project Manager for 'Making Every Contact Count' Health and Wellbeing
Dr. Deirdre Mulholland	Specialist in Public Health Medicine, HSE
Prof. Kieran Daly	Consultant Cardiologist, Clinical Lead of Acute Coronary Syndromes Programme. Represented by Brendan Cavanagh programme manager
Bronagh Travers	Clinical Nurse Specialist, National Clinical Programme for Heart Failure
Regina Black	Programme Manager, National Clinical Programme for Heart Failure
Niamh Smyth	Programme Manager – National Clinical Programme for Diabetes
Linda Kearns	Programme Manager – National Clinical Programmes for COPD and Asthma
Mairead Gleeson	National Group Programme Manager, Health & Wellbeing and Clinical Programmes
Dr. Orlaith O'Reilly	National Clinical Advisor and Programme Lead, Health and Wellbeing Division

# Appendix 2: Terms of Reference of Self-management Support Advisory Group

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- To advise and assist in the finalisation of the national framework for self-management support for chronic conditions, focusing on COPD, asthma, diabetes, and cardiovascular disease (heart failure, hypertension, ischemic heart disease and stroke)
- To advise on the consultation phase of the national framework for self-management support and to assist in framing the core issues/questions for the consultation process
- To assist the HSE self-management support work stream in developing the implementation plan for the national framework

