

Framework for self-management support, long-term health conditions



Access

Dignity and Respect

Safe and Effective Services

Communication and Information

Participation

Privacy

Improving Health

Accountability

National Healthcare Charter

you and your
health service



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Foreword

Our population is healthier today than at any time in the past. However, the prevalence of long-term conditions is increasing and they now account for 70% of healthcare costs and 80% of G.P. consultations.

The National Clinical Programmes were established in order to provide guidance to healthcare teams around the country on the provision of nationally standardised evidence based structured care, which in some areas is already saving lives, improving patient experience and making services more resource efficient.

In changing the way we provide care, a continuum of high quality services, health promotion, prevention, self-management support, primary care and specialised care needs to be available to the entire population.

There is a growing body of evidence which suggests that most patients want more information about their condition and that they want more partnership with providers in the management of their own healthcare.

This framework suggests three main strands of action in our efforts to promote self-management:

- 1) Empower patients to make better use of consultations with professionals and to take a greater role in managing their own health conditions;
- 2) Enable healthcare professionals to engage in more shared decision making and to provide better self-management support including personalised self-management care plans;
- 3) Improve access to self-management supports including; information, technology, education, and social supports.

The above will require a major cultural change throughout the health services and it will take some time to achieve the fully engaged scenarios described in the Wanless Report for the UK health services in 2004. If we take the opportunity now to build on the work already done by clinical programmes, our health promotion staff and the Your Health Programme by committing to this transformation of the model of healthcare we can improve public health, empower patients and make our health services more sustainable in the future.

Patient advocacy networks, patients and their carers, the voluntary sector, health professionals and stakeholders from all sectors look forward to making this a reality. We would like to take this opportunity to thank all of those who have contributed to this work and look forward to implementing the actions outlined in this document.

Dr. Pat Doorley, National Director Public Health

Greg Price, National Director Advocacy

Empower patients to make better use of consultations with professionals and to take a greater role in managing their own health conditions

Enable healthcare professionals to engage in more shared decision making and to provide better self-management support including personalised self-management care plans

Improve access to self-management supports including; information, technology, education, social supports and emergency healthcare.

Introduction

This document outlines a framework for embedding self-management support within mainstream health services in Ireland. It was prepared in response to a key objective of the National Clinical Programmes to achieve measurable improvements in the quality of life of people living with long-term health conditions.

This framework document:

- 1) describes self-management and related terms;
- 2) outlines the evidence on the effectiveness of self-management;
- 3) broadly sets out core elements of care which are integral to supporting people to self-manage long-term health conditions; and
- 4) identifies actions for a way forward.

It explicitly addresses **Self-Management Support** for long-term health conditions, which is described as the work of organisations, systems, health providers or carers in supporting individuals in managing their conditions. It also includes the provision of information, education and other supportive interventions to improve individuals' confidence and skills in managing their health condition. (Reijekn et al, 2008: 120)

The goal of self-management support is to enable patients to perform three major functions:

- i) medical management of their illness;
- ii) carrying out normal roles and activities; and
- iii) managing the emotional impact and the adjustment problems which are associated with developing a long-term health condition (see page 7) (Lorig & Holman 2003 adapted).

The term **self-management** specifically refers to people who are living with a long-term health condition and encompasses their everyday self-care activities. Self-management is the process each person develops to manage their condition, specifically; managing the symptoms, medication and treatment, coping with the emotional effects of the condition and adapting to the impact of the condition on activities of daily living (WA, 2009).

Informed and empowered patients. Self-management support informs and empowers patients to have the knowledge skills and confidence to manage their own health and healthcare, so that they:

- Make healthy lifestyle choices
- Make informed and personally relevant decisions about their treatment and care
- Adhere to treatment regimes
- Experience fewer adverse events
- Use less healthcare.

Shared expertise – The ideal relationship between health professionals and patients takes into account the shared expertise of both, to achieve the best outcome for the patient.

SHARED EXPERTISE

| CLINICIAN | PATIENT |
|-----------------------|-----------------------|
| Diagnosis | Experience of illness |
| Disease aetiology | Social circumstances |
| Prognosis | Attitude to risk |
| Treatment options | Values |
| Outcome probabilities | Preferences |

Academic theory

Self-efficacy

The principles of self-management are developed in a number of theoretical models, mostly within the fields of health psychology, sociology and behavioural science. Of these, self-efficacy theory is most widely referred to (Bandura 1997).

Self-efficacy refers to an individual's belief in their capacity to successfully learn and perform a specific behaviour. A strong sense of self-efficacy leads to a feeling of control, and willingness to take on and persist with new and difficult tasks.

When applied to health, this theory suggests that patients are empowered and motivated to manage their health problems when they feel confident in their ability to achieve this goal.

On this view, interventions for improving self-management should focus on confidence building, and equipping patients with the tools (knowledge and skills) to set personal goals and develop effective strategies for achieving them.

Individuals and their carers specifically need:

1. To have a good understanding of their condition and know how to manage it.
2. To be able to work with healthcare professionals and others to discuss and agree treatment plans and goals.
3. To be able to monitor their condition and manage their symptoms, and know when and how to access specialist services.
4. Be able to follow and maintain the treatment planned agreed with their healthcare team, family and others.
5. Be able to cope with and manage the impact of the condition on their physical and emotional well-being and maintain their everyday activities of living
6. Be able to change their lifestyle behaviours in order to prevent further deterioration or progression of their condition and improve their general health
7. Be able to access and use support services (NHPAC, 2006).

Adjustment problems

Types of adjustments problems in long-term health conditions and key stages where people need support

Not all people adjust well to living with long-term health conditions. The types of adjustment problems that commonly develop with are outlined here, and relate to the key stages of disease progression outlined in Diagram 2.

Diagram 1: Common adjust problems

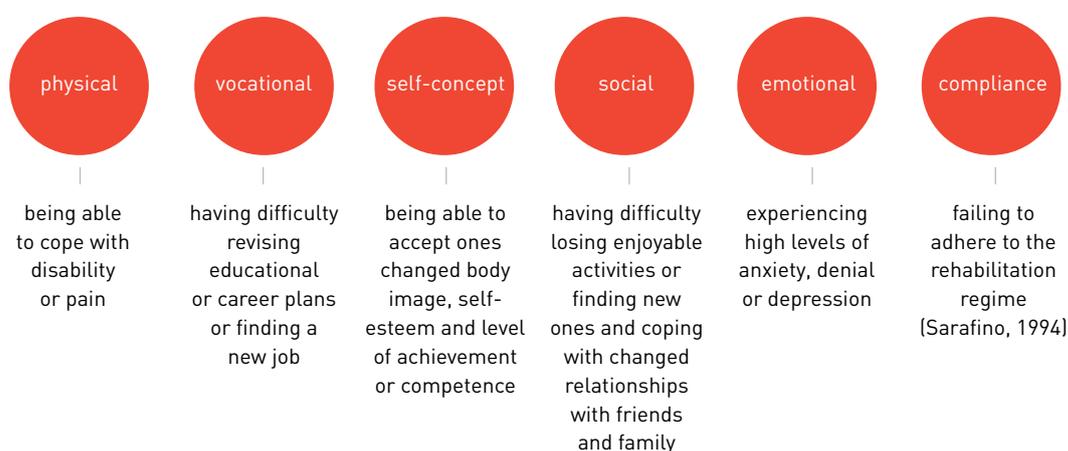
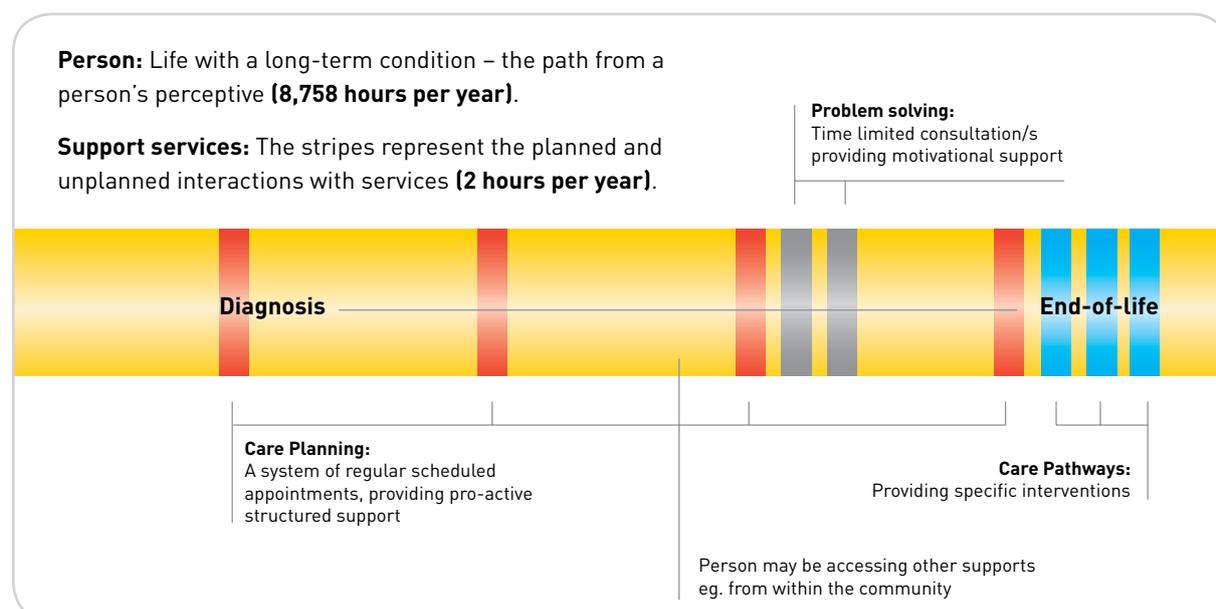


Diagram 2: Who's condition is it anyway?



There are key stages during the progression of long-term health conditions, where people need support to self-manage their health. Broadly these stages can be defined as diagnosis, living for today, progression, transitions and end-of-life.

Table 1: Key stages when people need support:

| KET STAGES | ISSUES | IMPACT OF SELF-MANAGEMENT |
|-------------------------|---|--|
| Diagnosis | <ul style="list-style-type: none"> • By this point someone’s life and ability to manage may have already been seriously affected by symptoms. • People feel challenged about their place in the world and the reality of their situation. | <ul style="list-style-type: none"> • Helps people come to terms with diagnosis. • Key to helping people reconnect with themselves and others. • Helps people make better decisions about treatment options. |
| Living for today | <ul style="list-style-type: none"> • People need information and skills to maintain optimum wellbeing. • Serious risk of social exclusion. | <ul style="list-style-type: none"> • Supports people to navigate an often difficult journey. • Challenges social exclusion by helping build bridges back into society and social roles. |
| Progression | <ul style="list-style-type: none"> • Cycle of illness and wellbeing arising from fluctuations in conditions. • Increasing severity of symptoms. • Struggle to get additional support during flare-ups. • Possible loss of capacity. | <ul style="list-style-type: none"> • Helps to avoid (or minimise the extent of) flare-ups. • Enables people to recognise early warning signs and react effectively. • Tackles psychological impact of flare-ups or progression. • Supports changing needs. |
| Transitions | <ul style="list-style-type: none"> • Moving between services, sometimes to different levels/types of support. • Dealing with multiple needs/conditions and therefore a range services. • Often a stressful time and this can have serious impact, including on the person’s condition. | <ul style="list-style-type: none"> • Supports person to manage transition processes. • Maintains focus on person’s needs ensuring services are organised around these. • Provides person with control at a time when this can be undermined. |
| End-of-life | <ul style="list-style-type: none"> • Difficult time involving complex challenges. • Death may be premature. • Person may have to cope with symptoms of condition alongside additional challenges of end of life. | <ul style="list-style-type: none"> • Supports person to meet range of challenges and maintain control. • Addresses broader needs e.g. emotional, family and lifestyle. |

Patient education and self-management

Different clinical conditions require varying approaches and forms of self-management support. For example, people with diabetes and asthma require very specific technical information and educational support about diet, exercise and medication in order to be able to manage and control these specific conditions. Some other chronic conditions, such as depression and chronic pain, require less technical skills so the self-management support for such conditions focuses on providing more generic cognitive and behaviour change education and support (De Silva, 2011).

However, these generic forms of SMS may also be beneficial for people with specific conditions such as diabetes, asthma, arthritis and heart disease, which are associated with a higher prevalence of mental health problems, such stress, depression and anxiety (Goodwin et al, 2010). Self-management support for these specific conditions has, heretofore, tended to focus on bio-medical, technical information and education (De Silva, 2011), with relatively little attention afforded to the social or emotional aspects of these conditions.

Table 2: Differentiating Patient Education & Self-Management Education

Source: Bodenheimer et al (2002) cited in Coulter & Ellins, 2006: 87-88.

| | TRADITIONAL PATIENT EDUCATION | SELF-MANAGEMENT EDUCATION |
|--------------------------------------|---|---|
| What is taught? | Information & technical skills about the disease. | Practical communication and problem solving skills. |
| How are problems formulated? | Problems reflect the inadequate medical control of the condition. | The person identifies problems experienced which may or may not be related to the disease/condition. |
| Relation of education to the disease | Education is disease-specific and teaches information and technical skills related to the disease. | Education provides problem-solving skills relating to the consequences of chronic disease in general. |
| The theory underlying the education | Disease specific knowledge creates behaviour change, which in turn produces better clinical outcomes. | Support the person to develop confidence in their ability to make life-improving changes (self-efficacy) which produces better clinical outcomes. |
| The goal | Compliance with the behaviour change taught to the patient to improve clinical outcomes. | Increased self-efficacy to improve clinical outcomes. |
| The educator | A health professional. | Health professional, peer-leader or patient-led, often in group settings. |

Health policies on self-management support (SMS) and related service developments have tended to focus, almost exclusively, on the provision of structured self-management education programmes (Jordan et al, 2008; Coulter & Ellins, 2006). Although self-management education is often regarded as an aspect of patient education, these two activities are quite different from each other). On a number of dimensions as outlined in Table 2: Education programmes that teach practical self-management skills are more effective than information-only patient education (De Silva, 2011; Coulter & Ellins).

Self-management education programmes (SMEP) vary widely, and as a result it is difficult to collate and analyse this data to identify the most effective SM education interventions (Coulter & Ellins 2006; Reijnen et al, 2008). However self-management education programmes can be broadly grouped under the following two categories:

- i) condition-specific education programmes;
- ii) generic, community-based group education programmes. Both of these approaches are now briefly outlined.

1) Condition-specific self-management education programmes

These structured education programmes have been developed to support people self-manage specific conditions. Most research studies on condition-specific self-management education programmes have involved people with asthma, diabetes or arthritis and more recently chronic obstructive pulmonary disease, angina and depression (Coulter & Ellins, 2006).

Such condition-specific self-management education programmes are usually led by health professionals within healthcare settings and generally tend to focus on educating individuals on the medical and technical management of the condition (Reijnen et al, 2008).

2) Generic peer-led community-based self-management education programmes

The Chronic Disease Self-management Programme (CDSMP) developed by Professor Lorig and colleagues at Stanford University (www.stanford.org) is the most widely developed generic self-management education programme. An underlying assumption of the programme is that people with chronic conditions have similar concerns and problems; people have to learn how to manage their condition and also need to learn how to cope with the emotional and social impact of the condition on their daily lives.

The programme is a structured, educational programme for people with any chronic condition, which is delivered in two and half hour sessions over six weeks and is highly participative. Generic community based self-management education programmes are most suitable for people living with a number of conditions, especially older people, attending an education programme specific to one condition would not be appropriate for these people (Harris, et al 2008). However, there is also some evidence that generic self-management education programmes do not fully meet participants' information needs in relation to their own specific condition (Philips et al, 2010; Coulter & Ellins, 2006). The CDSMP operates as the Expert Patient Programme within the UK. A number of Irish organisations deliver the CDSMP; Arthritis Ireland; Ceart PatinetWise in Kilkenny; the Meath & Adelaide Hospital in Tallaght and it is currently being piloted by the HSE within a Primary Care Network in Donegal.

Evidence on self-management

The evidence indicates that self-management support is an integral principle and component underpinning quality driven, effective healthcare. The definition of self-management is very broad and interventions are varied, so studies often involve very different interventions and populations which make comparative reviews problematic.

Most studies in the field indicate that group based patient works. Although self-management support and research into what works is still in its infancy there is rapidly growing consensus that self-management does work and those strategies which enable behavior change are fundamental to improving health outcomes.

There is emerging evidence that those interventions that specifically aim to increase patients levels of self-efficacy or activation are more likely to produce positive outcomes in terms of behavior change and health outcomes.

Information-only patient education has limited effectiveness, and improvements on outcomes other than knowledge have not been found. Educational programmes teaching practical self-management skills are more effective than the provision of information alone.

The literature relating to self-management support has been systematically reviewed by Coulter & Ellins (2006) and more recently by Battersby et al (2010) and De Silva (2011). These systematic reviews report that a broad variety of activities and interventions are described as self-management support, all of which vary widely in terms of theory, content, approach, duration, target group, settings and outcome measures.

At present, the evidence for self-management support (SMS) is fragmented and spread across a number of related databases, in particular self-management education interventions. The following areas have not been adequately evaluated; a) long-term outcomes; b) cost-effectiveness; c) the comparative effectiveness of different interventions, or d) which components of complex interventions are most effective (Coulter & Ellins 2006).

However, despite these important gaps, a sufficiently robust body of knowledge is emerging from research data which clearly indicates the most effective forms of self-management support for people with long-term conditions, these are presented in the table below, (Brady & Murphy, 2011; De Silva, 2011; Battersby et al, 2010).

Evidence on condition specific programmes

Cochrane reviews on self-management support for COPD, Diabetes, Asthma, Heart Failure and Arthritis found evidence of reduced hospital admissions, improved clinical outcomes and increased quality of life and well-being for participants (Reijnen, et al, 2008).

A Cochrane systematic review of group-based diabetes education programmes found evidence indicating that such programmes are associated with clinically important improvements in participants' health outcomes, specifically glycated haemoglobin (Hb1Ac), fasting blood glucose levels and diabetes knowledge at 4-6 months and at 12 months follow-ups (Deakin et al, 2009). The review also found evidence of reduced requirements for diabetes medication, improved control of diabetes and improved self-management skills, increased self-empowerment and food-related quality of life outcomes at 12-14 month follow-ups. Small improvements in blood pressure and triglyceride levels were evident in the short-term 4-6 month whilst small reductions in body weight were sustained up to 12-14 month follow ups.

For people with arthritis, self-management education is associated with significant improvements in self-efficacy and quality of life measures, but has a smaller impact on important outcomes such as pain and functional disability (Lorig & Holman, 2003). One explanation for this may be that diabetes, asthma, hypertension are conditions for which specific skills such as diet, blood-sugar control and medication management can be taught, whereas with arthritis the goals are less easy to define (Battersby et al, 2010: 563).

Many of these condition-specific education programmes have developed to such an extent that they are now structured programmes, which are recognised as core standards of care within a number of clinical care programmes/services, specifically Diabetes^[1], Asthma^[2], Arthritis and Cardiac Rehabilitation programmes of care. Structured self-management education for people with diabetes (CODE; DESMOND; DAFNE) is one of the Integrated Standards of Care for Diabetes in Ireland (HSE, 2009b).

Evidence on generic and community based programmes

In 2011 a systematic review was conducted by the Centers for Disease Control and Prevention to examine the specific effects of two self-management education programs developed at Stanford University. The programs examined were (1) the generic Chronic Disease Self-Management Program (CDSMP), a 6-week series of classes, and (2) the Arthritis Self-Management Program (ASMP), a similar series of classes designed specifically for people with arthritis. These investigations included both RCTs and longitudinal program evaluations and examined multiple outcomes that reflected physical and psychological health status (including self-efficacy), health behaviours, and healthcare utilization.

The findings highlighted the substantial effect on individuals' health related quality of life and the

physical, psychological and social impact of chronic health conditions. They also suggested that the ASMP and CDSMP contribute to improvements in psychological health status, self-efficacy, and select health behaviours and that many of those improvements are maintained over 12 months. While the effects are modest, they have great public health significance when the cumulative impact of small changes across a large population is considered. Furthermore, if sustained, these shifts may have a substantial effect on health-related quality of life and the physical, psychological, and social impact of chronic health conditions.

The authors point out that at the population level, these interventions could have a considerable public health effect due to the potential scalability of the interventions, the relative low cost to implement them, wide application across various settings and audiences, and the capacity to reach large numbers of people.

In addition to healthcare professionals' medical management, these interventions provide individuals who have chronic conditions opportunities to develop the knowledge, skills, and confidence to appropriately self-manage disease-related problems. Finally they conclude that self-management, as well as the self-management supports that communities and health systems provide, are essential components of the chronic-care model that is reshaping how care is delivered to people with chronic health conditions.

However, in order to fully realise the potential benefits of such group-based self-management education programmes, they need to be fully integrated within clinical care-pathways for people living with chronic health conditions- as a standard of care (Philips et al, 2010). Self-management education programmes on their own are of limited effectiveness if they are isolated from the mainstream healthcare services (De Silva 2011; Battersby et al, 2010)

^[1] International Standards for Diabetes Education (DECS, 2003)

^[2] GINA (2008) Global Strategy for Asthma Management and Prevention www.ginasthma.org.

Table 3: A summary of the most effective forms of self-management support:

| SELF-MANAGEMENT SUPPORT INTERVENTIONS | EXPECTED IMPACT AND OUTCOMES |
|--|---|
| <p>Structured use of targeted information resources within clinical care</p> <p>Structured self-management education and support for people with specific conditions integrated within routine care-planning processes and care -pathways; (with the active involvement of health professionals)</p> | <ul style="list-style-type: none"> - Improved knowledge and reduced anxiety levels - Improved confidence & levels of involvement with clinicians - Improved knowledge & understanding - Improved confidence and coping ability - Improved health behaviours - Improved adherence to treatment & care plans - Improved health outcomes at 4-6 & 12 month follow-ups - May reduce hospital admission rates - May be cost-effective |
| <p>Generic self-management education programmes (peer-led, community-based); i.e:</p> <ul style="list-style-type: none"> - Chronic Disease Self-Management Programme (CDSMP) - Expert Patient Programme (EPP) | <ul style="list-style-type: none"> - Improved knowledge & understanding - Improved confidence and coping ability - Improved quality of life & self-efficacy - Improved mental health outcomes - Improved health behaviours - Improved social support - May improve clinical health outcomes - May reduce hospital admissions, improve access and use of other health services - May improve adherence to treatment & medication - May be cost effective |
| <p>Interactive, web-based self-management education programmes</p> | <ul style="list-style-type: none"> - Improved knowledge and understanding - Improved social support - Improved health outcomes - Improved health behaviours - May be cost-effective |
| <p>Medication assistive aids and devices</p> | <ul style="list-style-type: none"> - Improved adherence to medication and treatment plans |
| <p>Support Groups and Networks</p> | <ul style="list-style-type: none"> - Improved knowledge and confidence in self-managing conditions - Improved self-management behaviours - Improved social support - Improved quality of life for individuals their carers |
| <p>Home-based self-monitoring (anticoagulation blood pressure and diabetes); Telehealth</p> | <ul style="list-style-type: none"> - May improve health outcomes - May improve quality of life - May be cost effective |
| <p>Telephone support/Telecare</p> | <ul style="list-style-type: none"> - Improved quality of life - Improved social support - Improved health behaviours - May be cost-effective |

Where the evidence is less strong, this is indicated by including 'may' in the list of expected outcomes; Adapted from data sourced via www.investinegagement.info / www.pickereurope.org

The coordinated and systematic implementation of specific self-management support interventions across the health system could help to improve people's self-management efforts and their quality of life, and may contribute to a more efficient use of healthcare.

The most effective forms of self-management support are clearly identifiable within the literature and are summarised in the following table:

The coordinated and systematic implementation of specific self-management support interventions across the health system could help to improve people's self-management efforts and their quality of life, and may contribute to a more efficient use of healthcare resources (www.investinengagement.info). However, no single intervention on its own is fully effective: People's self-management knowledge and skills evolve over the course of their chronic condition and the level of self-management support required will vary depending on the stage of their condition, their personal circumstances and capacities (DH, 2009).

Summary

In summary the research literature indicates that the provision of self-management support generally helps to improve people's quality of life, health and well-being to a lesser or greater degree depending on the specific self-management intervention and approach utilised.

Self-management Support interventions which focus on self-efficacy and behavioural change appear to be most effective in terms of improving individuals' quality of life and health outcomes and reducing emergency use of health services (De Silva, 2011).

Overall there is good evidence to support provision of disease specific programmes and community based peer led programmes. Support for self-management needs to be integrated into a model of innovative care and personalised care planning between professionals and patients.

Embedding support for self-management within mainstream health services

The evidence identifies the importance of patients as partners in their own care and the importance of personalised care planning supported by information, education, community support and technology as critical elements of helping people to cope with managing a long-term health condition. These elements are depicted on Diagram 4, and described in terms of their implications for patients receiving care their carers and professionals delivering care.

Health systems have often been organized with the needs of the clinician and the system taking priority in the delivery of care to patients. In such a model the Professional is at the center of the system – he or she has exclusive access to knowledge and the patient is expected to comply with the instructions given by health professionals.

In many countries this is now changing: healthcare is considered a process of co-production in which professionals and patients jointly work on solving health problems with the inclusion of the wider support networks such as his/her family and support group.

In order to implement such a model the following changes are suggested:

- Both professionals and patients are required to change a mindset which is based on hierarchical expectations towards one based on dialogue and co-production.
- Health systems and their functioning need to become more “readable” so that patients can navigate them according to their needs.
- Health professionals need to be effective communicators and listeners.
- Information needs to be much more easily available and understandable.

Patients need to prepare for the interaction with the healthcare systems, ask questions, express needs and expectations and implement jointly agreed treatment programmes.

Health services and health professionals support patient empowerment by supporting self-management, working with the patient in an equal partnership, on an equal platform. This means that the focus is very much on the patient.

What is important to note is that this empowers the lives of not only the patient but also of those who support people with long-term health conditions.

CHANGING MODELS

| | CONVENTIONAL MODEL SYSTEM | CO-CREATING HEALTH MODEL SYSTEM |
|----------------------------|---|---|
| Training | Clinicians trained in ‘communications’ skills to enable them to get agreement to clinician determined goals | Clinicians trained in skills to support people to determine and enact their own goals (eg. motivational interviewing) |
| Information flows | Results sent to clinician to share with patient during consultation | Person receives results in advance of consultation unless they determine otherwise |
| Appointments system | Allows for only fixed time 1;1 consultation | Allows different types of consultation e.g. group, telephone, email |
| Engagement | Individually-based representative | Community-based participative |

Skills for healthcare professionals

To ensure that self-management and self-management support is effective it is essential that people with long-term health conditions and the care teams are supported in developing their core skills that enable changes in health behaviors and beliefs’.

The skills for healthcare professionals include: (Wagner et al. 2001)

- Establishing an empathic clinician-patient relationship
- Joint agenda setting for each consultation
- Collaborative goal setting
- Exploring ambivalence about change
- Using problem-solving skills
- Using systematic tools to support goals’ follow-up

What will support for self-management mean for patients using health services and interacting with professionals?

- **Partnership** – Individuals will be acknowledged as partners in their healthcare and offered appropriate support in self-managing their chronic health condition. Individuals will feel understood valued and involved in their healthcare

- Self-management **personalised care-planning** processes, decisions and goals will reflect individuals’ personal experiences, needs and preferences. Patients will be provided with the information and support required to enable them to take an active role in developing a personal, written self-management care-plan.

Interventions which provide support and build self-efficacy

- Each person’s health **information** needs individually assessed to inform and guide care-planning process and decisions. People will be supported with the information (verbal & written) they need to help them:
 - Understand their condition, the associated symptoms and impact on their daily lives;
 - Correctly use their medication;
 - Understand when and how to access specialist help, access peer and social support groups & networks and change lifestyle behaviours.
- **Individuals and their carers:**
 - will have access to structured self-management **education programmes** appropriate to their specific health needs; and
 - have access to appropriate tools and **technologies** to support them self-manage their condition at home for managing medicines and also emergencies.

CHANGING CLINICIANS ROLES

| OLD APPROACH | NEW APPROACH |
|--|---|
| Believes knowledge creates behaviour change | Believes supported self-efficacy plus knowledge create behaviour change |
| Gives expert advise and prescription | Provides enabling support |
| Seeks compliance with clinician determined goals | Seeks exploration of person’s goals |
| Scientific focus on condition | Empathetic focus on person |
| Lead part | Supporting role |
| Reactive | Proactive |

Self-management support long-term health conditions

Partnerships

Implementing a strategic plan for self management support will require three main partnerships (outlined in Diagram 4).

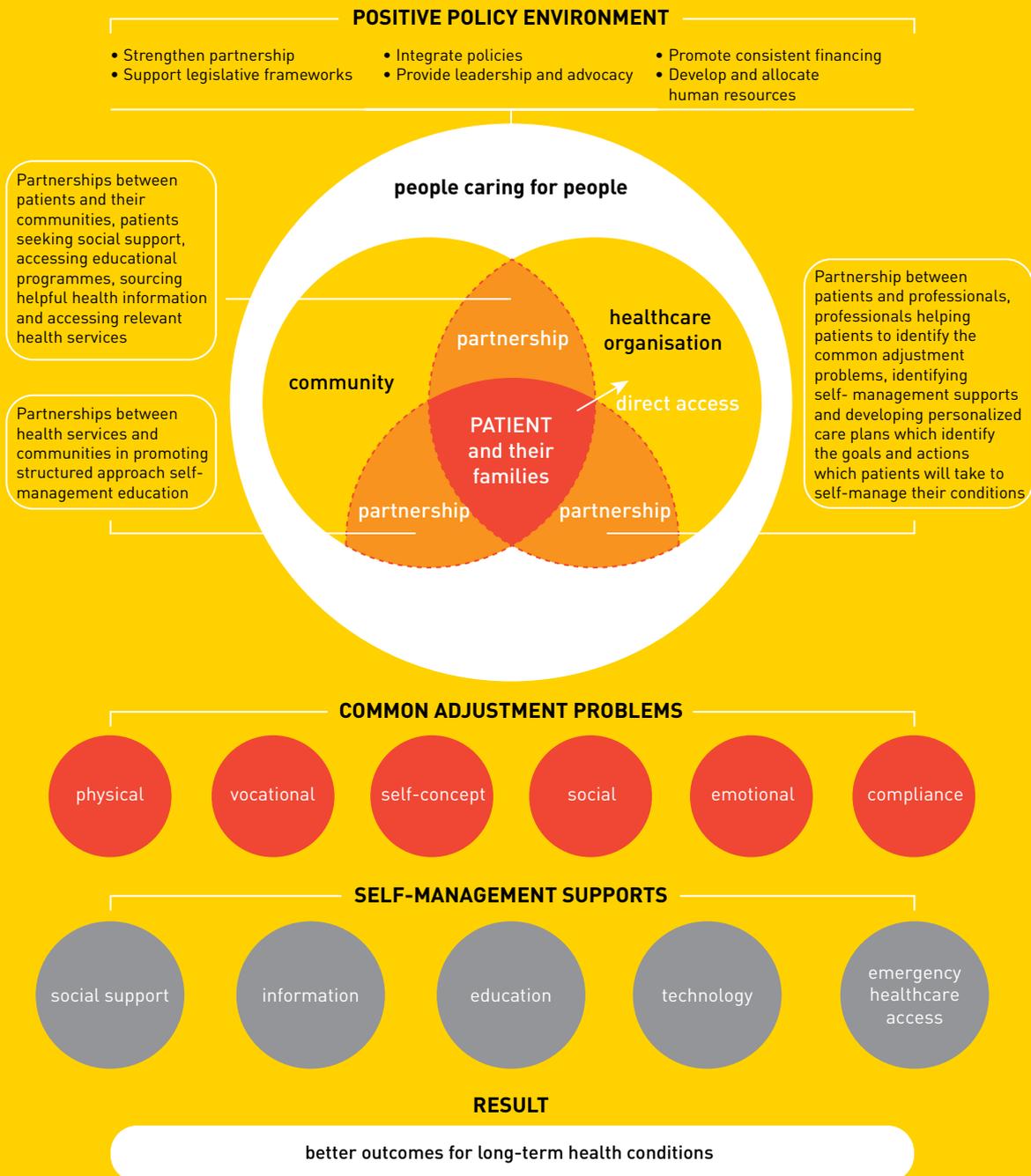
- 1) partnership between patients and professionals, professionals helping patients to identify the common adjustment problems, identifying self management supports and developing personalized care plans which identify the goals and actions which patients will take to self manage their conditions;
- 2) partnerships between health services and communities in promoting structured approach self management education;
- 3) partnerships between patients and their communities, patients seeking social support, accessing educational programmes, sourcing helpful health information and accessing relevant health services.

SELF-MANAGEMENT SUPPORTS



Table 4: Developing a strategy to support patients to self-manage long-term health conditions

Working together to address the common adjustment problems for people with long-term health conditions, and finding solutions which address their needs. The core elements of self-management support are outlined in the diagram below:



Solutions for a way forward

Developing and implementing Self-Management Support within the Irish Healthcare System:

Self-management support requires a whole system approach, specifically requiring high-level leadership and support to build capacity in three key areas:

- i) Individuals capacity to live with long-term health conditions;
- ii) Healthcare staff;
- iii) The healthcare system.

An implementation plan has been outlined in the next section to help identify ways in which we can embed self-management support across the Irish healthcare system and in particular the National Clinical Care Programmes. (see section 1.3.1 for matrix)

The implementation plan for this framework is based on the core elements described below and identified in the evidence as critical for supporting self-management across the Irish healthcare system.

| | 1. Patient | 2. Enabled healthcare professional | 3. Healthcare organisation and community |
|---------------|---|---|---|
| Aim | Make better use of self-care support | Provide better self-care support | Improve access to self-care support |
| Method | <p>Relevant information and support based on:</p> <ul style="list-style-type: none"> • Current need • Personal priorities • Negotiated plan | <p>Changed professional response:</p> <ul style="list-style-type: none"> • Assessment • Sharing decisions • Supporting change • Self-care support options • Self-management care planning | <p>Improving:</p> <ul style="list-style-type: none"> • Staff training • Data on local resources • Patient access to support |

Objectives

In order to achieve measurable improvements in the quality of life of people living with long-term health conditions and to complement the work done by the National Clinical Programmes, the following high level objectives have been identified.

1. **Patient:** Empower patients to make better use of consultations with professionals and to take a greater role in managing their own health conditions;
2. **Enabled healthcare professional:** Enable healthcare professionals to engage in more shared decision making and to provide better self-management support including personalised self-management care plans;
3. **Healthcare organisation and community:** Improve access for patients to self-management supports including; information, technology, education, social supports and emergency healthcare.

Actions for implementation

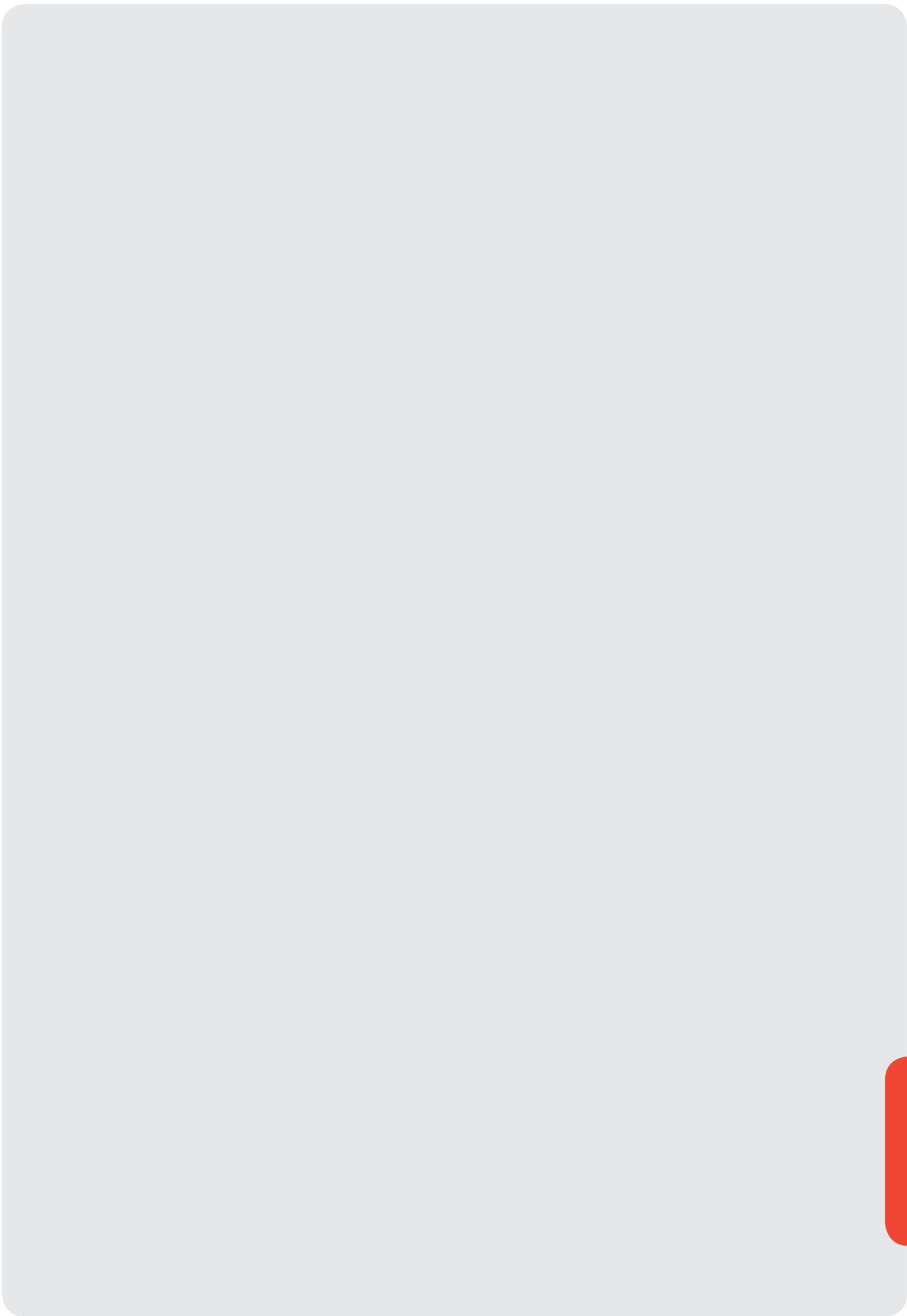
In order to achieve these high level objectives, the following actions have been identified.

- 1 Working with key stakeholders:** Establish a working group of key stakeholders including senior clinicians and voluntary representatives who have a role in overseeing the implementation of this framework within specific programmes.
- 2 Training professionals:** Identify validated self-management tools and resources and adapt for the purposes of training professionals to support implementation of this work.
- 3 Care pathways:** Self-management support should be explicitly integrated within all clinical care pathways.
- 4 Contracts and service level agreements:**
 - a. In relation to contracts with health professionals (eg. GPs and Pharmacists) the HSE should ensure that self-management support is an integral part of the care pathway for patients with long-term health conditions;
 - b. In relation to service level agreements with NGOs, where appropriate, the HSE should ensure that training is provided to volunteers who are working with support groups in the community.
- 5 The Stanford peer led model:** Adopt the peer led Stanford Model of structured self-management support as it already has been implemented in the Donegal area and develop a plan to implement and evaluate it across Ireland. This should be done while maintaining the quality standards achieved in Donegal.
- 6 Building capacity:** Engage with NGOs and other key stakeholders who already have tutors trained to masters level in self-management education programmes with the aim of developing further structured peer led self-management programmes in the community.
- 7 Map and profile:** Continue to map self-management programmes which are already being delivered throughout Ireland and make available this information to healthcare professionals and the patients.
- 8 Health literacy:** Incorporate the work on the HSE A to Z of diseases and conditions into the framework on self-management.
- 9 Patient empowerment resources:** Develop resources aimed at patients to encourage them to make better use of consultations with healthcare professionals and to seek self-management support (eg. 'It's Safe to Ask' booklet).
- 10 Evaluation:** Develop an evaluation framework to measure the above outlined objective.

Operational managers will be designated to over see the implementation of the above outlined actions.

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