HSE Transformation Programme
.... to enable people live healthier and more fulfilled lives

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The Health Service Executive
4.1 Chronic Illness Framework

*July 2008*
Introduction and policy context

Chronic illness is defined as long term conditions which can be treated but not cured. These conditions include diabetes, heart failure, chronic obstructive pulmonary illness, dementia and mental health problems, asthma, musculoskeletal diseases, and a range of disabling neurological conditions, many of which are preventable.

Key features of chronic illnesses are:
- complex and multiple causes,
- usually have a gradual onset,
- occur across the life cycle, being more common with older age,
- can cluster in individuals by virtue of age, common risk factors, and possible common systemic responses.
- compromise quality of life through physical limitations and disability,
- long-term persistent, leading to a deterioration in quality of life,
- costly in terms of service provision
- a significant perpetuator of health inequalities,
- the most common causes of premature death.

Against this background, it is incumbent on the Health Service Executive (HSE) to plan for the prevention and management of chronic illness. In doing so it will take account of:
- Department of Health and Children - Quality and Fairness: A Health System For You,
- HSE Corporate Plan,
- HSE Transformation Programme,
- Programme for Government,
- HSE Population Health Strategy,
- Department of Health and Children/Health Service Executive National Strategy for Service User involvement in the Irish Health Service, and,

Purpose of this framework

The purpose of the framework is to identify the way forward so as to prevent chronic illness where possible and to detect, minimise and manage the impact of chronic illness on individuals and the population.

This Framework for the prevention and management of chronic illness is the overarching framework for all disease specific strategies (e.g. diabetes, heart failure, COPD etc) which will be developed based on this Framework.

Key to this is a recognition that multiple strategies are required, involving a whole Government approach, if we are to be in any way successful in promoting health and in preventing the burden of chronic illness in the population. This framework identifies the key leadership role that the HSE has to play in advocating for the necessary changes across all sectors and the role for agencies external to the HSE.

It is recognised that the current health care system is fragmented and too focused on episodic secondary care. A continuum of quality health services spanning health promotion, prevention, self management support, primary and specialist care should be available to the whole population. This Framework emphasises the need to integrate services for the patient and deliver them in the least complex and most appropriate setting.

Burden of Chronic Illness

Worldwide the rise in the prevalence of chronic illness is having a significant impact on the
delivery of health and social services. It is estimated that the care of people with chronic illness consumes between 70-80% of all health care spending.

People with chronic illness are far more likely to:

- attend their General Practitioner (GP)- 80% of GP consultations relate to chronic illness,
- present at an Emergency Department (ED)- 66% of patients admitted through EDs have exacerbations of their chronic illness,
- be admitted as an inpatient ,
- use more inpatient bed days than those without a chronic illness – 60% of hospital bed days are accounted for by people with a chronic illness. In addition, a small proportion of patients (5%) who have a chronic illness use 40% of inpatient bed days,
- suffer increasing morbidity, have compromised quality of life and die prematurely.

Whilst the current burden on the health and social care system is quite high, it is expected to rise even further. A combination of factors is contributing to the rising prevalence of chronic illness, including the ageing of the population, technological and therapeutic advances in medicine, increasing longevity and changing patterns of disease and lifestyle behaviours that predispose to the development of a range of chronic illnesses.

The most recent population projections estimate that that by 2041 there will be between 1.3 and 1.4 million persons aged 65 years and over compared to 460,000 in 2006. This implies that 20 to 25 percent of the population will be aged over 65 years in 2041 compared with 11% now.

The success both in prevention and treatment of specific illnesses e.g. heart attacks, has resulted in people surviving the acute phase of their illness and progressing to live with a long term chronic illness. In addition, as a result of technological advances the numbers of children and young people moving into adulthood with long-term illnesses are also increasing, as are the numbers of children and younger people being diagnosed with chronic illness such as asthma and type 1 diabetes.

Data from SLÁN 2007 indicate a rising trend in key risk factors for chronic illness. These include smoking, overweight and obesity, lack of physical activity, lack of adequate nutrition and diet, and a high prevalence of untreated high blood pressure and high cholesterol levels.

A key trend emerging from SLÁN 2007 is the preponderance of high risk factors in the lower socio-economic groups which will lead to a widening of health inequalities into the future by virtue of increasing the burden of chronic illness on this population.

It is well recognised internationally that the management of chronic illness needs to change. Inadequate management of chronic illness leads to unnecessary ED presentations and inappropriate hospital admissions. It has been shown that chronic illness can be better managed in a well developed multi-disciplinary primary care setting, provided the necessary supports are put in place for patients and their carers.

Integration of services and access to self-care programmes have been found to be the most effective interventions to reduce the burden of illness.

In addition, it is well recognised that there is a need to incorporate a multifaceted and comprehensive prevention approach to reduce the number of new cases of chronic illness if progress is to be made.
**Distribution of Chronic Illness**

Within the population (see figure 1) the majority currently do not have a chronic illness and may or may not have, or be exposed to risk factors which predispose them to chronic illness. A recent SLAN survey showed that 90% of over 40 year olds had at least one risk factor for chronic illness.

In addition there are those who have an undiagnosed chronic illness who require early diagnosis, secondary prevention and appropriate management. It is estimated that over half of those with diabetes mellitus have not yet been diagnosed.

Of the population of patients with identified chronic illness, they can be divided into three main levels of complexity:

**Level 1:** Individuals who have a chronic illness which can be well controlled by the patient themselves with primary care support. (Approximately 80% of patients).

**Level 2:** Individuals with more complex illness. They may have one or more chronic illness of varying severity, but are not at high risk of hospitalisation, if they are well managed in the community. (Approximately 15% of patients).

**Level 3:** Individuals with complex conditions, often with complications. They require specialist care, intensive intervention and are at high risk of hospitalisation. (Approximately 5% of patients).

It is important to appreciate that these three levels are not distinct cohorts of patients; people in each level can improve or disimprove and move between the levels.

In order to promote, improve and protect the health of the whole population from chronic illness, the HSE’s Chronic Illness Framework will be population focused to include the well population and those with chronic illness who will continue to require high level, integrated, evidence based care at both specialist and primary care levels.

**Key goals of the HSE Chronic Illness Framework**

*For the well population the goal is:* To protect, promote and improve the health of the population and reduce risk factors to enable people to lead healthier and fulfilled lives with improved quality of life, and prevent the onset of chronic illness.

*For those who have developed a chronic illness the goal is:* To provide individuals, groups and carers with early diagnosis, education, optimal clinical and social care in the most appropriate setting, stable control of their condition, self-management support, avoidance of complications, improved outcomes and best quality of life.
For those whose chronic illness deteriorates the goal is:
To provide individuals, population based groups and carers with the knowledge to recognise deterioration, optimal clinical and social care in the most appropriate setting, stable control of condition, rehabilitation and palliative support where appropriate in order to ensure best outcomes and best quality of life.

Chronic Illness Framework

In order to achieve these goals the HSE has developed the Framework outlined below, based on the nine elements of the HSE Population Health Strategy (Figure 2). These nine elements form the cornerstone for developing the Framework.

This Framework requires action on the determinants of health and self management support, as well as delivering high quality integrated health care services, which ensures that those with chronic illness can move between the different levels of complexity of care, so that they return to the least complex and appropriate level of care.

The Framework demonstrates a clear association between the health care sector and the community.

The scope of this Framework and the associated actions are sufficiently comprehensive to encompass all forms of chronic illness. However, it is acknowledged that for some specific chronic illnesses more specific actions will be required.

Figure 2: Population Health Strategy for developing a framework for the prevention and management of chronic illness
1. Addressing the wider determinants of health and tackling health inequalities

In order to address the wider determinants of health and to tackle health inequalities in relation to chronic illness, there is a need to analyse the full spectrum of factors and their interactions known to influence and contribute to health.

Commonly referred to as the determinants of health, these factors include; social, economic and physical environments, early childhood development, health and lifestyle behaviours, individual capacity and personal skills, human biology and health services.

A key strategy utilised in addressing the wider determinants of health and tackling health inequalities is the development of policies to improve population health. This involves working towards policy which addresses health inequalities in the first instance and which results in safer and healthier environments, goods and services. This is especially important in addressing chronic illness. This requires complementary approaches including legislation, fiscal measures, taxation and organisational change.

Action points

The HSE will:
- ensure that there is adequate support to build supportive healthy public policies by engaging in partnership with Government Departments and other agencies in order to address the prevention and management of chronic illness.
- provide evidence and advocate for the development and implementation of policies designed to improve the health of the population and reduce the negative impact of the wider determinants of health e.g. prioritise the implementation of existing task force strategies: alcohol, tobacco, obesity, breastfeeding, health promotion.
- Prepare annual pre-budget submissions on evidence based fiscal policy measures to promote health.
- adopt a disease prevention and health improvement approach across the continuum from primary prevention through secondary and tertiary prevention and including palliation and end of life care, spanning from infancy to old age.
- advocate strongly for and support the health proofing all Government strategies.
- advocate reducing health inequalities and developing and implementing a health inequalities framework.

2. Planning for health and social well being and not just health and social care services

Health is a resource for every day life, not an object of living; it is a positive concept emphasising social and personal resources as well as physical capacities (WHO).

The HSE has a statutory role in ensuring we plan for and provide quality based health and social care services. However it has an equally important role in planning to ensure that the population enjoys and benefits from the best possible health status.

For those with a chronic illness every effort must be made to ensure that they are facilitated to live their lives in a way that maximizes their health and social well being in a supportive environment.
**Action points**

The HSE will:

- create supportive environments to generate living and working conditions, including health care facilities that are safe, stimulating, satisfying and enjoyable. This action goes beyond the protection and sustainability of the quality of the physical environment to the inclusion of strategies to foster conditions for optimal levels of health in social and community environments.

- ensure significant integration across sectors will take place to provide a supportive environment for the maintenance of good health in the population, including those who are living with chronic illness.

- strengthen inter-sectoral liaison and collaboration across government and non-government agencies and align sectoral priorities for chronic care.

- provide and ensure leadership and advocacy for chronic illness in the HSE and across related sectors / organisations, including management, clinical and administrative streams.

- ensure that resources are allocated across the continuum to support health promotion, prevention, best quality integrated health services, self management support, audit, monitoring and evaluation, especially for new developments.

- ensure services are accessible and appropriate, and are provided in the community and as close to home as possible. Particular efforts are required to reduce inequity of access to disadvantaged and special needs populations with chronic illness, and to ensure cultural sensitivity and appropriateness of services provided.

- Maximise its purchasing power to promote availability of healthier foods in health service establishments (e.g. low salt bread).

3. **Developing and employing reliable evidence to improve health and social care outcomes**

A population health approach for the prevention and management of chronic illness uses evidence based decision making.

This includes evidence based measures to promote and improve health and social care outcomes and evidence based clinical management measures.

Evidence-based clinical management refers to the systematic defining and application of the best available evidence to guide clinical decision-making and management. That is, clinical management should be guided by evidence regarding best practice such as the recommendations for care found in scientifically based, peer-reviewed and consensus driven guidelines, clinical pathways and disease-specific clinical management programs. The literature indicates that evidence-based clinical management programs have been associated with:

- improvements in adherence to guidelines by clinicians
- improvement in disease control
- increased patient satisfaction.

**Action points**

The HSE will:

- use evidence on health status and the determinants of health and effectiveness of interventions to assess health.
identify priorities, develop strategies and inform decisions to improve health.

- ensure the best available evidence underpins health service development and is made available for health service providers to inform decision-making and care delivery. This includes implementing and building on best practice models of service delivery, and disseminating and evaluating best practice models and practice guidelines for chronic illness.

- provide systems that incorporate assessment, diagnosis and chronic disease complexity stratification processes, including clinical information systems that facilitate call, recall and follow up information including decision support systems so that the patient is dealt with rather than the disease (i.e. a person centred approach rather than a (single) disease centred approach.

- promote and support organisational change to ensure service design and delivery is based on assessment and stratification of population and individual needs so as to utilise the most effective technologies and available resources.

- work with the Department of Health and Children in developing evidence based health screening programmes.

- develop and disseminate health promotion and prevention ‘best practice’ guidelines e.g. the Health Promoting Hospitals Programme.

4. Making choices for health investment

Using a population health approach for chronic illness, investment should be directed to those areas that have the greatest potential to positively influence health.

Formal needs assessment, both at a service and community level, is a key element in determining the appropriateness of investment and includes the objective identification of needs on the basis of best evidence and consultation with users, service providers and the public.

Action points

The HSE will:

- secure and allocate adequate resources in an efficient and cost effective way which acknowledges the importance of chronic illness as a key enabler of developing effective chronic care systems.

- ensure that the strategic health research framework encompasses chronic illness in order to facilitate the translation of the outputs of that research into clinical practice.

- utilise health technology assessment encompassing medical devices and pharmaceuticals to enhance clinical decision making and resource allocation.

- ensure that all Directorates prioritise the introduction of best evidence cost effective interventions e.g. smoking cessation services in hospital and community settings, influenza and pneumococcal vaccination programmes.

- prioritise and invest in screening programmes that are evidence based and
meet the best international quality standards e.g. diabetic retinopathy services.

- ensure mechanisms for clinical and management leadership are in place to drive and support organisational change processes needed for effective chronic care and ongoing monitoring of quality of care.

- provide effective leadership and governance to ensure appropriate community participation in service planning and development processes.

- provide a highly skilled and well-supported workforce able to demonstrate clinical leadership and to work in providing multidisciplinary care to deliver quality person centred care which is appropriate for people with chronic disease.

- resource and implement the Health Inequalities Framework to address key determinants of health and address health inequalities, thereby reducing the health gradient.

5. Measuring and demonstrating the return for investment in health and social care services

The HSE has an obligation to demonstrate that investments in health and social care services are appropriately measured and evaluated so as to demonstrate clear cost effective outcomes.

Appropriate systems for monitoring and evaluation are essential in ensuring that strategies, services and system for chronic illness are monitored for effectiveness, appropriateness and efficiency on an ongoing basis.

Ongoing monitoring is a key activity that guides and informs service providers and people with chronic illness in tailoring the elements of chronic care, (such as evidence-based clinical management, care coordination, psychosocial support, self-management support and rehabilitation) to different and changing individual requirements.

Action points

The HSE will:

- embed systems in all levels of service delivery to monitor outcomes and effectiveness and ensure the provision of care within a quality and safety framework.

- ensure that specific and measurable outcomes are agreed to monitor the implementation of chronic illness frameworks.

- develop patient registration systems for individual chronic illness, starting with diabetes mellitus.

- ensure that specific and measurable health outcome targets are agreed in advance of funding and that appropriate key performance indicators (KPI) are put in place. The audit of Building Healthier Hearts, the Cardiovascular Strategy, demonstrated substantial health and social gain had been achieved through implementing that strategy.

- emphasise and measure health and quality of life outcomes, as well as clinical outcomes.

- continually evaluate bed utilisation in the acute settings to ensure appropriate use of resources and provision of care.
6. Shifting the balance from hospital to primary care and health promotion

In order to reorient health services, there is a need to develop and provide high quality, integrated, evidence based clinical and curative services at the appropriate level and setting. Equally important is the need for a greater emphasis on the provision of health promotion and prevention services which support individuals and communities in a more holistic way.

This shift is an essential component to achieving the objectives of the HSE Transformation Programme and acknowledges the demonstrated connections between health and broader social, political, economic and physical environmental conditions which contribute to the prevention and management of chronic illness.

**Action points**

The HSE will:
- prioritise the prevention and management of chronic illness in the annual estimates and planning cycles.
- prioritise secondary prevention and self management programmes on a population basis for people with chronic illness.
- provide high quality care, in particular by the strengthening of quality primary care services and interventions, to ensure that the key role of primary care teams in promoting health is realised and that chronic illness is treated and managed in the most appropriate setting.
- provide skills based training in health promotion for primary care teams and community organisations.
- ensure staff are skilled in adopting a person centred approach and have the capacity to work effectively in multidisciplinary teams across various sectors is critical along with evidence based clinical decision making.
- build workforce capacity to meet the future needs of people with chronic illness.

7. Integrating services across the continuum of care

Integrating services for chronic illness is critical for the HSE both internally between the various service directorates and externally between other agencies.

Integrating health promotion, primary preventive, secondary preventive, primary health care and specialist services is essential to maximise the effectiveness of the health care system to manage chronic illness and minimise its effect on the population. Of particular importance is the use of information systems in planning and supporting health care services.

In supporting a comprehensive chronic illness model a combination of clinical information systems, information about demographics and health status, information on cultural, social and economic trends is combined with community health needs assessments that are led by community groups. Clinical information systems are essential for integrating care across primary and secondary service providers.
**Action points**

The HSE will:

- provide care that is integrated across disease entities and across service providers and settings. Multidisciplinary care involves an appropriate mix of generalist and specialist health service providers across a range of professional disciplines working collaboratively across acute and community sectors and private and public domains.

- ensure that care is coordinated by one or more members of the multidisciplinary team involved in service delivery. Care coordination relates to both chronic care and social and other support services, and is based on ongoing assessment and review of the needs and goals of individuals with chronic illness.

- provide person centred care coordinated across the care continuum from prevention to palliation. This requires the development and maintenance of effective partnerships. These partnerships in turn enable the integration of care across multiple service providers and organisations in the acute and community sectors and across private and public domains.

- balance the provision of services between health promotion, prevention, management and treatment to ensure that chronic illness is prevented where possible, identified early and its impact minimised where it exists.

- develop effective multidisciplinary team working and integration across hospital and community based services to ensure best quality care and hospital avoidance.

- develop programmes of education and specialist support for multidisciplinary health care professionals.

- ensure client index and information governance systems are put in place to underpin integrated and safer care.

8. **Proactively engaging and working with other sectors to improve health**

Working in partnership within the HSE and with sectors outside the HSE is a key component of a population health approach. This is a critical action in developing and sustaining a robust chronic illness model.

It involves working in partnership with community groups to set priorities and to collectively achieve goals that enhance the health of the community. Health promotion plays a key role in mobilising communities to promote health using their knowledge of the determinants of health and working with community leaders.

Equally critical is the role of the primary care team, which includes general practitioners, public health nurses and allied health professionals in working closely with communities to improve health. Strong partnerships with statutory agencies and the community and voluntary sector to promote, improve and protect health are essential.

**Action points**

The HSE will:

- develop active partnerships with statutory and voluntary agencies to promote, improve and protect health and build social capital.

- Engage with all relevant stakeholders across government, non-government and community sectors, with emphasis on the crucial role of general
practitioners, in providing chronic care, to ensure synergy of effort and optimal utilisation of all available resources, avoiding duplication and waste. Ensuring continuity of integrated care and sustainability of initiatives and service delivery are pivotal.

- provide disease specific information as an integral part of client information system.
- support the expansion of the healthy cities/communities projects.

9. Engaging the population on the issue of their own health

An informed and articulate population is better placed to manage their own health, to take decisions that will protect and improve health and to engage effectively with the HSE in discussions on health and social well being and the services provided.

Developing personal skills can be applied to the theory and practice of ‘self-management’, which is a core element of chronic illness models. It refers to the development of personal skills for health and wellness and to the support of self-management in coping with an illness.

This will involve strategies in the community as well as in the health system. Supporting personal development of individuals and communities goes beyond traditional health education, such as those dealing with smoking, nutrition and physical activity to addressing the determinants of health.

Traditional health education programmes are important, but are just one strategy which must be integrated into a broader approach addressing the prevention and management of chronic illness.

**Action points**

The HSE will:

- position individuals living with chronic illness and their needs at the centre of care, including their interaction and experience with the health system, for particular episodes of care, in different clinical settings and across the course of life. It will involve tailoring of care for and working in partnership with individuals and their carers and families, especially for those with more than one chronic illness.
- provide scalable tailored programmes for self management, facilitated by efficient IT systems. These improve clinical outcomes and reduce health care utilisation cost.
- strengthen community action and support the development of personal skills and self management.
- actively work in partnership with community development programmes to set priorities for and achieve goals that enhance the health of the community.
- facilitate the active engagement of the Expert Advisory Groups with their appropriate communities as exemplified by the Diabetes EAG in their interaction with Diabetes Federation Ireland.
- ensure that all directorates provide information, training and services which facilitate patient self management.
- support the development of community based resources, managed by HSE and local health care teams e.g. health information points (web, print).
• facilitate group support programmes, self help and disease support groups for those diagnosed with chronic illness, their families and carers.

• provide educational resources, skills training and psychological support to patients to assist them in managing their care.

• build skills and capacity for protecting personal health and wellness.

• emphasise the central role that individuals and patients have in managing their own health and care by involving them and educating them in their own care management.

• provide scalable graduated programmes for self management support for patients with a chronic illness and support families and carers at all stages of the patient journey.
Key Implications of the Chronic Illness Framework for the HSE

1) The HSE, through its Chief Executive Officer, its Board, senior managers and staff will play a leadership role and champion this Framework at all levels. The HSE will take a strong proactive position in advocating for healthy public policy in its own right and in partnership with other sectors to build public policy.

2) The HSE is developing and will implement an overall strategy for the health of the population which will focus specifically on addressing health inequalities.

3) The HSE will ensure a full spectrum of health promotion, self management and clinical services is available to the whole population. Primary care services will be appropriately designed and adequately resourced in order to realise their key role in promoting health and properly managing chronic illnesses in the most appropriate setting. In addition it will also ensure that the hospital sector is configured to provide the support specialist services required. A key driver in facilitating this process will be the development of integrated shared care protocols and packages for specific disease entities.

4) The HSE will provide programmes to enable and enhance patients’ self management.

5) The HSE will utilise the National Strategy for Service User Involvement in the Irish Health Sector to engage with communities and service users in facilitating them to contribute to planning, delivery and evaluation of key services.

6) The HSE will identify and utilise key levers including rewarding excellent performance to ensure the implementation of the Chronic Illness Framework and will consider mechanisms for incentivising delivery.