Director-General Health and Chief Executive NHS Scotland

Chief Medical Officer Directorate

The Scottish Government

CEL 23 (2009)

16 June 2009

Dear Colleague,

IMPROVING HEALTH & WELLBEING OF PEOPLE WITH LONG TERM CONDITIONS IN SCOTLAND: A NATIONAL ACTION PLAN

Better Health, Better Care indicated that we would be producing what was then referred to as a Long Term Conditions Delivery Plan. That work has now reached fruition as the Action Plan attached to this CEL, which sets out our vision for improving the health and wellbeing of those in Scotland living with any kind of long term condition. It also specifies the key actions designed to turn that vision into a reality.

The Action Plan has been developed with the help of a wide range of contributors and also reflects the discussions which took place at the Long Term Conditions Collaborative's event on 14 May this year.

While the CEL is directed primarily at NHS Boards and their Chief Executives, we are aware that this is not a piece of work the NHS can take forward on its own. One of the main messages from people living with long term conditions is the need to integrate health and social care. Implementation of this Action Plan will therefore involve partnership with local authorities and the voluntary sector. The Long Term Conditions Alliance Scotland will work with its voluntary sector members, the Scottish Government and the NHS and its partners to help policies and services develop in response to the experiences of people living with long term conditions.

The Action Plan has at its centre the 7 High Impact Changes developed through the Long Term Conditions Collaborative (LTCC). The LTCC is a key resource for NHS Boards and CHPs to use in continuously improving systems and delivering sustainable improvements, and is therefore a delivery vehicle for the Action Plan.

In delivering this Action Plan, NHS Boards and their partners will need to keep a clear focus on narrowing the health gap.

The Action Plan forms a key part of our new Healthcare Quality Strategy and reflects the increasing importance which we expect NHS Boards to place on issues relating to the quality of people's experience of services.

Addresses

For action
NHS Board Chief Executives, Medical Directors and Directors of Nursing
Local Authority Chief Executives, Directors of Social Work and Housing
General Managers, CHPs
Chief Executive, Long Term Conditions Alliance Scotland

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INVESTOR IN PEOPLE
POSITIVE ABOUT DISABLED PEOPLE

NHS Boards are expected to report progress to the Health Directorates' Long Term Conditions Programme Delivery Board, which in turn is responsible for providing the Health Management Board with monitoring reports on this *Better Health, Better Care* workstream.

Yours sincerely,

Dr Kevin Woods
Director General, Health

Dr Harry Burns
Chief Medical Officer

Improving the Health & Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan

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Foreword by Dr Harry Burns, Chief Medical Officer

Improving the Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan fulfils the commitment in **Better Health, Better Care** to publish a delivery plan for the next stage of our work on long term conditions.

The plan reflects the fact that around 2 million people in Scotland have at least one long term condition and that this brings with it profound human, social and economic costs for Scottish society. We also know that the prevalence and impact of such conditions is linked to deprivation and that our ability to support people in managing their conditions is therefore a vital part of our overall response to the challenge of tackling health inequalities throughout our country.

This Action Plan does not attempt to summarise all the work that is taking place across Scotland to improve the health and wellbeing of people living with long term conditions, including the social work and housing initiatives that are relevant to long term conditions, in particular through the Single Outcome Agreements. It focuses explicitly on the 7 key changes that we expect NHS Boards, working with their partners, to deliver over the next few years. It describes the support that NHS Boards can expect, along with the responsibilities and timescales for making these changes happen.

I have been chairing a Long Term Conditions Steering Group, on which the Long Term Conditions Alliance Scotland provides an independent voice. Together, we have been working to ensure that policy is driven by the needs and experiences of people living with long term conditions. The Steering Group is now evolving into a Long Term Conditions Programme Delivery Board, charged with advising policy makers and healthcare managers on how best to implement the improvements that we all want to see in the quality of care and support offered to people with long term conditions. This Action Plan will be used by the Programme Delivery Board to assess the progress we make over the next few years and enable us to ensure that we deliver on our commitments in a timely fashion.

I hope that in reading the Action Plan you get a clear sense both of our ambition for Scotland and our determination to achieve it.

OUR VISION

Our vision is that throughout Scotland, those with long term conditions and those who support them, feel valued, confident and able to enjoy full and positive lives.

This requires:

- **A culture which supports people with long term conditions and their carers to be the lead partners in decisions about their health and wellbeing.**
- **A workforce that has the awareness, environment, knowledge, skills, confidence and capability to enable people to live well with their conditions.**
- **Health, housing, social services, community and voluntary partners to work together with people with long term conditions and their families.**

Figure 1 Scotland's Mutual Care Model for Long Term Conditions

PART 1: A FRAMEWORK FOR CHANGE

The Challenge

1. Long term conditions, or chronic diseases as they tended to be referred to, are conditions that last a year or longer, impact on a person's life, and may require ongoing care and support. The definition does not relate to any one condition, care group or age category, so it covers children as well as older people and mental as well as physical health issues. Common long term conditions include epilepsy, diabetes, some mental health problems, heart disease, chronic pain, arthritis, inflammatory bowel disease, asthma and chronic obstructive pulmonary disease (COPD).

2. Around 2 million people in Scotland have at least one long term condition, and one in four adults over 16 reported some form of long term illness, health problem or disability.

3. Long term conditions become more common with age. By the age of 65, nearly two-thirds of people will have developed a long term condition. Older people are also more likely to have more than one long term condition: 27% of people aged 75-84 have two or more such conditions.

4. The human costs and the economic burden of long term conditions for health and social care are profound. Sixty per cent of all deaths are attributable to long term conditions and they account for 80% of all GP consultations. People with long term conditions are twice as likely to be admitted to hospital, will stay in hospital disproportionately longer and account for over 60% of hospital bed days used. Most people who need long term residential care have complex needs from multiple long term conditions.

5. There are clear links between long term conditions, deprivation, lifestyle factors and the wider determinants of health. People living with a long term condition are likely to be more disadvantaged across a range of social indicators, including employment, educational opportunities, home ownership and income. Someone living in a disadvantaged area is more than twice as likely to have a long term condition as someone living in an affluent area, and is more likely to be admitted to hospital because of their condition.

6. People living with long term conditions are also more likely to experience psychological problems. Around one in three people with heart failure and diabetes and one in five people with coronary heart disease and chronic pain will experience depression. Prolonged stress alters immunity, making illness more likely and recovery more difficult, especially for those who are already unwell.

7. A significant number of long term conditions are genetic in origin. The Single Gene Complex Needs Project aims to integrate health and social care to build capacity and improve the quality of life of this group of people.

The Context

8. The Scottish Government has set out an ultimate 'Purpose' which unites public services and requires them to work in partnership to deliver sustainable economic growth and opportunity for everyone in Scotland to flourish. NHSScotland has a central role in supporting this purpose. It includes a key requirement for NHSScotland to develop services which will enable people in Scotland to live healthier, longer lives. **Better Health, Better Care** (Scottish Government, 2007) set out the Action Plan for NHSScotland which is intended to deliver this outcome. Increasingly this will be focussed on the priority of raising the quality of NHSScotland healthcare services to world leading levels.

9. A new Healthcare Quality Improvement Strategy is also being developed, to create a clear vision and focus for the range of improvement work already being driven forward across NHSScotland. The proposed approach will support the six dimensions of quality*:*

Patient centred	providing care that is responsive to individual patient preferences, needs and values and assuring that patient values guide all clinical decisions
Safe	avoiding harm to patients from care that is intended to help them
Effective	providing services based on scientific knowledge
Efficient	avoiding waste, including waste of equipment, supplies, ideas, and energy
Equitable	providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status
Timely	reducing waits and sometimes harmful delays for both those who receive care and those who give care

Source: Institute of Medicine

10. To support quality improvement, we need a system of decision support that enables clinical care to be delivered in line with the preferences of people with long term conditions and the best available scientific evidence. This requires the development and dissemination of guidelines that have been developed in conjunction with people with long term conditions. There also needs to be a supporting infrastructure of training and education for all practitioners alongside support that allows people with long term conditions to make well-informed decisions.

11. One of the key drivers of healthcare quality is person-centred services. Approaches across NHSScotland increasingly focus on the development and delivery of healthcare services around each individual's preferences and requirements. These approaches include the work to develop a 'mutual' NHS in Scotland. Establishing and communicating people's rights, expectations and responsibilities is a major strand of this approach. Another strand is the *Better Together* Programme which is gathering evidence on what people in Scotland expect of their NHS. It will then measure actual patient experience of healthcare services. From this, we can inform action to improve services. The programme is concentrating initially on 3 areas of patient experience: stays in hospital, primary care and long term conditions. We will ensure that this work aligns with the actions set out in the Long Term Conditions Action Plan.

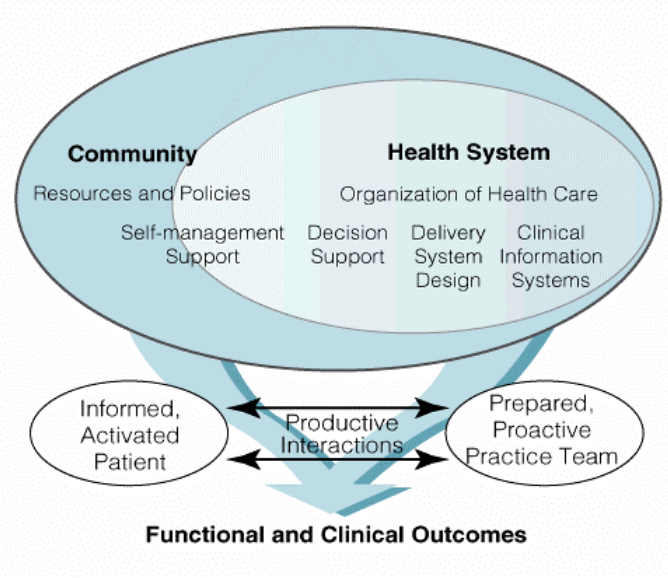
12. A further strand is the **Talking Points: Personal Outcomes Approach** to assessment, care planning and review now being implemented in most community care partnerships in Scotland. It places each person's desired outcomes at the heart of the design and delivery of their care and support, so that they can continue to live at home.

An Integrated Approach

13. Scotland's approach to the management of long term conditions is based upon the Chronic Care Model developed by Ed Wagner [1] and his colleagues at the MacColl Institute for Healthcare Innovation. This suggests that the quality of support for people with long term conditions can be improved if action is taken to create the conditions that support a productive partnership between informed and empowered people with long term conditions on the one hand, and prepared, proactive health teams on the other.

[1] Wagner E H **Chronic Disease Management : What will it take to improve care for Chronic Illness?**: Effective Clinical Practice 1998 1:2-4

Figure 2: Wagner's Chronic Care Model[2]



14. NHS Scotland aims to create these conditions by**:**

- supporting self management by empowering people with long term conditions to become more involved in managing their own health and healthcare and the impact of living with long term conditions;
- building services around the needs of people with long term conditions, with a broad approach to quality improvement in order to deliver better, faster and more local access to healthcare health services;
- setting standards and providing toolkits to enable best practice and to make sure people get the care they need;
- enabling information to be created, used and shared by and for the benefit of people with long term conditions; and
- addressing the needs of the workforce, in particular through developing structures to allow more time for consultations and promote continuity of care.

15. Our vision for long term conditions adapts Wagner's Chronic Care model to better reflect NHS Scotland's integrated system, with its focus on quality improvement and its emphasis on a mutual care approach as described in **Better Health, Better Care**. The 6 domains of the Chronic Care Model have been mapped to 6 key components of the model for long term conditions care in Scotland (see Figure 1):

- a partnership between informed, empowered people with long term conditions and prepared, proactive multi-professional care teams, drawing on the power of people's stories;
- a strategy (**Gaun Yersel'**) and resources to support Self Management;
- an integrated system of care across primary care, hospitals, social work, housing, community and voluntary sectors;
- decision support (programming evidence-based medicine and clinical guidelines into care and support delivery processes) through quality improvement and workforce development supported by standards, guidelines, education, practice development and Managed Clinical Networks;
- care enabled by information systems that support sharing of data; and
- delivery assured through the national performance framework, HEAT targets and the Community Care Outcomes Framework.

[2] Wagner E H **Chronic Disease Management : What will it take to improve care for Chronic Illness?**: Effective Clinical Practice 1998 1:2-4

16. This approach recognises the need to mobilise resources beyond NHSScotland in order to improve the lives of people with long term conditions. Community Health Partnerships (CHPs) have a vital role to play in prioritising and co-ordinating such activity and many have already used the Long Term Conditions Self-Assessment Toolkit to support them in this task. The Toolkit remains available and can be used to help CHPs benchmark their services against those provided elsewhere in Scotland and develop action plans to improve their local systems, structures and care pathways.

Supporting Self Management

17. Better awareness of their long term condition helps people understand their symptoms and experiences and improves their long term health and wellbeing. The role of the care professional is to encourage self confidence and the capacity for self management and to support people to have more control of their conditions and their lives and promote their efforts to enhance their health and wellbeing. This means having a shared approach to setting goals and problem solving, and signposting people to the type of support and information they need. It also means having a more outcome-focused approach to planning and reviewing their individual situation. It should take account, too, of people's inherent ability for self-healing and recovery.

18. Scotland's approach to self management is set out in the strategy document **Gaun Yersel!**. This was developed by the Long Term Conditions Alliance Scotland (LTCAS) in partnership with people with long term conditions, and describes a set of principles that encapsulate the core messages of the strategy.

19. LTCAS is an independent, national charity that brings together hundreds of voluntary and community organisations across Scotland to give a national voice to ensure the interests and needs of people living with long term conditions are addressed. It does this through influencing and campaigning, supporting and improving practice, supporting the voluntary and community long term conditions sector and tackling health inequalities

20. The Long Term Conditions Alliance ,continues to play a lead role in implementing many of the recommendations in **Gaun Yersel!**. In particular it is responsible for:

- managing the Self Management Fund that builds the capacity of voluntary and community groups to support self management;
- gathering evidence of innovative practice and positive developments in self management;
- operating a "long term conditions hub" that provides support for the work of the range of voluntary sector organisations that represent people with long term conditions; and
- supporting a shared approach to long term conditions policy development with the Scottish Government.

21. Effective self management relies on the provision of accurate, relevant, timely and accessible information offered from a trusted source on a basis which people feel is sensitive to their situation. The National Health Information Support Service is developing a single public portal for an online health information resource. It will also offer quality-assured local and national information from the NHS and other sectors, including the third sector, a national health information helpline; and a network of branded health information support centres, embedded in local communities.

Integrated Services

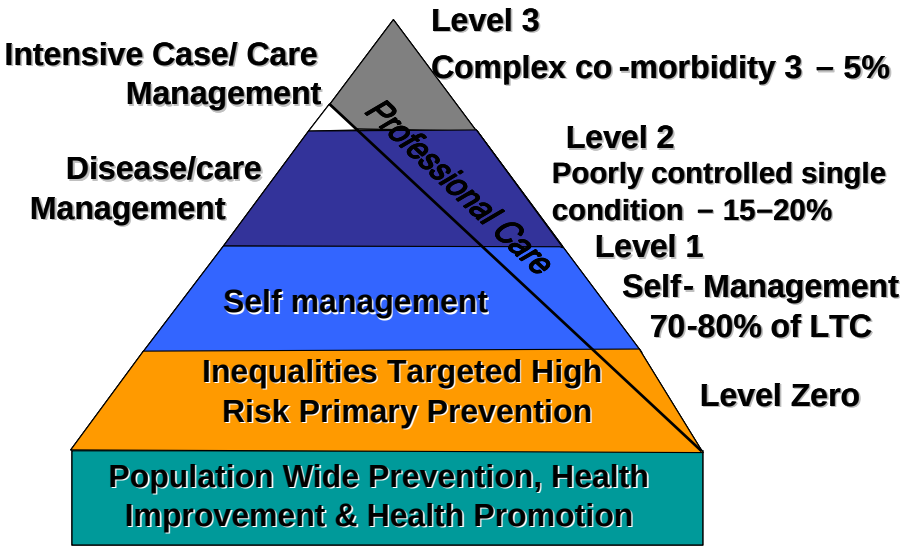
22. Scotland's model of long term conditions management is based upon a structured, systematic and integrated approach to the provision of care.

23. With the right information, advice and support, most people are able to manage their own conditions. However, the intensity of co-ordination and support required will vary according to the morbidity, dependency and complexity of the conditions involved. NHSScotland therefore needs to provide support at 4 levels:

- a solid foundation of population-wide prevention, health promotion and targeted health improvement activity, through action to prevent disease, raise awareness of risks to health and support healthy lifestyle choices. This is essential given the high prevalence of long term conditions which are preventable, and the health inequalities associated with living with long term conditions;
- self management, where people with long term conditions are given the information and other practical support they require to manage their own conditions in a way that helps them use this information to their own benefit;
- condition management in which a greater level of professional support is required to help avoid complications or slow the progression of disease; and
- for those with particularly complex needs who require a more intensive level of care, often referred to as 'case / care management', a co-ordinated and proactive approach to improve health and help them avoid being admitted unnecessarily to hospital.

24. This approach is designed around the needs of individuals and is based on work done initially by organisations such as Kaiser Permanente (see figure 3).

Figure 3: Kaiser Permanente Pyramid (adapted)



25. The model is a dynamic one. People move up and down the pyramid as their condition, their ability to cope and their sense of wellbeing fluctuates, or as external factors change. The intensity of co-ordination and support people receive generally changes in response to this movement. The challenge for professional care services is to shift towards providing proactive anticipatory support to reduce flare-ups, promote greater stability, increase confidence and control and enable a timely return to a need for less intensive support. This requires action by NHS Scotland across each of the components of the long term conditions model. The role of self management applies at all levels of the pyramid.

Managed Clinical and Managed Care Networks

26. Managed Clinical Networks (MCNs) and Managed Care Networks have a key role in quality improvement and clinical engagement and contribute to planning of services across the whole system (SEHD (2007) HDL 21). MCNs engage with people with long term conditions, the voluntary sector and clinical communities across acute and primary care, and deliver evidence-based care supported by appropriate governance arrangements.

27. Through their quality assurance and audit programmes, MCNs connect local teams to timely information on outcomes. This is a powerful lever for change in practice and nurtures a sense of pride, motivation and satisfaction in their work. For maximum impact and adherence, evidence-based care pathways, protocols and best practice guidelines are most effective when embedded in day-to-day care delivery processes and in a way that prompts their use. Gaps and variance from care pathways can be minimised and easily recognised.

Telehealthcare

28. The emergence of telehealthcare presents an additional opportunity in terms of long term conditions pathways, support systems and protocols. Decision support tools, combined with telehealthcare solutions, guide clinicians towards correct and safe practice and allow better skill mix of teams. Examples which support self management and effective care delivery include: remote monitoring; specific alerts enabling swift and appropriate

responses to events such as seizures, falls and heart attacks; facilitation of social networking and peer support; and environmental sensors and equipment which enable increased control and safety in the home.

Workforce

29. Developing workforce capability is critical for success. Levers for independent contractors such as GPs and community pharmacists, and emerging workforce models for community nursing and Allied Health Professionals, are considerable opportunities for expanded scope of practice and new approaches to skill mix. We need to prepare and equip staff for new roles and approaches to care by identifying their learning needs and addressing gaps through locally delivered practice development initiatives, building on existing educational provision. This can be achieved, where appropriate, through access to tailored learning resources for long term conditions and making changes to their existing practice. We also need to develop staff confidence and capability in using telehealthcare solutions to support proactive continuous care for people with long term conditions.

Information systems

30. The Chronic Care model identifies the need for information systems that support effective decision-making amongst all partners. Information is vital in order to enable NHS Boards' clinical staff to work with people who want to develop care plans that are appropriate to their needs. In particular, this information should enable NHS Boards to target anticipatory care at those thought to be most at risk from their condition.

31. Through the work of NHS National Services Scotland and its partners, information systems are therefore being developed to support:

- registration;
- risk-stratification of the population as a basis for identifying individuals at high risk of flare-ups and recurrent admissions;
- recall – information to co-ordinate and manage the care of each individual; and
- review – information for monitoring, performance management and quality improvement.

32. ISD is continuing to develop the SPARRA (Scottish Patients at Risk of Readmission and Admission) risk prediction tool, which is currently based on hospital admissions data, including exploring the possibility of incorporating risk factors present in other datasets such as primary care, social care and prescribing data. Some NHS Boards are also developing their own local risk-stratification or case-finding tools. Access will be supported by SCI Gateway, using tools to deliver integration. An essential part of this strategy will be to design, develop, and implement a system which delivers the information management functions that support a personal health record or electronic care plan to enable engagement, self management, risk prediction and clinical information support for long term conditions. This will be assisted by an approach to information governance which actively enables data sharing across the whole health system and with care partners from other agencies, in line with the universal goal of individual safety.

Delivery

33. Scotland's integrated performance framework helps focus investment and action on improving health, wellbeing and outcomes for people with long term conditions.

34. Within NHS Scotland, this is achieved through a focus on meeting a series of 30 performance targets, known as the HEAT (Health, Efficiency, Access and Treatment) targets

that reflect the Scottish Government's key priorities for health and healthcare. These are set out in Annex A, along with their links to the national outcomes of the Scottish Government and to the Community Care Outcomes Framework which is being used by Community Care Partnerships to support delivery of relevant outcomes in the Single Outcome Agreements.

35. In 2009-10, 5 of the 30 HEAT targets apply specifically to the management of long term conditions. These are:

- T6: Reduce long term conditions admissions/bed days
- T7: Improve quality of health care experience
- T8: Increase Complex Care at home
- T10: Reduce rate of attendance at A&E
- T12: Reduce 65+ emergency bed days

36. Work is also taking place to develop new or amended targets that better reflect the strategies and approaches now being adopted to the management of long term conditions. In particular, consideration is being given to new targets that:

- focus on improvements to services for people with long term conditions;
- reflect the role of NHS Boards in empowering and enabling people with long term conditions to manage their own conditions.

37. Each of the 14 territorial NHS Boards submits an annual Local Delivery Plan that sets out their projected performance against each of these HEAT targets. These are then used as the basis for both ongoing performance management by Scottish Government and, in particular, the process of annual review, led by Scottish Ministers.

38. The Long Term Conditions Collaborative (LTCC) is the national quality improvement programme designed to support NHS Boards to deliver sustained improvements in the quality of care provided for people with long term conditions throughout Scotland. The national programme team ensures that work on long term conditions is integrated with other improvement activities across NHS Scotland. In order to realise shared opportunities to improve the experiences of patients across Scotland, the team ensures that the programme works in an integrated way with the 18 Week Referral to Treatment Time programme, the Mental Health Collaborative, Scottish Patient Safety Programme, the **Better Together** programme, the Rehabilitation Framework, the Joint Improvement Team and the Outcomes Approach to Community Care.

39. Improving the quality, experience and safety of support for people with long term conditions by delivering services that are clinically effective and responsive to people's needs, but which are also more efficient and make best use of skill mix and local resources, will be of significant benefit to the whole system. Meeting the challenge of better supporting people with long term conditions will unlock considerable capacity in the system to meet a raft of stretching Access targets and will support a shift in the balance of care. Delivering the improvements outlined in this Action Plan is essential for the future sustainability of services given the demographic, economic and workforce challenges Scotland is facing.

40. The Long Term Conditions Collaborative has developed a set of clear and tangible improvements that will make a big impact on the way people with long term conditions manage their own conditions are supported by others. These High Impact Changes (HIC) are generic, apply across the Long Term Conditions pathway and reflect different domains of Wagner's Chronic Care model (Figure 2). The High Impact Changes also map to key components of Scotland's model for long term conditions (Figure 1) that reflects NHS Scotland's integrated system and mutual care approach as described in **Better Health, Better Care**.

41. Each HIC is made up of a bundle of improvement actions based on changes that have been tried and tested by health and social care practitioners in the UK and beyond and reflect what people have said should be done to improve their experience of living with long term conditions.

Achieving the Vision for Long Term Conditions Management requires all NHS Boards to commit to action in 7 areas

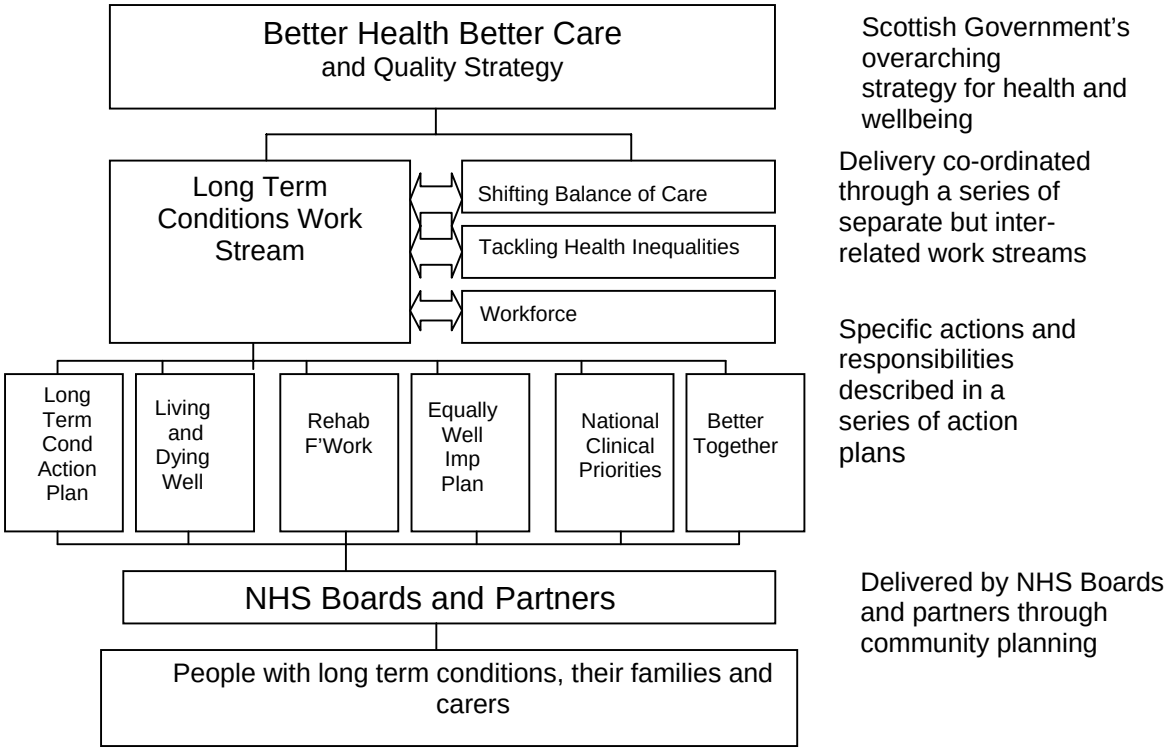
LTC Mutual Care model	LTCC High Impact Changes
Partnership	We empower people living with long term conditions, their carers and the voluntary sector to be full partners in planning, improving quality and enhancing the experience of care.
Mutuality	We support people with long term conditions and their unpaid carers to be involved in person-centred care planning.
Self Management	We commission self-management peer support for people with long term conditions and their carers and provide relevant, accessible information.
Workforce Development	We train staff to have the right knowledge, skills and approach to long term conditions care.
Integrated Care	We provide better, local and faster access to healthcare, social care and housing services for long term conditions.
Quality Improvement	We strengthen the contribution of Managed Clinical/Care Networks (MCNs) in improving support for people with long term conditions
Clinical Information Systems	We have information systems that support registration, recall and review of people with multiple conditions, and support data sharing across all partners.

42. The Action Plan for delivering these High Impact Changes is set out in detail in Part 2. Where more than one agency is included in the 'Lead Responsibility' column, it is for those agencies to decide collectively which of them will take responsibility for reporting on progress, and for ensuring whatever wider engagement is considered necessary.

Supporting Delivery

43. The Long Term Conditions Action Plan is one of a number of initiatives within Scottish Government that come together in order to improve the lives of people with long term conditions. The key relationships are set out in graphical form in Figure 4.

Figure 4: Strategic Fit



44. Through their Local Delivery Plans, NHS Boards will be expected to report on progress on the actions placed on them. The Health Directorates' Long Term Conditions Steering Group will, with publication of this Action Plan, become a Programme Delivery Board chaired by the Director of Healthcare Policy and Strategy with responsibility for reporting overall progress on implementation of the Action Plan, as part of the Scottish Government Health Directorates' monitoring of all the **Better Health, Better Care** workstreams.

PART 2: AN ACTION PLAN FOR IMPROVEMENT

Change 1

Improve the experience of care by empowering people with long term conditions to be full partners

Action	Timescale	Lead Responsibility
1. Encourage feedback on individual experiences from people with long term conditions as part of the national *Better Together* programme.	From 2009 onwards	NHS Boards
2. Establish local service improvement programmes with clear operational links to the experiences shared through *Better Together*.	From 2009 onwards	NHS Boards
3. Share information on changes and improvements made as a result of local improvement programmes with other participants and key stakeholders of the *Better Together* Programme.	From 2009 onwards	NHS Boards
4. Adopt and implement an outcomes-focussed approach to assessment, care planning and review for community care, such as Talking Points: Personal Outcomes Approach.	April 2009 onwards	Joint Community Care Management Teams
5. Regularly review outcomes and data generated from individual assessments, care plans and reviews to inform service redesign.	June 2009 onwards	Joint Community Care Management Teams
6. Agree a Strategic Partnership Agreement between Scottish Government and the Long Term Conditions Alliance Scotland (LTCAS) setting out their respective roles for ensuring that the voice of people with long term conditions, their unpaid carers and organisations that represent them is heard within the policy development process.	May 2009	Long Term Conditions Unit LTCAS
7. Enhance the capacity of voluntary sector organisations to represent the views of people with long term conditions and their unpaid carers through the work of the long term conditions hub.	From 2009 onwards	LTCAS, LTCU

Change 2

Support people with long term conditions to be involved in care planning

Action	Timescale	Lead Responsibility
1. Use the Community Pharmacy Chronic Medication Service to support people to be more involved in managing their own medicines, whether in the community or in hospital.	From April 2009	NHS Boards
2. Produce guidance and resources for NHS Boards to support the adoption of models and approaches which offer a range of emotional and psychological support to people living with a long term condition at different stages of their condition.	February 2010	Long Term Conditions Unit, LTCAS, NES
3. Develop e-health demonstrators that encourage people with long term conditions to access information on their personal health, such as electronic care plans, personalised test results and clinical information.	End 2009	Ehealth Programme Board; Long Term Conditions Unit, NHS 24
4. Develop joint guidance on multi-agency anticipatory care planning and advanced care planning through the Long Term Conditions Collaborative and Living and Dying Well programmes.	December 2009	NHS Boards, Local Authorities, LTCC, Living & Dying Well, LTCAS, NES
5. Develop multi-agency anticipatory care plans for people with long term conditions that are shared between in hours and out-of-hours services and functionally useful for clinicians.		NHS Boards, Local Authorities, NHS 24, eHealth, eCare
6. Embed NHS Carer Information Strategies in all NHS Board areas.		Scottish Government Primary and Community Care Directorate, Carers' organisations.

Change 3

Build capacity to support self management

Action	Timescale	Lead Responsibility
1. Consider the development of a HEAT target to promote and encourage self management.	September 2009	LTCU, LTCC, LTCAS
2. With LTCAS, establish a Self Management fund (£2m p.a. for two years) to build capacity to support self management within the voluntary and community sectors. The fund will support a range of programmes, including those that enable voluntary organisations to work in partnership with the NHS, local authorities and other key partners.	April 2009 – March 2011	Long Term Conditions Unit (LTCU) and Long Term Conditions Alliance Scotland (LTCAS)
3. Support NHS Boards to raise awareness of self management amongst NHS managers, practitioners and people living with long term conditions, and to facilitate integration of health, social care and voluntary sector support for self management to develop and share best practice.	September 2009	LTCU, LTCAS, NHS Boards
4. Introduce and help sustain a National Health Information Support Service as NHS Scotland's primary source of information aimed at supporting people in Scotland to manage their conditions more effectively across Scotland.	September 2009	NHS 24, LTCAS
5. Raise awareness of self management amongst NHS managers, practitioners and people living with long term conditions.	October 2009 - March 2010	LTCAS, LTCU, NHS Boards, NES, NHS QIS
6. Provide an electronic means for people with long term conditions to support each other by easily accessing, contributing to and sharing local information.	2010-12	LTCU, LTCAS, NHS National Services Scotland
7. Disseminate the document **Supporting people with long term conditions to Self Manage: Essential guide to multiagency knowledge and skills** and support the development of education and resources which enable healthcare workers to develop the awareness, knowledge, skills and values which support self management.		NES, LTCU, NHS Boards, LTCAS
8. Extend online access to Cognitive Behavioural Therapy (CBT), as part of work to extend telephone-based support.		NHS 24
9. Scope existing health literacy literature and definitions, to consider options for identifying the scale and effect of poor health literacy in Scotland,	2009-10	Scottish Government Public Health and Health Improvement

and addressing the challenges presented.		Directorate; LTCU; NES; NHS24, LTCAS.
10. Produce guidance on supporting people towards developing services which help promote people's capacity for self-healing and recovery.		Centre for Integrative Care, LTCAS, LTCU.

Change 4

Provide staff with access to the training that ensures that they have the right knowledge, skills and approach to long term conditions care

Action	Timescale	Lead Responsibility
1. Consult NHS Boards regarding education needs and gaps and analyse findings to identify key educational priorities. Produce and disseminate a long term conditions learning needs analysis tool to NHS Boards, to identify local learning needs. Support and, if appropriate, expand the long term conditions education database, in light of ongoing review and evaluation of current database).	March 2010	NES
2. Develop a Managed Knowledge Network micro-portal and other community services to support a Long Term Conditions "Community of Practice" for staff learning and development.	March 2010	LTCC
3. Build on thinking and learning from aligned programmes such as 'Patient Experience', palliative care and mental health to support healthcare staff to develop and put into practice those communication, interaction and relationship approaches, skills, values and knowledge which are consistent with the notions of person-centredness, mutuality and which enable self management.	During 2009	NES with LTCU, NHS QIS, LTCAS, NHS Boards
4. Build on education initiatives for anticipatory care and advanced planning within palliative care and, where appropriate, make available or adapt for the wider long term conditions environment.	During 2009	NES
5. Work with higher education providers to promote and integrate the principles of self management within relevant education at all levels.	During 2009 and 2010	NES, LTCAS, LTCU
6. Publish capabilities for intermediate care, rehabilitation, information literacy and self management.	2011	NES, LTCAS,
7. Provide training on rehabilitation, re-ablement, anticipatory care and advanced care planning for staff working within Care Homes.	2011	NHS Boards, Rehabilitation Framework Implementation Group, LTCAS, Care Commission for Scotland
8. Link NHS staff training programmes with Continuous Learning Framework for social care staff.	April 2010	NHS Workforce Unit, Scottish Social

		Services Council

Change 5

Introduce a systematic and integrated multi-agency approach across CHPs to provide better, local and faster access to services for people with long term conditions who require proactive and co-ordinated support

Action	Timescale	Lead Responsibility
1. Promote the use of the 'improving complex care' resource produced through the Long Term Conditions Collaborative and Partnership Improvement and Outcomes Division (PIOD) and implement the 10 approaches set out in the document.	From 2009 onwards	NHS Boards, LTCC, PIOD
2. Agree and implement plans to roll out proactive integrated care management through the Long Term Conditions Collaborative and PIOD.	By 2011	NHS Boards, Local Authorities
3. Promote the use of National Minimum Information Standards (NMIS) for assessment, care and support, and review (2008) to support sharing of quality information across multi-agency staff teams.	From April 2009	Community Care Partners, Partnership Improvement Outcomes Division, SGHD.
4. Provide systematic primary care and specialist healthcare services for people in care homes, including the use of advanced / anticipatory care plans to guide decisions around end of life care.	By 2011	NHS Boards, Care Commission for Scotland.
5. Use telehealth and telecare support, with an emphasis on helping people to self manage their conditions at home.	December 2009	NHS Boards, NHS24, Scottish Centre for Telehealth, Joint Improvement Team, Local Authorities.
6. Introduce vocational rehabilitation services in each NHS Board area	2011	NHS Boards, Implementation Group for Rehabilitation Framework.
7. Consider how key working or local area co-ordination approaches could be delivered with and for people with long term conditions.		LTCU, LTCAS, NHS Boards, Local Authorities.

Change 6

Strengthen the contribution that Managed Clinical / Care Networks make to the management of long term conditions by extending their reach and ensuring full patient and carer involvement in their work

Action	Timescale	Lead Responsibility
1. Establish MCNs for neurological conditions, in line with the NHS Quality Improvement Scotland draft clinical standards for neurological services.		NHS Boards, Neurological Alliance of Scotland
2. Establish respiratory MCNs including work to improve the management of asthma in children and young people.	End 2009	NHS Boards, NHS QIS, British Lung Foundation, Asthma UK, Chest, Heart & Stroke Scotland
3. Establish Regional MCNs that address the recommendations of the NHS QIS GRIPS report on services for chronic pain.	From 2009	NHS Boards, LTCU, NHS QIS
4. Ensure that every MCN undertakes a programme of work to embed telehealthcare solutions in their pathways for people with long term conditions.	2011	NHS Boards, Scottish Centre for Telehealth
5. Review the structure of each MCN to ensure that people with long term conditions, carers and the voluntary sector are enabled to participate in the planning, delivery and evaluation of services, drawing on experience from the 'Hearty Voices' and similar programmes.	From 2009	NHS Boards, LTCAS
6. Develop integrated proactive pathways of care for common long term conditions	End 2010	NHS Boards, Local Authorities
7. Ensure MCNs develop a quality assurance programme leading to accreditation, as set out in HDL(2007)21.		NHS Boards, NHS QIS
8. Ensure, where appropriate, that key interface with local authority housing and social care is developed by each MCN.		NHS Boards, Local Authorities, MCNs

Change 7

Adopt and sustain information systems that support registration, recall and review for people with multiple conditions, and enable effective data sharing across all relevant partners and care settings

Action	Timescale	Lead Responsibility
1. In order to develop a system for person-based estimates of prevalence for specific/all long term conditions, including indicators of complexity, risk and multiple morbidity, create a national GP extractor tool service, to enable sharing of data in QOF registers.	By the end of 2009	NHS NSS (NISG)
2. Publish minimum data standards for long term conditions, linked to National Minimum Information Standards (NMIS) (2008).	By the end of 2009	NHS NSS
3. Enhance SPARRA by expanding the cohort for whom a risk can be estimated beyond those with a recent history of hospital admission, as part of providing the support required to enable all CHPs to identify systematically people with long term conditions at risk of unscheduled admission to hospital, and share information across primary, secondary, tertiary and social care.	December 2010	NHS NSS
4. Progress work on ecare and information governance through data sharing partnerships so that health and social care teams share appropriate information about people with multiple long term conditions and complex needs in a systematic way, building on NMIS.	December 2010	NHS Boards
5. Use SPARRA or a proven alternative to identify those at risk of unscheduled admissions.	Immediate	NHS Boards

Annex A

HEAT Targets relevant to long term conditions, and related Community Care Outcomes

E 4	Efficiency Savings: Non-routine inpatients average length of stay
E 4	Efficiency Savings: Review to New Outpatient Attendance Ratio
A 8	48 Hour Access – GP Practice Team
A 8	Advance booking – GP Practice Team
A 10	18 weeks RTT
A 10	New outpatients: Maximum 12 weeks from referral
A 10	Inpatients & Day Cases: Maximum 12 weeks
T 2	QIS clinical governance and risk management standards improving
T 3	Reduce the annual rate of increase of defined daily dose per capita of anti-depressants to zero by 2009/10, and put in place the required support framework to achieve a 10% reduction in future years.
T 6	To achieve agreed reductions in the rates of hospital admissions and bed days of patients with primary diagnosis of COPD, Asthma, Diabetes or CHD, from 2006/7 to 2010/11
T 7	Improvement in the quality of healthcare experience (links to Community Care Outcomes Framework User and Carer Experience measures S1, S2, S3)
T 8	Balance of care for older people with complex care needs(links to Community Care Outcomes Framework measure BC2)
T 10	Rate of attendance at Accident and Emergency
T 12	Reduction in emergency bed-days for patients aged 65+ (links to Community Care Outcomes Framework measure R1)

Annex B

Community Care Outcomes Framework

Themes	Code	Measure	Type	Data Source / Status
User & Carer Experience	S1	% of community care service users feeling safe.	Outcome	Data drawn from National Minimum Information Standards (NMIS) 2008
	S2	% of users and carers satisfied with their involvement in the design of care package.	Outcome	Data drawn from NMIS
	S3	% of users satisfied with opportunities for social interaction.	Outcome	Data drawn from NMIS
Faster access	A1	No. of patients waiting in short stay settings, or for more than 6 weeks elsewhere for discharge to appropriate setting.	Output	HEAT Standard
	A2	No. of people waiting longer than target for assessment, per 000 population.	Output	Pending Implementation of Lord Sutherland's Review of Free Personal Care
	A3	No. of people waiting longer than target time for service, per 000 population.	Output	Pending Implementation of Lord Sutherland's Review of Free Personal Care
Support for carers	C1	% of carers who feel supported and capable to continue in their role as a carer.	Outcome	Data drawn from NMIS
Quality of assessment and care planning	Q1	% of user assessments completed to national standard.	Process	Data drawn from NMIS and local systems
	Q2	% of carers' assessments completed to national standard.	Process	Data drawn from NMIS and local systems
	Q3	% of care plans reviewed within agreed timescale.	Output	Data drawn from NMIS
Identifying those at risk	R1	No. of emergency bed days in acute specialties for people 65+, per 100,000 pop.	Outcome	HEAT target T12
	R2	No. of people 65+ admitted as an emergency twice or more to acute specialties, per 100, 000 pop.	Outcome	National indicator reported in Scotland Performs
	R3	Percentage of people 65+ admitted twice or more as an emergency who have not had an assessment.	Output	Measure administered through ISD
Moving services closer to users patients	BC1	Shift in balance of care from institutional to 'home based' care.	Input	No overarching measure
	BC2	% of people 65+ with intensive needs receiving care at home.	Input/ Outcome	Measure administered through ASD (HEAT target T8)
	BC3	% of people 65+ receiving personal care at home.	Output (proxy)	Measure administered through ASD

Annex C

Better Health, Better Care Work Streams

- Long Term Conditions;
- Efficiency & Productivity;
- eHealth;
- 18 Weeks RTT Standard;
- Early Years;
- Healthcare Associated Infection;
- Mental Health;
- Mutuality & Equality;
- Neurosciences;
- Patient Experience;
- Patient Safety;
- Shifting the Balance of Care;
- Tackling Health Inequalities;
- Unscheduled Care;
- Workforce;
- Remote and Rural

Annex D

Long Term Conditions Collaborative Resources

http://www.elib.scot.nhs.uk/SharedSpace/ist/Pages/login.aspx?ContainerID=207650