Key messages

Managing long-term conditions

AUDIT SCOTLAND

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Key messages

Background

1. Long-term conditions – sometimes referred to as chronic diseases – last a year or longer, limit what a person can do, and may require ongoing medical care.[1] Examples include chronic obstructive pulmonary disease (COPD), epilepsy, asthma and diabetes.

2. Managing long-term conditions is seen as the biggest challenge facing healthcare systems worldwide, with 60 per cent of all deaths attributable to them.[2] Across the UK it is estimated that people with a long-term condition:

- account for 80 per cent of all GP consultations
- are twice as likely to be admitted to hospital
- stay in hospital disproportionately longer
- account for over 60 per cent of hospital bed days.[3]

3. In Scotland, it is estimated that around a million people have at least one long-term condition and that nearly a third of households contain at least one person with a long-term condition.[4 5]

4. Prevalence increases with age (Exhibit 1). The number of people in Scotland aged 75 and over is projected to rise by 75 per cent from 0.37 million to 0.65 million over the period 2004 to 2031. Over the same time the number of people of working age is projected to fall by seven per cent from 3.18 million to 2.96 million.[6] In addition, as life expectancy goes up and the number of older people increases, it is likely that a growing number of people in Scotland will suffer from one or more long-term condition.[7] This highlights the need for effective service and workforce planning to ensure that patients receive good quality care provided by the right number of trained staff.

5. Links have been established between deprivation and individual long-term conditions. For example, a King's Fund study looking at COPD medical admissions in the UK between 2000 and 2002 found that the rate of hospital admission for COPD rises, as deprivation increases. Further analyses found that around 31 per cent of such admissions could be attributed to deprivation.[8]

6. Over recent years there has been a move to treat more people with long-term conditions in the community. However, a considerable amount of care is still carried out in hospitals (Exhibit 2).

7. *Delivering for Health* sets out a programme of action for the NHS in Scotland based on the recommendations made in *Building a Health Service Fit for the Future* (also known as the *Kerr Report*).[9 10] The overall emphasis is on providing the majority of care in the community as locally as possible, with a focus on improving health and reducing health inequalities; providing more integrated and targeted care in local settings; reducing hospital admissions; providing systematic support for people with long-term conditions; and allowing patients and carers to have more of a say in what services they receive. The Scottish Executive Health Directorates (SEHD) have given the responsibility for driving the shift in the balance of care locally to NHS boards, with implementation and delivery by Community Health Partnerships (CHPs).

Our study

8. We examined services for adults with long-term conditions generally, focusing on two conditions in particular – COPD and epilepsy. We selected these conditions as there has been little evaluation of these compared with other long-term conditions such as diabetes or asthma.

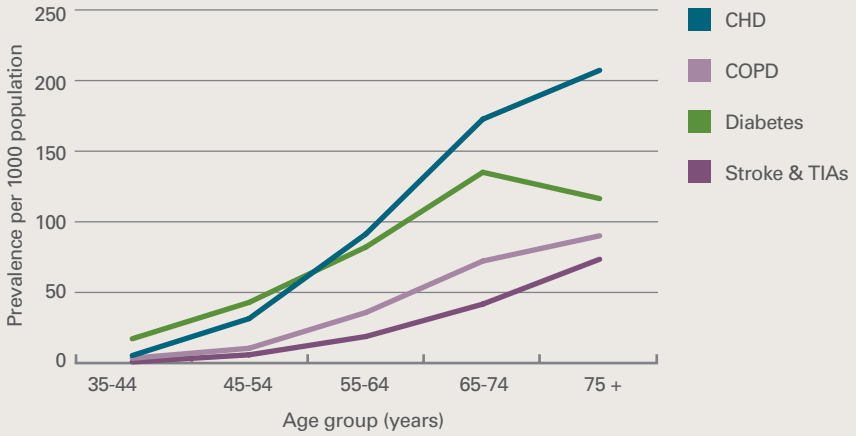
9. In summary, we:

- analysed quantitative activity data on long-term conditions
- estimated and analysed current spend on long-term conditions
- reviewed documents and interviewed staff at the SEHD and at a sample of NHS boards (including health professionals specialising in COPD or epilepsy), CHPs and council social work departments. (The fieldwork was carried out in six NHS board areas: Ayrshire and Arran, Borders, Forth Valley, Greater Glasgow and Clyde, Highland and Tayside)[11]
- held focus groups with people with COPD or epilepsy in the sample board areas
- surveyed GPs and practice nurses in the sample board areas.

1 *Chronic conditions: Making the case for ongoing care,* Partnerships for Solutions, John Hopkins University, December 2002.
2 *Preventing chronic diseases: a vital investment,* World Health Organisation, 2005.
3 *Chronic disease management. A compendium of information,* Department of Health, May 2004.
4 *A health and well-being profile of Scotland,* NHSScotland, 2004.
5 *Scottish Household Survey,* Scottish Executive, 2003.
6 *Projected population of Scotland (2004-based),* Registrar General for Scotland, October 2005.
7 *Drivers for change,* Kendrick S, SEHD, 2004.
8 *COPD Medical Admissions in the UK: 2000/01-2001/02,* King's Fund, August 2004.
9 *Delivering for Health,* Scottish Executive Health Department, November 2005.
10 *A national framework for service change in the NHS in Scotland. Building a health service fit for the future,* Scottish Executive Health Department, May 2005.
11 Limited fieldwork and a focus group were also undertaken in Shetland.

Exhibit 1

Prevalence of selected long-term conditions by age (coronary heart disease (CHD), COPD, diabetes, and stroke and transient ischaemic attacks (TIAs)) for men in Scotland, 2005/06

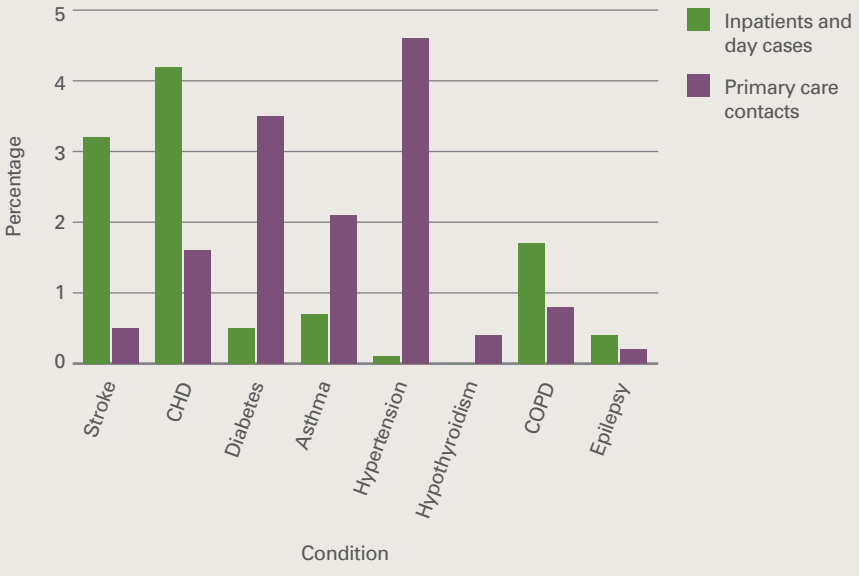


Note: CHD includes acute myocardial infarction (heart attack), angina and heart failure.

Source: ISD Scotland, 2005/06

Exhibit 2

Balance of care in hospitals and primary care for long-term conditions included in the Quality and Outcomes Framework, 2004/05



Source: ISD Scotland, 2004/05

Key findings

In order to provide more community services for people with long-term conditions, NHS boards, through CHPs, need to redesign services and transfer resources from acute to community settings. However, decisions on the best use of resources are currently being made on limited evidence – there is little information at a national or local level about the activity, cost and effectiveness of services for people with long-term conditions.

10. There is limited information on cost and activity at a Scotland-wide level to support the major decisions involved in changing services for people with long-term conditions. The SEHD did not estimate the cost of implementing new models of care for long-term conditions outlined in *Delivering for Health*.

11. This is mirrored at a local level where activity and cost information on long-term conditions is not collected consistently across different parts of the NHS, or between the NHS and social work. This means that it is difficult to plan effectively.

12. In the absence of cost data on long-term conditions, we used economic modelling to estimate the cost of services for people with COPD and epilepsy – our two tracer conditions. We estimate that the direct cost to the NHS in Scotland for 2004/05 for COPD services was just over £98.5 million and for epilepsy services just under £38 million. This is likely to be an underestimate of total costs because we were unable to estimate social care costs. It also excludes any costs relating to services provided by the voluntary sector and family carers. Therefore, the NHS costs do not reflect full costs.

13. Excluding prescribing costs, hospital costs still account for more than half of the overall expenditure in the NHS for both COPD and epilepsy (Exhibit 3, overleaf).

14. Given the lack of cost and activity data it is not surprising that there has been very little evaluation of the cost-effectiveness of services for people with long-term conditions. This gap urgently needs to be filled, as decisions on the use of resources are being made with limited evidence about what works for patients.

15. We found some evidence that developing community services can contribute to reduced hospital admission rates for patients with COPD (Exhibit 4, overleaf). However, these services are not widespread, and even within a board may not be available across the whole area.

Exhibit 3
Estimated cost of COPD & epilepsy services to the NHS in Scotland, 2004/05

	Day cases & bed days (£)	Outpatient and A&E (£)	Other (£)	Primary care (£)	Prescribing (£)	Total (£)
COPD	40,613,044	14,626,964	9,161,098	15,031,843	19,077,568	98,510,517
Epilepsy	11,546,048	5,974,573	949,821	1,515,676	17,957,172	37,943,290

Notes: 'Other' relates to laboratory tests and other procedures, eg blood tests, x-rays, scans.
Prescribing costs relate to prescribing in the community and hospitals.

Source: Economic analysis for Audit Scotland, 2006

Exhibit 4
Summary of community-based COPD services in six NHS board areas and bed days per patient

NHS board	Pulmonary rehabilitation	ESD/HAH	Community nurse-led service	COPD bed days per patient	Comparison to Scottish average COPD bed days per patient
Ayrshire & Arran	Yes	Yes	No	1.61	+20%
Borders	No	No	No	1.97	+47%
Forth Valley	Yes	Yes	No	1.17	-13%
Greater Glasgow & Clyde	Yes	Yes	No	1.35	+1%
Highland	Yes	No	No	1.75	+30%
Tayside	Yes	No	Yes (in part)	1.21	-10%

Notes: ESD: early supported discharge; HAH: hospital at home scheme.
Bed days per patient = the total number of COPD bed days divided by the total number of COPD patients.
The Scottish average COPD bed days per patient is 1.34.

Source: Audit Scotland fieldwork, 2006/07; ISD data 2004/05

Generally there is enthusiasm from staff for *Delivering for Health* as a guide to improving services for long-term conditions. Progress in developing community-based services for asthma and diabetes has been good, but there are a number of practical barriers to providing better community services for all patients with long-term conditions. There is a need to:

- join up health and social care provision more effectively
- ensure that relevant staff have access to comprehensive information on people's care needs
- introduce real incentives for change.

16. The majority of respondents to our GP and practice nurse surveys said that they are treating more patients with long-term conditions in the community; providing early intervention to avoid hospital admissions; and encouraging health promotion among patients with long-term conditions.

17. Community services for people with asthma and diabetes are better developed than for other long-term conditions, aided by the use of the local enhanced services provision in the new General Medical Services (nGMS) contract and joint working between specialists in hospitals and primary care practitioners. Although the developments are condition-specific, some elements, such as good communication between hospitals and GP services, are essential to the development of community services for patients with other long-term conditions.

18. CHPs have a key role in developing local services but not all CHPs are fully developed, and we found limited evidence of transferring resources from secondary to primary care to date. More work is needed to ensure that local health and social care providers are signed up to joint strategies for supporting people with long-term conditions; and that there is transparency about the transfer of resources between health and community services. This transparency is essential as patients do not differentiate between health and social care provided in the home. There is

scope for social care staff, with some additional training, to address wider health needs of people with long-term conditions.

19. Different types of information are held about patients by various parts of the NHS and social work. The lack of progress in providing access to comprehensive patient information is seen as a major barrier to delivering joined-up services for long-term conditions. Social care staff do not routinely hold information about a person's condition, making it difficult to quantify the amount of social care provided to people with long-term conditions.

20. In Scotland, there are no explicit targets for shifting the balance of care into community-based services. There are limited financial incentives apart from through the Quality and Outcomes Framework (QOF).[12] In England, from next year, the Department of Health will not approve primary care trusts' local delivery plans unless there is a clear strategy for shifting care, and resources, into the community.[13]

21. *Delivering for Health* stated that the SEHD would develop a national strategy for long-term conditions by 2006. Although various initiatives have been developed at a national level (eg, a model to identify people at risk of hospital admission), the lack of an overarching strategic plan for people with long-term conditions at a national level has affected the ability of boards to comprehensively plan local services.

People with more than one long-term condition are less likely to be receiving systematic joined-up care across all the services they receive.

22. People with more than one condition are more likely to need more intensive care and support but generally they are not yet receiving this in a structured way. There are a number of small pilots around Scotland testing a model where a key contact in the primary care team is responsible for coordinating the contribution of various professionals involved in a patient's care but this is still in early development.

23. A number of NHS boards have piloted and tested predictive models for identifying patients most at risk of admission to hospital and in need of intensive care by a key contact. A national tool called Scottish Patients At Risk of Readmission and Admission (SPARRA) has been developed by the Information Services Division (ISD) and is being implemented in CHPs and board areas using local data.

Patients want better information about their long-term conditions and many want greater involvement in their own care.

24. Participants in our focus groups would have welcomed more information when they were diagnosed, particularly about the long-term implications of their condition, the services available, and where to get more information. They felt that this would have helped them play a more active part in their own care.

25. In particular, there was little awareness about the availability of social care services and many relied on considerable support from family and friends. In Scotland in 2004, around one in eight adults were providing unpaid care to another person.[14]

26. There is scope for public bodies to work with the voluntary sector to ensure that all patients diagnosed with a long-term condition receive comprehensive information about their condition. The Long-Term Conditions Alliance for Scotland (LTCAS) is taking forward some of this work, particularly around how patients can take a more active role in their own care. Condition-specific information for patients should be supplemented with better information about local services.

Key recommendations

- The SEHD, NHS boards and local authorities should collect better information on activity, cost and quality of services for long-term conditions to support the development of community services.
- The SEHD, NHS boards and local authorities should evaluate different ways of providing services to ensure cost-effectiveness and share good practice.
- NHS boards should take a more strategic role to ensure better working between CHPs and the acute sector to support the development and resourcing of community services.
- The SEHD should prioritise work on developing systems to ensure that comprehensive information on patients is available to all professionals so they can assess and manage the total care package for each individual. A timescale should be set for this.
- The SEHD and NHS boards should agree targets to support the development of community-based services.
- The SEHD should consider providing guidance and support for NHS boards and councils so they can develop shared business plans for resource transfer to facilitate shifting the balance of care.
- NHS boards and local authorities, through CHPs, should ensure comprehensive information is given to patients about their condition, and the health and social care services available, at the time of diagnosis.

12 The QOF is part of the new General Medical Services contract and is a system for paying general practices for the care provided to patients relating to particular long-term conditions and for funding quality improvements.
13 *Our health, our care, our say: a new direction for community services,* Department of Health, January 2006.
14 *Scottish Household Survey Analytical Topic Report: Characteristics and Experiences of Unpaid Carers in Scotland,* Scottish Executive Social Research, 2006.

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