

Managing long-term conditions



Prepared for the Auditor General for Scotland and the Accounts Commission
August 2007

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Acknowledgements

Audit Scotland gratefully acknowledges the time and effort given by NHS and council staff participating in this review and the people who attended our focus groups. Special thanks go to the British Lung Foundation Scotland and Epilepsy Scotland. Thanks also to ISD Scotland for its data analysis and to Ian Binnie and Andrea Kinver at BMRB who carried out our GP and practice nurse surveys. We are also grateful to Dr Andrew Walker and Corinne O'Dowd from the University of Glasgow who carried out the economic modelling.

We would also like to thank the project advisory group (members listed in Appendix 1) who provided valuable advice and feedback throughout the study.

Jillian Matthew and Mark Diffley managed the project with support from Christine Ferns and Kenny Reilly.

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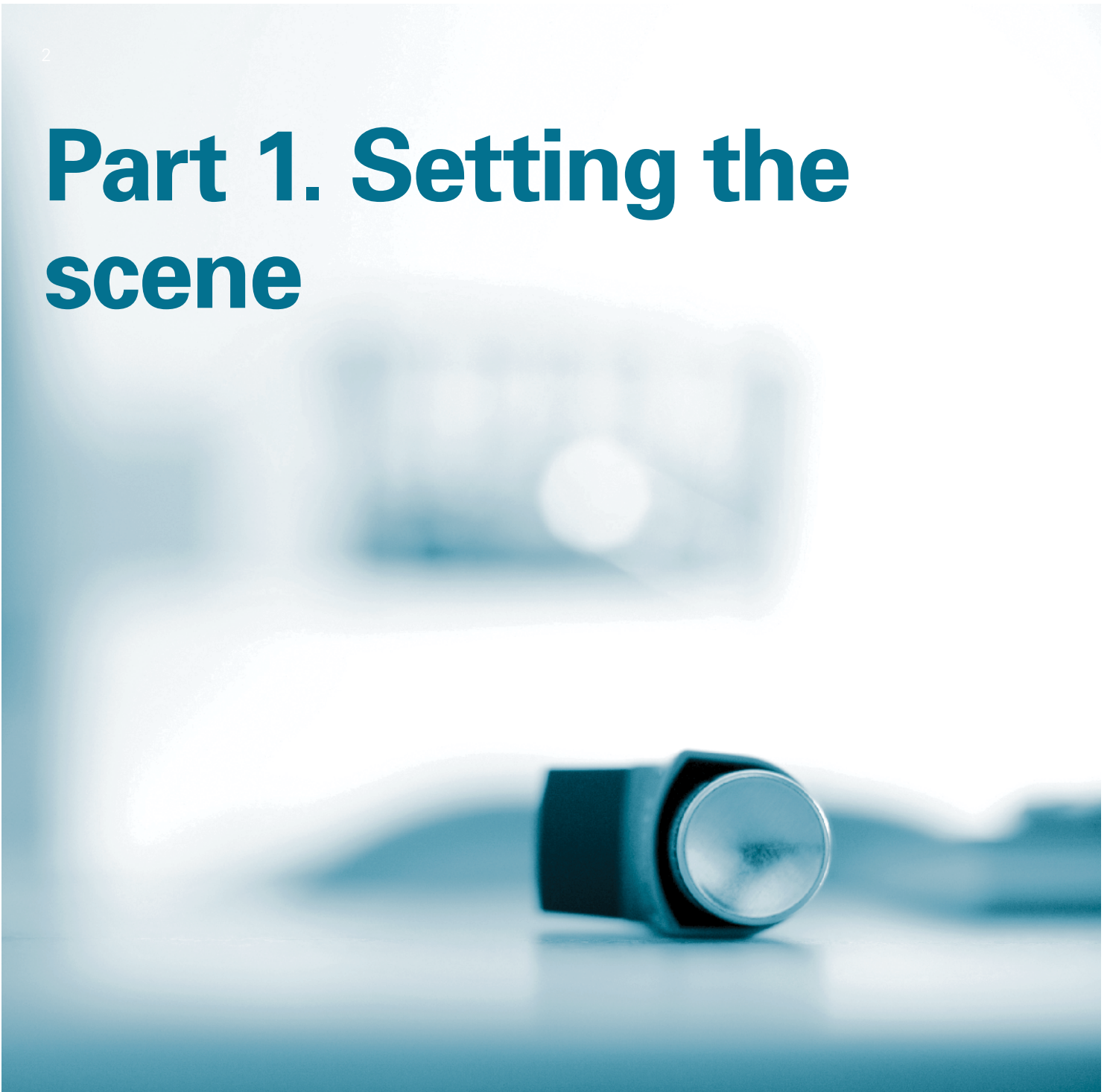
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Part 1. Setting the scene



In Scotland, it is estimated that around one in five people have at least one long-term condition.



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 epilepsy, asthma, diabetes and chronic obstructive pulmonary disease (COPD), which includes a number of conditions including emphysema and chronic bronchitis.

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:

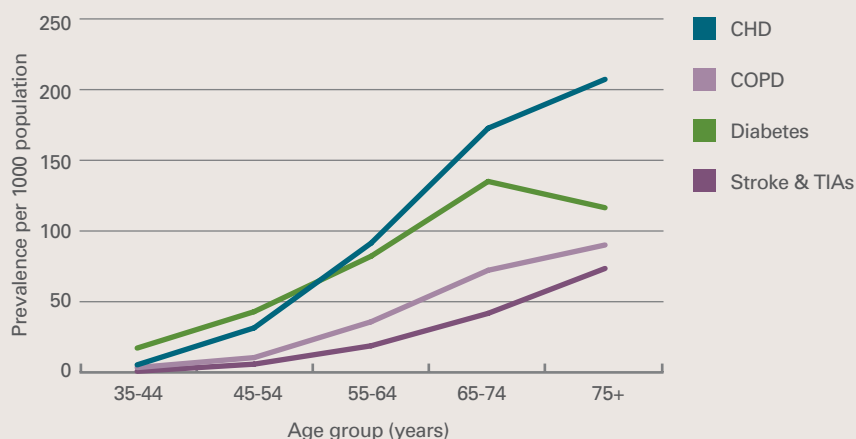
- account for 80 per cent of all GP consultations
- are twice as likely to be admitted to hospital
- stay in hospital disproportionately longer
- account for over 60 per cent of hospital bed days.³

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. If prevalence rates remain the same the total number of people with COPD will rise by 33 per cent between 2007 and 2027, from 99,139 to 127,188; and for the same period the total number of people with

Exhibit 1

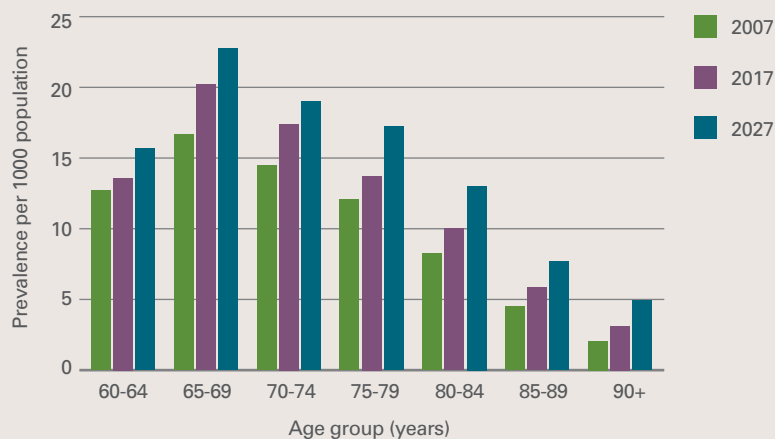
Prevalence of selected long-term conditions by age (coronary heart disease (CHD), COPD, diabetes, and stroke and transient ischaemic attacks (TIAs)) for men in Scotland, 2005/06



Note: CHD includes acute myocardial infarction (heart attack), angina and heart failure.
Source: Information Services Division (ISD) Scotland, 2005/06⁷

Exhibit 2

Projected prevalence of COPD in people aged 60 and above over the next 20 years



Source: ISD Scotland, 2004/05; GAD population projections, 2005

epilepsy will rise by 13 per cent from 19,200 to 20,987. The most significant increases for both conditions occur in people aged 60 and over – 34 per cent

for COPD and 45 per cent for epilepsy. (Exhibit 2 and Exhibit 3, overleaf).⁶ In addition, as life expectancy goes up and the number of older people

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 These projected increases for COPD and epilepsy were estimated by applying the UK Government Actuary's Department (GAD) projected population increases by age group to the prevalence figures for COPD and epilepsy on the Quality and Outcomes Framework (QOF) registers in 2004/05.

7 ISD is part of NHS National Services Scotland.

increases, it is likely that a growing number of people in Scotland will suffer from one or more long-term condition.⁸

5. Over the period 2004 to 2031, the number of people of working age is projected to fall by seven per cent by 2031, from 3.18 million to 2.96 million.⁹ 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.

6. Links have been established between deprivation and behavioural factors known to affect health, and also with individual long-term conditions. For example, smoking is the most important preventable cause of ill health and premature death in Scotland, with more than 13,000 smoking-related deaths per year. People living in the most deprived areas are more than twice as likely to be current smokers than those in the least deprived areas.¹⁰ 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.¹¹ Deprived populations also have considerably higher levels of deaths due to coronary heart disease (CHD), with deaths in the most deprived ten per cent of the population being five times higher than that in the least deprived ten per cent (Exhibit 4).

7. 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.

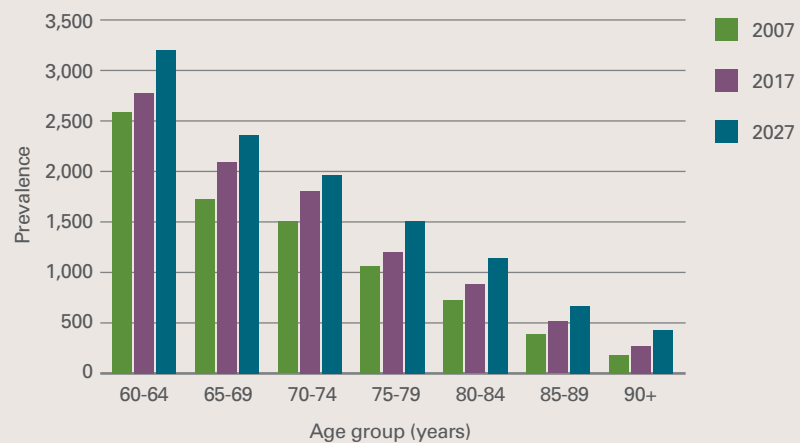
8. *Delivering for Health* sets out a programme of action for the NHS in Scotland based on the recommendations made in

Building a Health Service Fit for the Future (also known as the *Kerr Report*).^{12 13} 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 responsibility for driving the shift in the balance of care locally to NHS boards, with implementation and delivery by Community Health Partnerships (CHPs).

Exhibit 3

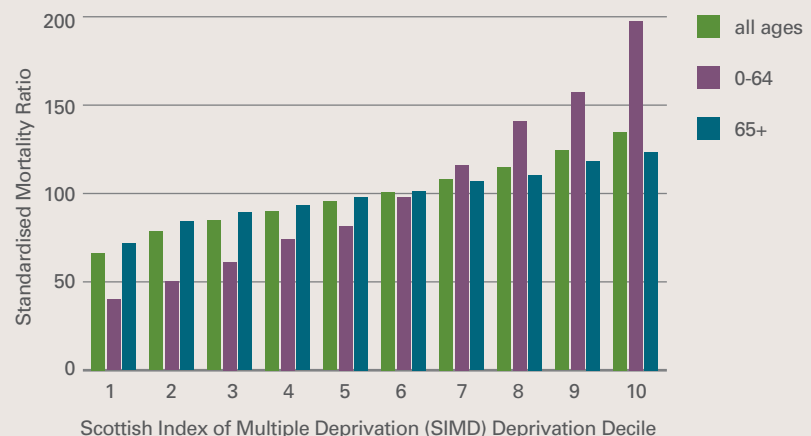
Projected prevalence of epilepsy in people aged 60 and above over the next 20 years



Source: ISD Scotland, 2004/05; GAD population projections, 2005

Exhibit 4

Deprivation and deaths from Coronary Heart Disease, 2001 to 2005



Note: The SIMD scale describes the least deprived proportion in decile 1 through to the most deprived in decile 10.

Source: ISD Scotland, 2001-05

8 *Drivers for change*, S Kendrick, SEHD, 2004.

9 *Projected population of Scotland (2004-based)*, Registrar General for Scotland, October 2005.

10 Scottish Public Health Observatory: http://www.scotpho.org.uk/web/site/home/Behaviour/Tobaccouse/tobacco_data/tobacco_socialclass.asp

11 *COPD Medical Admissions in the UK: 2000/01-2001/02*, King's Fund, August 2004.

12 *Delivering for Health*, SEHD, November 2005.

13 *A national framework for service change in the NHS in Scotland. Building a health service fit for the future*, SEHD, May 2005.

Key messages

9. In our review we found that services for people with long-term conditions are improving but there is considerable progress to be made to provide cost-effective, community-based care.

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

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

Recommendations

10. Our report includes recommendations at the end of each chapter. External auditors will be following up progress against each of these based on the self-assessment checklist for NHS boards in [Appendix 5](#).

Our study

11. 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. In summary, we:


- analysed quantitative activity data on long-term conditions
- estimated and analysed current spend on long-term conditions ([Appendix 2](#))
- 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 at boards was carried out in six areas: Ayrshire and Arran, Borders, Forth Valley, Greater Glasgow and Clyde, Highland and Tayside)¹⁴
- held focus groups with people with COPD or epilepsy in the sample board areas ([Appendix 3](#))
- surveyed GPs and practice nurses in the sample board areas ([Appendix 4](#) and [report supplement](#)).

12. A separate document aimed at non-executive members of health boards accompanies our report. This document highlights issues arising from this report which will support non-executives in exercising their scrutiny role.

Part 2. Activity, cost and effectiveness of services

A hand holding a pen, with a blurred background of a person's face. The image is in shades of blue and white, with a soft focus on the hand and pen.

There is little information at a national or local level about the activity, cost and effectiveness of services for people with long-term conditions.

A solid blue rectangular block at the bottom of the page.

Key message

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.

Robust planning and decision-making need to be supported by comprehensive information about activity, cost and effectiveness of services

13. *Delivering for Health* sets a major challenge for the NHS and its partners as it involves a significant shift in how services for people with long-term conditions are currently planned, designed and delivered. This needs to be underpinned by robust information about activity, cost and effectiveness of services. This information is needed across the NHS and social care, at both national and local levels.

Most treatment for some long-term conditions is still carried out in hospitals

14. Information systems in the NHS have traditionally focused on the hospital sector with community information still needing further development. Systems such as the Quality and Outcomes Framework (QOF) and Practice Team Information (PTI) are still relatively new, and comprehensive information about community activity in the NHS is therefore not yet available. Activity information about social care services for people with long-term conditions is not available as social care data are not collected about individual diseases.

The total number of people treated in hospital is slowly increasing

15. The total number of inpatient and day cases for all causes of illness across Scotland has increased marginally between 1997/98 and 2005/06, from 1,200,329 to 1,233,646 (an increase of less than three per cent over eight years). In relation to our two tracer conditions, inpatient and day cases for COPD increased by 25 per cent to 20,838 over the same period, and decreased for epilepsy by five per cent to 5,288.

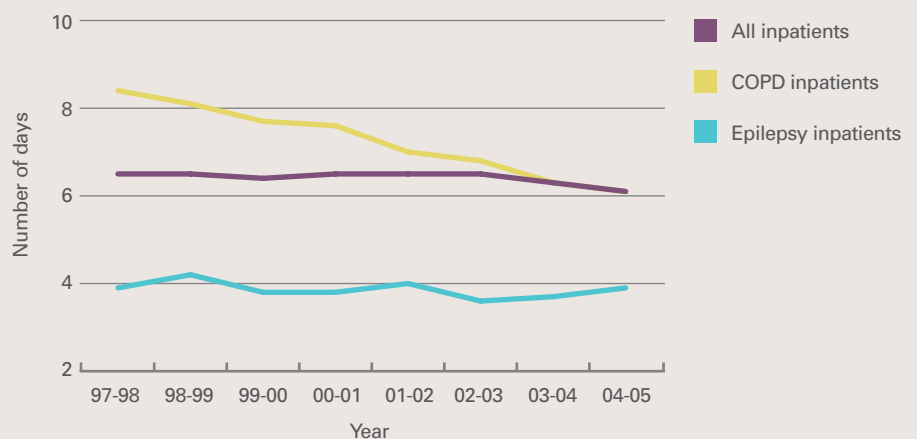
People with a number of long-term conditions spend a longer time in hospital

16. The average length of stay in hospital for all inpatients has gradually reduced between 1997/98 and 2004/05, from 6.5 to 6.1 days. Over the same period, the average length of stay for patients with COPD fell from 8.4 to 6.1 days but stayed at around four days for those with epilepsy ([Exhibit 5](#)).

17. Often people have more than one long-term condition and this can affect how long they stay in hospital. For example, due to the nature of the conditions, it is common for people with COPD or epilepsy to have depression or anxiety, and many of the focus group participants said they had experienced these mental health problems. As prevalence increases with age, many older people with COPD or epilepsy will have other non-related conditions. For example, other conditions experienced by the people attending the focus groups include osteoporosis, angina, asthma and hypothyroidism. [Exhibit 6 \(overleaf\)](#) shows that the average length of stay for patients with a main diagnosis of COPD or epilepsy increases with the number of other conditions present. In 2004/05, the average number of conditions per patient for those admitted to hospital with COPD was 3.2 conditions, and for epilepsy 3.7 conditions.

Exhibit 5

Average length of stay for inpatients in Scotland, 1997/98 to 2004/05



Source: ISD Scotland

People with COPD or epilepsy are often readmitted to hospital and can be admitted to hospital several times a year

18. Although the length of stay in hospital is generally decreasing the percentage of people with a main diagnosis of COPD or epilepsy readmitted to hospital within 28 days of being discharged is increasing (Exhibit 7).

19. In 2003/04, a total of 10,214 COPD patients were admitted to hospital, of whom 19 per cent were admitted twice during the year and 16 per cent were admitted three or more times. In the same year, 3,330 patients were admitted to hospital for epilepsy, of whom 17 per cent were admitted twice and 11 per cent were admitted three or more times.

20. The increase in COPD and epilepsy patients being readmitted to hospital within 28 days of being discharged, together with the increase in the numbers being admitted on several occasions during the year, highlight the importance of having good community support in place, and good communication among all those who are involved in a patient's care, to help avoid admission to hospital (see Part 3).

Exhibit 6

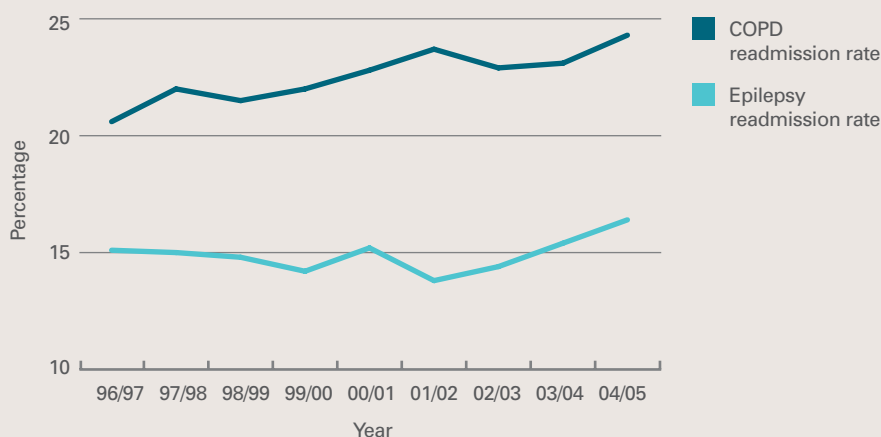
Average length of stay in hospital for COPD and epilepsy patients in Scotland by number of conditions present, 2004/05

Number of conditions present	Average length of stay (days)	
	COPD as main diagnosis	Epilepsy as main diagnosis
1	4.6	2.8
2	5.5	2.6
3	6.2	3.4
4	6.4	4.9
5	6.8	6.7
6	8.2	8.7

Source: ISD Scotland

Exhibit 7

Readmission to hospital within 28 days for Scotland where COPD or epilepsy is the main diagnosis, 1996/97-2004/05



Source: ISD Scotland

The treatment for some long-term conditions is still mainly hospital-based

21. The level of healthcare being provided in the community is increasing but for some long-term conditions the majority of treatment is still carried out in hospitals (Exhibit 8). For example, for CHD services over four per cent of all inpatient and day cases relate to CHD patients compared to less than two per cent of all primary care contacts. The amount of social care provided to people with long-term conditions is unknown as social care data do not identify disease-specific information, making it impossible to quantify activity.

22. The QOF is a fundamental part of the new General Medical Services (nGMS) contract introduced in April 2004. The QOF is a system for paying general practices for the care provided to patients relating to particular long-term conditions and for funding quality improvements. QOF payments accounted for about £134.5 million of a total £642 million spent on general medical services in Scotland for 2005/06.¹⁵ Participating in the QOF is optional although 1,020 practices across Scotland (98.9 per cent) took part in 2005/06.

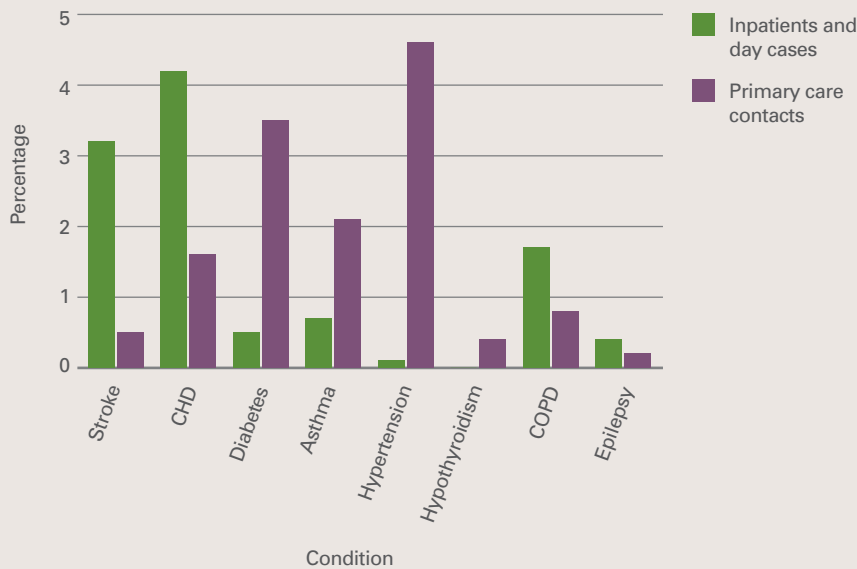
23. The QOF measures achievement against a range of indicators, with points and payments awarded according to the level of achievement. Part of this relates to practices' performance against ten conditions, including COPD and epilepsy.¹⁶ Examples of indicators against

¹⁵ www.isdscotland.org

¹⁶ The ten QOF conditions are: secondary prevention in CHD; stroke and transient ischaemic attack (TIA); hypertension; diabetes mellitus; COPD; epilepsy; hypothyroidism; cancer; mental health; and asthma.

Exhibit 8

Balance of care in hospitals and primary care for some of the long-term conditions included in the QOF, 2004/05



Source: ISD Scotland, 2004/05

which practices' performance are measured include specific indicators for each condition relating to patient registers, initial diagnosis and ongoing management.

24. While QOF data are only available for three years, early indications are that the number of times a person has contact with primary care staff during the year has increased in the second year for the ten QOF conditions but then has dropped again slightly in the third year (Exhibit 9). This may be due to practices calling patients in for review when the system was first introduced who they had not seen for some time.

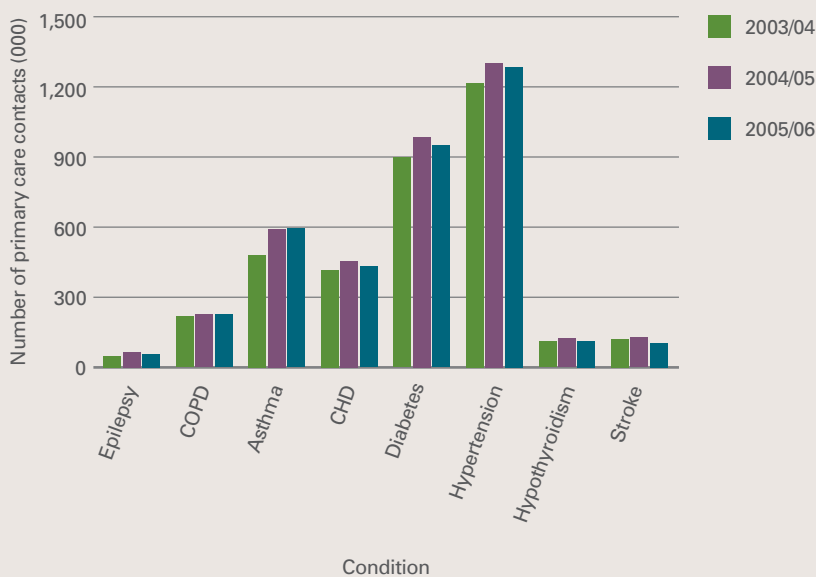
25. Exhibit 10 (overleaf) shows that the number of contacts that COPD patients have with their GPs fell over the period 2003/04 to 2005/06 while contact with practice nurses increased. This reflects the wider role that nursing staff are having in the care of patients. Over the same period the level of contact that epilepsy patients had with both GPs and practice nurses initially increased but then fell (Exhibit 11, overleaf). Again this is likely to be due to practices reviewing more patients in the first two years of the new system being introduced. Also, unlike COPD there is less scope for practice nurses to manage patients, unless they have had additional training, as much of the contact will relate to medication review and prescribing which is generally the responsibility of GPs.¹⁷

The full cost of long-term conditions is not available

26. There is limited information at a Scotland-wide level about the cost of services 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*.

Exhibit 9

Level of contact people with long-term conditions have with general practice



Source: ISD Scotland, 2003/04-2005/06

17 The Practice Team Information system collects and analyses data from 55 general practices across Scotland, and includes information about GPs and practice and community nurses.

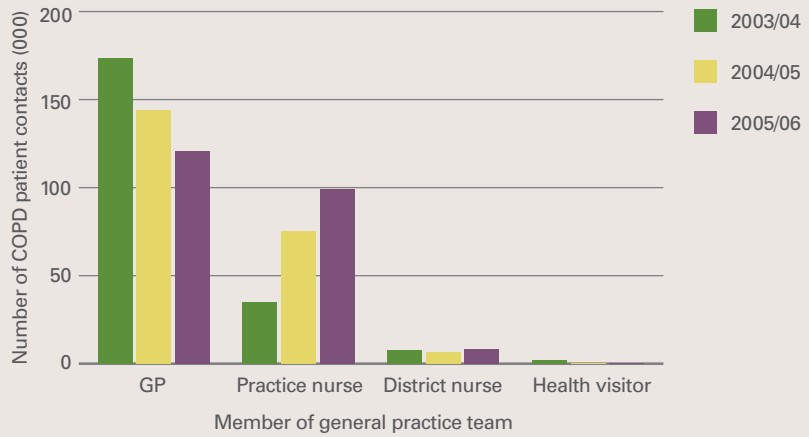
27. Some cost data have been published estimating the cost of cancer, CHD and diabetes services to the NHS in Scotland.^{18 19} The most comprehensive of these is the work done on cancer services which put the overall cost for 2000/01 at £425 million and included costs such as screening, research, capital expenditure and input from Special Health Boards. The estimated cost of CHD services to the NHS in Scotland in 1999 was £434 million, while the estimate for diabetes services was £320 million for 2002/03. However, both estimates are considered quite crude – at best these are snapshots at one point in time and did not offer a basis for monitoring or planning change.

28. The lack of cost data at a national level is mirrored at a local level, where cost information on long-term conditions is not collected consistently across different parts of the NHS, or between the NHS and social work where costs cannot be identified. The SEHD expects NHS boards, through their CHPs, to redesign services, transfer resources from acute to community settings, and fund new developments within existing budgets. However, it is difficult for boards to plan for this due to the lack of consistent and comprehensive cost information in both health and social care.

29. Some NHS boards are developing systems to collect more information about specific conditions. NHS Greater Glasgow and Clyde is starting to collate all cost information, across primary care and hospitals, relating to specific conditions. NHS Tayside is developing electronic systems to capture more comprehensive information on specific conditions. These developments will allow both boards to begin to track spend on long-term conditions throughout their board areas.

Exhibit 10

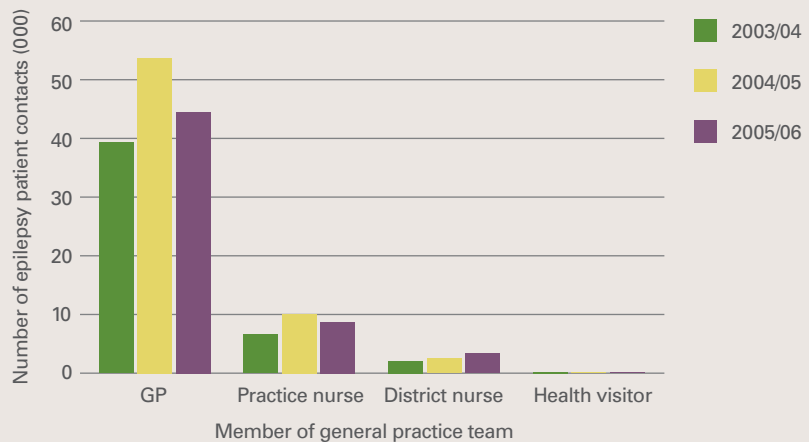
Members of the general practice team with whom COPD patients had contact, 2003/04 to 2005/06



Source: ISD Scotland

Exhibit 11

Members of the general practice team with whom epilepsy patients had contact, 2003/04 to 2005/06



Source: ISD Scotland

18 *The Cost of Cancer Care in Scotland 2002*, ISD Cancer Information Group, September 2003.

19 *The Future Burden of CHD and Diabetes in Scotland: The Value of Health Care Innovation. A Final Report for ABPI Scotland*, NERA Economic Consulting, September 2005.

Exhibit 12**Estimated cost of COPD services to the NHS in Scotland, 2004/05**

NHS board	Day cases & bed days (£)	Primary care (£)	Outpatient and A&E (£)	Prescribing (£)	Other (£)	Total (£)
Argyll & Clyde ²⁰	3,140,477	1,151,088	1,120,084	1,614,683	701,526	7,727,859
Ayrshire & Arran	3,617,449	1,119,456	1,089,304	1,323,594	682,248	7,832,052
Borders	969,253	245,939	239,315	277,545	149,886	1,881,938
Dumfries & Galloway	1,255,943	436,522	424,764	470,235	266,036	2,853,500
Fife	2,158,890	925,394	900,469	1,419,618	563,978	5,968,349
Forth Valley	1,805,949	768,341	747,646	1,276,243	468,263	5,066,442
Grampian	3,627,584	954,654	928,940	1,268,889	581,810	7,361,877
Greater Glasgow	9,500,209	3,505,300	3,410,886	4,437,909	2,136,292	22,990,595
Highland	1,719,213	487,607	474,474	605,820	297,170	3,584,285
Lanarkshire	4,516,186	1,679,501	1,634,264	2,171,603	1,023,565	11,025,120
Lothian	4,781,198	1,681,715	1,636,419	1,951,788	1,024,915	11,076,034
Orkney	56,426	17,714	17,237	19,833	10,796	122,005
Shetland	50,086	4,587	4,463	5,926	2,795	67,857
Tayside	3,145,682	1,288,688	1,253,977	1,579,809	785,386	8,053,542
Western Isles	268,499	15,816	15,390	24,292	9,639	333,636
Scotland	40,613,044	15,031,843	14,626,964	19,077,568	9,161,098	98,510,517

Notes: The total cost of COPD in Scotland will not exactly add up to the sum of the cost of COPD across the individual boards. This is due to adjusting the QOF prevalence figure to include people not registered with a GP or not included in the QOF. Prescribing costs relate to prescribing in the community and hospitals. Other costs include laboratory tests and other procedures, eg blood tests, x-rays and scans.

Source: Economic analysis for Audit Scotland, 2006

We used economic modelling to estimate the cost of COPD and epilepsy services

30. 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. While data were available on inpatient, day case services and some aspects of prescribing, other figures had to be estimated from previous research studies elsewhere in the UK.²¹

Managing people with COPD costs the NHS over £98.5 million

31. We estimate that the direct cost of COPD to the NHS in Scotland was just over £98.5 million in 2004/05 (Exhibit 12). This is an underestimate of the overall cost of care due to lack of information on social work costs and costs relating to services provided by the voluntary sector and family carers. Also, the prescribing costs only include one medicine (Tiotropium)

as this is the only medicine licensed solely for the treatment of COPD.²²

An average cost of £1,036 per patient suggests that most people diagnosed with COPD have fairly severe disease **32.** The QOF shows just over 90,000 people have COPD. Adjusting for people not registered with a GP or not covered in QOF data, this suggests 95,042 cases overall.²³

20 NHS Argyll and Clyde was dissolved on 31 March 2006. Responsibility for the area was incorporated into the two neighbouring boards, NHS Greater Glasgow (now known as NHS Greater Glasgow and Clyde) and NHS Highland.

21 A more detailed explanation of how the economic modelling was carried out can be found in Appendix 2.

22 Other medicines are routinely prescribed for COPD but they are also licensed for the treatment of asthma and there was not sufficient information available to estimate what proportion of these medicines are prescribed for COPD.

23 The total number of people registered with a GP is less than the total population of Scotland meaning the total number of people registered on QOF is likely to be an underestimate. Therefore, the number of people registered on QOF with COPD was multiplied by the ratio of the total population of Scotland to the total number of people registered with a GP.

Exhibit 13

Estimated cost of COPD services per patient, 2004/05

NHS board	Day cases & bed days (£)	Primary care (£)	Outpatient and A&E (£)	Prescribing (£)	Other (£)	Total cost per patient (£)
Argyll & Clyde	432	158	154	222	96	1,062
Ayrshire & Arran	511	158	154	187	96	1,107
Borders	623	158	154	178	96	1,210
Dumfries & Galloway	455	158	154	170	96	1,034
Fife	369	158	154	243	96	1,020
Forth Valley	372	158	154	263	96	1,043
Grampian	601	158	154	210	96	1,220
Greater Glasgow	429	158	154	200	96	1,037
Highland	558	158	154	197	96	1,163
Lanarkshire	425	158	154	205	96	1,038
Lothian	450	158	154	184	96	1,042
Orkney	368	158	154	166	96	942
Shetland	80	158	154	137	96	626
Tayside	386	158	154	194	96	988
Western Isles	714	158	154	163	96	1,286
Scotland	427	158	154	201	96	1,036

Source: Economic analysis for Audit Scotland, 2006

33. The average cost per COPD patient is £1,036, although this is likely to cover a wide range (Exhibit 13). For example, while prescribing costs per head are around £201 on average, some patients may not be receiving any prescribed medication.²⁴ The only data we could obtain that show the variance of service provision among boards relates to bed days and Tiotropium prescribing. Therefore, the cost per patient is identical for some elements since they were estimated from UK research studies. For the mainland NHS boards, the total cost of providing COPD services ranges from £988 per patient on average in NHS Tayside to £1,220 in NHS Grampian.

34. Research quoted in the National Institute for Health and Clinical Excellence (NICE) COPD guidelines suggests the annual cost of managing a patient at each stage of their disease is: mild £150; moderate £308; and severe £1,307.²⁵ From the data available it is not possible to say how many of the 95,042 patients in Scotland fall into each of the severity stages, but our estimated cost per patient of £1,036 suggests that most known COPD patients in Scotland have fairly severe disease.

Managing people with epilepsy costs the NHS about £38 million

35. We estimate the direct cost of epilepsy to the NHS in 2004/05 to be just under £38 million (Exhibit 14). As before, the total cost is likely to be an underestimate for overall care due to lack of information on costs relating to social care and services provided by the voluntary sector and family carers.

24 *The burden of COPD in the UK: Results from the confronting COPD survey*, M Britton, Respiratory Medicine Vol. 97 (2003) (SUPPLEMENT C), S7 I-S79.

25 *Chronic Obstructive Pulmonary Disease: NICE Guideline*, National Institute for Health and Clinical Excellence, February 2004.

Exhibit 14

Estimated cost of epilepsy services to the NHS in Scotland, 2004/05

NHS board	Day cases & bed days (£)	Primary care (£)	Outpatient and A&E (£)	Prescribing (£)	Other (£)	Total (£)
Argyll & Clyde	1,203,509	131,727	519,250	1,589,556	82,549	3,526,591
Ayrshire & Arran	773,053	111,833	440,829	1,277,608	70,082	2,673,405
Borders	537,931	29,176	115,006	362,976	18,283	1,063,372
Dumfries & Galloway	201,668	41,703	164,388	456,742	26,134	890,635
Fife	436,174	92,896	366,182	1,367,635	58,215	2,321,102
Forth Valley	601,250	76,498	301,542	1,170,829	47,938	2,198,057
Grampian	1,041,072	121,655	479,547	1,389,334	76,237	3,107,845
Greater Glasgow	2,151,279	293,754	1,157,935	3,418,187	184,085	7,205,240
Highland	345,621	58,726	231,489	556,449	36,801	1,229,086
Lanarkshire	1,485,474	155,825	614,241	2,032,447	97,650	4,385,637
Lothian	1,952,422	177,509	699,716	2,335,156	111,239	5,276,042
Orkney	8,405	2,539	10,008	42,168	1,591	64,711
Shetland	35,862	333	1,312	48,135	209	85,851
Tayside	548,748	120,573	475,282	1,818,059	75,559	3,038,221
Western Isles	223,578	1,998	7,875	91,873	1,252	326,576
Scotland	11,546,048	1,515,676	5,974,573	17,957,172	949,821	37,943,290

Notes: The total cost of COPD in Scotland will not exactly add up to the sum of the cost of COPD across the individual boards. This is due to adjusting the QOF prevalence figure to include people not registered with a GP or not included in the QOF.

Prescribing costs relate to prescribing in the community and hospitals.

Other costs include laboratory tests and other procedures, eg blood tests, x-rays and scans.

Source: Economic analysis for Audit Scotland, 2006

The average cost per patient of £1,042 may vary depending on how frequently people with epilepsy have seizures

36. From QOF data for 2004/05, there are 34,040 people with epilepsy in Scotland. This rises to 36,417 after adjusting for people not registered with a GP or not covered in QOF data.²⁶

37. We estimate the average cost per person with epilepsy to be £1,042 and this varies among boards

(Exhibit 15, overleaf). This is due to differences in: the prevalence of epilepsy reported in the QOF; hospital bed days for epilepsy; and variations in prescribing. Focusing on the mainland NHS boards, average costs per patient ranged from £871 in NHS Highland to £1,517 in NHS Borders. Previously published research suggests the cost per patient depends on seizure frequency but we were not able to collect Scottish data to verify this.²⁷

The cost-effectiveness of services for people with long-term conditions is unclear

38. 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.

26 If we assume Scotland to be ten per cent of the size of England and Wales, NICE's prevalence estimate (5-10 cases per 1,000) would suggest a range from 26,000 to 42,000, making the Scotland figures consistent with England and Wales. *Epilepsy in adults and children: NICE guideline*, National Institute for Health and Clinical Excellence, October 2004.

27 *Uptake and Costs of Care for Epilepsy: Findings from a UK Regional Study*, A Jacoby et al. *Epilepsia*, 39(7):776-786, 1998.

Exhibit 15

Estimated cost of epilepsy services per patient, 2004/05

NHS board	Day cases & bed days (£)	Primary care (£)	Outpatient and A&E (£)	Prescribing (£)	Other (£)	Total cost per patient (£)
Argyll & Clyde	380	42	164	502	26	1,114
Ayrshire & Arran	288	42	164	475	26	995
Borders	767	42	164	518	26	1,517
Dumfries & Galloway	201	42	164	456	26	889
Fife	195	42	164	613	26	1,040
Forth Valley	327	42	164	637	26	1,196
Grampian	356	42	164	475	26	1,063
Greater Glasgow	305	42	164	484	26	1,021
Highland	245	42	164	394	26	871
Lanarkshire	397	42	164	543	26	1,172
Lothian	458	42	164	548	26	1,238
Orkney	101	42	164	505	26	838
Shetland	208	42	164	279	26	719
Tayside	189	42	164	628	26	1,049
Western Isles	1,234	42	164	509	26	1,975
Scotland	317	42	164	493	26	1,042

Source: Economic analysis for Audit Scotland, 2006

More community services for people with COPD may reduce hospital admissions

39. We looked at the types of community-based COPD services provided in the six NHS board areas we audited and compared it to the mean number of bed days per patient, to establish if the presence or lack of these services had affected the rate of inpatient bed days for COPD patients.

40. We found some evidence that developing specific COPD services in the community may contribute to reduced hospital admission rates (Exhibit 16). However, these services are not widespread, and even within

a board area may not be available across the whole area. NHS Borders does not have any of the specific COPD services noted in Exhibit 16 and has the highest average number of bed days per patient. NHS Forth Valley, NHS Tayside, and NHS Greater Glasgow and Clyde appear to provide the widest range of services for COPD patients and also have a lower mean number of bed days per patient.

41. Within Dundee City CHP in Tayside, a community COPD service has been developed over the last six years where specialist COPD nurses carry out diagnosis and provide ongoing treatment and care for patients. In 2005/06, the total cost

of providing the community COPD service in Dundee was £500,000, an average of £143 per patient.²⁸ Around 50 per cent of patients have severe or very severe COPD. Data available for patients included in this service (a total of 4,120 COPD patients in 2005) appear to show that hospital admissions, and outpatient and GP appointments, have reduced for these patients (Exhibit 17).

28 This does not include prescribing costs.

Exhibit 16

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	Yes	Yes (in part)	1.21	-10%

Notes: ESD: early supported discharge; HAH: hospital at home scheme.

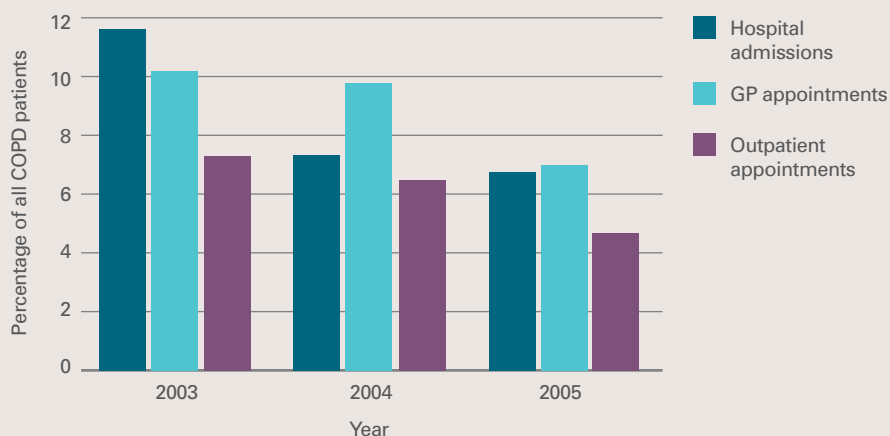
Bed days per patient = the total number of COPD bed days divided by the total number of COPD patients.

The Scottish average COPD bed days per patient is 1.34.

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

Exhibit 17

Percentage of patients in the Dundee nurse-led COPD community service admitted to hospital and attending GP and outpatient appointments, 2003-2005



Source: Audit Scotland fieldwork, 2006/07

42. Evidence is lacking around the impact and cost-effectiveness of specialist nurses. While the Dundee nurse-led community COPD service has a robust database around activity and clinical outcomes, no economic evaluation has been carried out. There is some evidence that specialist COPD services are cost-effective but without comprehensive evaluation of specialist staff or services, it is impossible to tell how these would impact on other parts of the service (Exhibit 18, overleaf).

Exhibit 18

A summary of the evidence for some specialist COPD services

Type of service	Scenario	Initial cost	Value for money
Smoking cessation – offer nicotine replacement to all smokers	If 10% of regular smokers quit smoking this would amount to 140,000 people. The cost per smoking cessation treatment per person is £171. ²⁹	£23.9 million	NICE quotes smoking cessation as the most effective way of preventing and slowing down the progression of COPD.
Opportunistic case finding among older smokers	If 10% of smokers aged 45-74 agreed to opportunistic testing this would amount to 449,056 people. The cost per GP consultation and a spirometry test is £33.91. ^{29 30}	£1.5 million	NICE assessed this method as being cost-effective.
Pulmonary rehabilitation – a course including exercise, education, advice and support	If there was around a 60% uptake among moderately severe COPD patients this would amount to 35,976 people. The cost per patient of pulmonary rehabilitation is £725. ³¹	£26.1 million	Pulmonary rehabilitation has been shown to improve participants' quality of life. There is evidence that it saves four bed days in hospital over the following year at £195 per bed day – a total of £780 per patient, amounting to £28.1 million overall. This is not a direct saving but would free up beds for other patients.
Hospital at home (HAH) / early supported discharge	Assuming 25% of hospital admissions for COPD are eligible for HAH, this would amount to 5,153 people. NICE randomised clinical trials suggest three patients per month, which equates to 143 nurses at £40,000 each. ³⁰	£5.7 million	The evidence is inconclusive – different research studies have freed up between 8-17 days per nurse per month at a cost per day of £188-£400.

Source: Economic analysis for Audit Scotland, 2006

The evidence for providing more community services for people with epilepsy is less certain

43. Community-based epilepsy services are less common. Managing people with epilepsy in the community is much more complex for a number of reasons:

- Epilepsy is difficult to diagnose, particularly in the early stages.
- There are many different types of epilepsy which present in different ways and across different age groups.
- A significant number of diagnoses made by non-specialists have been shown to be incorrect, therefore diagnosis should be made by

a neurologist or other epilepsy specialist; this often involves a number of tests that need to be carried out in a hospital setting.

- Antiepileptic drug treatment is complex and a number of different treatments may need to be tried before the most appropriate drug or combination of drugs is found, therefore such treatment should be started by an epilepsy specialist in agreement with the patient.
- In the most extreme cases of status epilepticus (where epileptic activity lasts for 30 minutes or more) emergency treatment and sometimes an admission to hospital are required, and severe harm or death can occur.³²

44. It is estimated that around 23 per cent of people in Scotland have been misdiagnosed with epilepsy, at a cost of £13.7 million.³³ This does not include those with epilepsy who have been misdiagnosed with having another condition for which the figures are not available. The potential effects on people's lives if epilepsy is not diagnosed and treated appropriately can be profound and even fatal – antiepileptic drugs are not always chosen and used appropriately by clinicians and it is likely the incidence of sudden unexpected death in epilepsy could be reduced if drug treatment is improved.³²

29 *Chronic Obstructive Pulmonary Disease: NICE Guideline*, National Institute for Health and Clinical Excellence, February 2004.

30 *Unit Costs of Health and Social Care 2006*, Personal Social Services Research Unit, University of Kent, 2006.

31 *Cost effectiveness of an outpatient multidisciplinary pulmonary rehabilitation programme*, T Griffiths et al. *Thorax* 2001;56:779-784.

32 *Diagnosis and management of epilepsy in adults: A national clinical guideline*, Scottish Intercollegiate Guidelines Network, April 2004.

33 *Epilepsy prevalence, incidence and other statistics*, Joint Epilepsy Commission, March 2005.

45. Many people with epilepsy are reviewed on an ongoing basis by their general practice team who often have limited knowledge of epilepsy. Research carried out across the UK, in: south-west Glasgow, Chester, Wrexham and a UK-wide study, shows the level of care provided to epilepsy patients varies greatly:^{34 35 36 37}

- Just under half had not been seen by a GP or an epilepsy specialist in the past year (Chester and UK-wide studies).
- Around a third had never seen an epilepsy specialist (south-west Glasgow and Wrexham studies).
- 11-16 per cent had been misdiagnosed with epilepsy (Chester and Wrexham studies).
- The proportion of epilepsy patients under regular review in outpatients was found to be six per cent in the south-west Glasgow study and 36 per cent in the Wrexham study, and 19 per cent of patients in the Chester study were being reviewed regularly in primary care.³⁸
- Documented remission rates (seizure-free for 12 months) ranged from 20 per cent in Wrexham to 37 per cent in south-west Glasgow.

46. In the Chester study, there was a clear link between high levels of regular review and increased remission rates in a comparison of ten general practices. The highest recorded remission rate was just over 60 per cent in a practice that carried out a regular review for almost 80 per cent of patients with epilepsy.

47. It has been proposed that observed remission rates of 65 per cent can be achieved in specialist neurology centres.³⁹ These figures are based on patients from as long ago as 1982, so newer treatments might increase this figure further. There is evidence from the Wrexham study that using specialist epilepsy staff to review patients not currently attending an outpatient clinic increases the number of people with epilepsy in remission but the cost-effectiveness of this approach is not clear.

48. In the south-west Glasgow study, practice nurses were able to review epilepsy patients, with some training and the use of a checklist. NHS Greater Glasgow and Clyde is planning to introduce a local enhanced service in 2008 to improve the management of epilepsy in the community, which will include an annual review by a practice nurse.

49. In the boards we audited there are varying levels of specialist support for people with epilepsy. The most comprehensive service was found in NHS Forth Valley which has two consultant neurologists, an epilepsy specialist nurse (who plays a large role in ensuring patients are on the most appropriate medication), and an epilepsy fieldworker (who helps largely with the psycho-social aspects of the condition). Voluntary organisations often provide community-based support for epilepsy patients such as Epilepsy Scotland's Community Support Service, and Quarriers' and Epilepsy Connections' fieldwork services. Boards should recognise these as a resource for providing epilepsy care.

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.

34 *Review of patients in general practice with a diagnosis of epilepsy: development of a practice nurse checklist and an assessment of resource implications*, Duncan R, Barlow G, Smith AC, SMJ 2005 50(3): 114-7.

35 *The development of a city-wide epilepsy register*, Minshall I, Smith D, Seizure (2006) 15, 93-97.

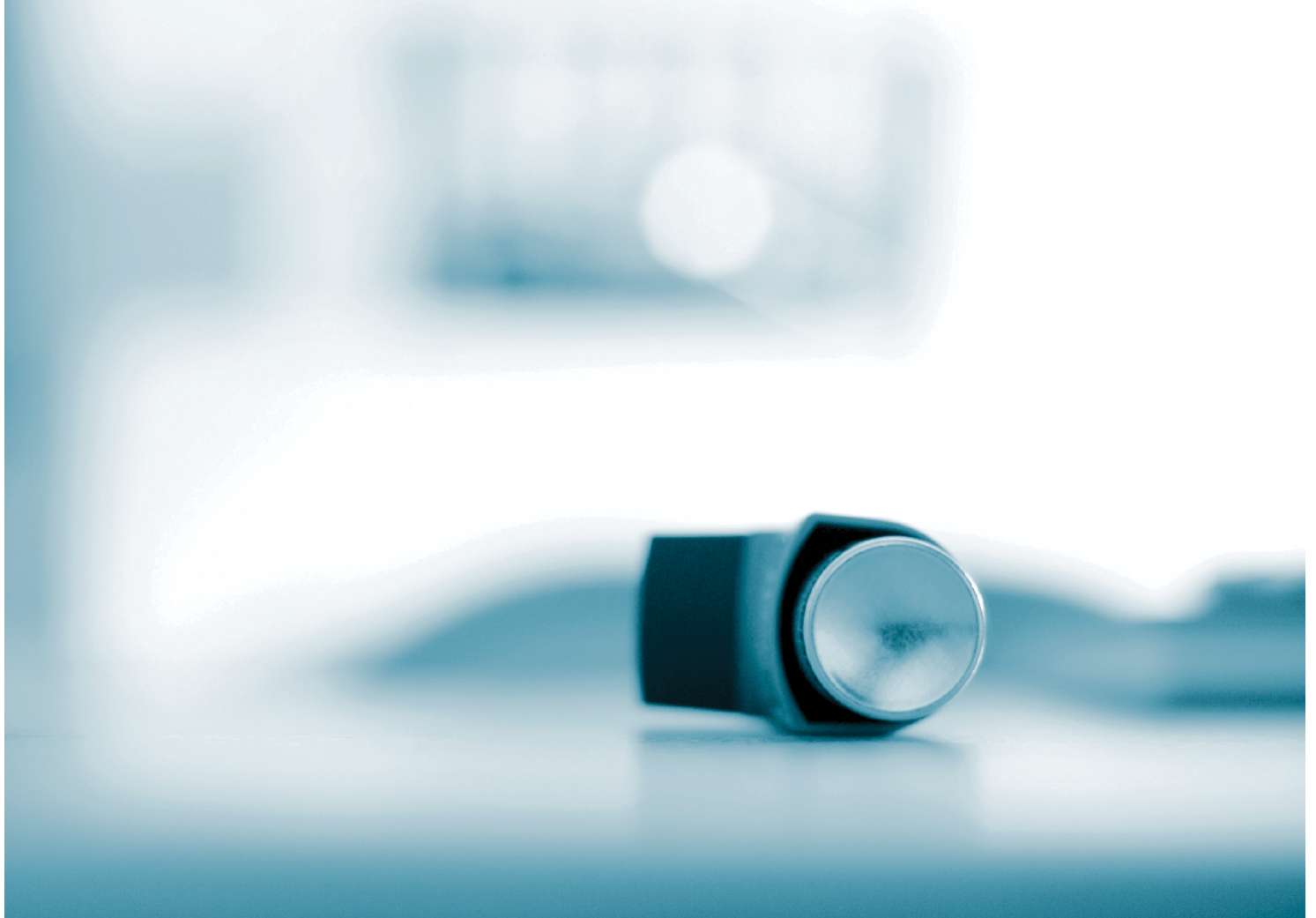
36 *Epilepsy in the UK: Misdiagnosis, mistreatment, and undertreatment? The Wrexham area epilepsy project*, Leach JP, Lauder R, Nicolson A, Smith DF, Seizure (2005) 14, 514-520 Elsevier.

37 *NHS services for epilepsy from the patient's perspective: a survey of primary, secondary and tertiary care access throughout the UK*, Moran N, Poole K, Bell G, Solomon J, Kendall S, McCarthy M, McCormick D, Nashef L, Johnson A, Sander J, and Shorvon, S, Seizure 2000; 9: 559-565.

38 These studies were carried out before the QOF was introduced and these figures are likely to have increased.

39 *Diagnosing refractory epilepsy: response to sequential treatment schedules*, R Mohanraj & MJ Brodie, European Journal of Neurology 2006, 13: 277-282.

Part 3. Shifting the balance of care



Services for people with long-term conditions are improving but there is considerable progress to be made to provide cost-effective, community-based care.



Key messages

- 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.
- People with more than one long-term condition are less likely to be receiving systematic joined-up care across all the services they receive.
- Patients want better information about their long-term conditions and many want a greater involvement in their own care.

Successfully shifting the balance of care needs support and action from all partners

The ageing population and more people with long-term conditions will put pressure on hospitals

50. The *Kerr Report* identifies the main challenges facing the NHS in Scotland over the next 20 years as the ageing population and an increasing number of people with long-term conditions. This will lead to continuing pressures on hospitals in dealing with emergency admissions. One of the main solutions proposed is to shift the balance of care. This

means increasing healthcare provision in local settings, such as in general practice and community hospitals, while reducing healthcare provision in large hospitals, with a focus on preventing emergency admissions. This needs to be accompanied by skilled staff working in the community, good communication among all partners and support for those people who wish to play a more active role in their own care.

51. Exhibit 19 (overleaf) summarises all the bodies involved in long-term conditions care and shows how the balance of care should be shifting. It is a complex picture and success in shifting the balance of care will need support and action from all partners.

52. The SEHD developed an action plan, *Delivering for Health*, in response to the *Kerr Report*. The plan sets out a number of aspirations for the NHS in Scotland for providing more care locally (Exhibit 20 overleaf).

More progress could be made in shifting the balance of care

53. Each NHS board has one or more CHP whose main role is to improve local NHS and joint services through partnership, integration and service design.⁴⁰ The SEHD has given NHS boards responsibility for driving the shift in the balance of care and providing systematic support for people with long-term conditions locally, with CHPs playing a key role. CHPs are expected to bring together all parties involved in providing long-term condition care in their area, for example general practice teams, community pharmacists, hospitals, social work, voluntary organisations, and patients and carers, and take a lead role in:

- easing access to primary care services
- taking a systematic approach to long-term conditions

- providing preventative care
- supporting people at home
- avoiding hospital admissions
- identifying opportunities for more local diagnosis and treatment
- enabling appropriate discharge and rehabilitation
- improving health and tackling inequalities
- improving specific health outcomes.

A clear national framework for long-term conditions would help NHS boards plan and develop local services

54. The challenges set out in the *Kerr Report* are complex and wide ranging. The timescale for implementing the national framework is 20 years, in recognition of the considerable time and effort required by staff in all parts of the NHS to achieve the changes identified. The majority of actions set out in *Delivering for Health* span 2005-07, with some going up to 2010 (Exhibit 21, overleaf).

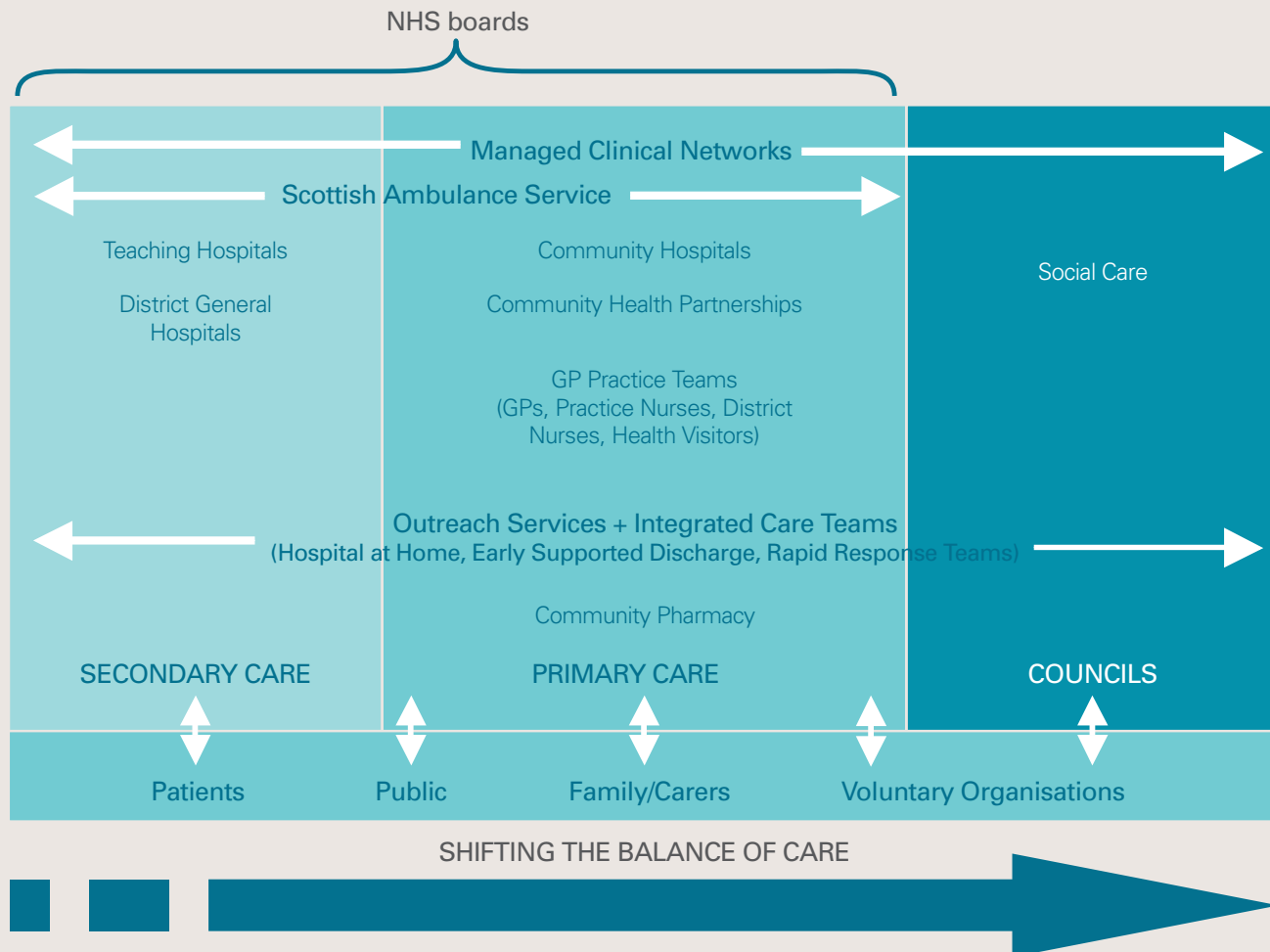
55. *Delivering for Health* stated that the SEHD should develop a national strategy for long-term conditions by 2006. Although various initiatives have been developed at a national level (eg, a model to identify people at risk of hospital admission), the lack of an overarching strategic plan for people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

NHS boards need to do more to shift the balance of care for long-term conditions

56. 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 QOF. The SEHD set timescales for implementing various strands in *Delivering for*

Exhibit 19

Summary of all the main parties involved in long-term condition care



Note: Different parts of the NHS as well as councils, voluntary organisations, patients and their families are all involved in long-term condition care. A shift in the balance of care to address changing healthcare needs will involve moving services and resources from secondary care into primary and social care, with more public and patient involvement.

Source: Audit Scotland 2007

Exhibit 20

The future model of healthcare proposed in *Delivering for Health*

Current view	Evolving model of care
Geared towards acute conditions	Geared towards long-term conditions
Hospital centred	Embedded in communities
Doctor dependent	Team based
Episodic care	Continuous care
Disjointed care	Integrated care
Reactive care	Preventive care
Patient as passive recipient	Patient as partner
Self care infrequent	Self care encouraged and facilitated
Carers undervalued	Carers supported as partners
Low tech	High tech

Source: *Delivering for Health*, SEHD, 2005

Health but not specific targets. In our fieldwork we found little support for setting targets for managing long-term conditions. Targets are being introduced in England where, from 2008, 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.⁴¹

57. Every NHS board in Scotland must prepare a local delivery plan incorporating a number of wide-ranging targets and measures under four high-level objectives collectively known as HEAT.⁴² Boards are held accountable on their progress against the HEAT objectives on an annual basis by the Health Minister. This process is based on information submitted to the SEHD in boards' local delivery plans. A few of the HEAT targets impact on long-term conditions care generally, for example there is a target to reduce emergency inpatient bed days and multiple emergency admissions for people aged 65 and over. There are also a number of health improvement

targets aimed at reducing or preventing long-term conditions.

58. Regardless of whether targets are in place, there is scope for boards to better prioritise developments in managing long-term conditions and encourage more partnership working, in particular between CHPs and the acute sector, to support the development of community services.

Many Community Health Partnerships have still to address key issues around managing long-term conditions

59. CHPs were established from 1 April 2005 onwards and are at varying stages of development. At the time of our fieldwork, many had not addressed key issues around long-term conditions as they had just got their structures in place or, in some cases, were still appointing key personnel. In addition, other structural change at a board level has been going on in some boards which has hampered progress in some CHPs.

60. Some boards and CHPs have specific long-term condition plans, for

example, the three CHPs in Tayside have individual plans which feed into an overall long-term conditions plan for NHS Tayside. Tayside also has a performance monitoring system (TayStat) which incorporates actions from *Delivering for Health* and its long-term condition plan, and clearly identifies progress against each (Exhibit 22, overleaf). In the other NHS boards we visited, there was not such clear and structured monitoring of local strategies for long-term conditions.

Partnership working is helping to shift the balance of care but could be improved

61. Good partnership working is a key factor in shifting the balance of care and improving services for people with long-term conditions, which CHPs should be coordinating locally. But while there are examples of good joint working for particular conditions, services or localities, more needs to be done to make partnership working more effective regardless of where a person lives or what condition they have.

Exhibit 21

Implementation of *Delivering for Health* and associated guidance, 2005-07

Date	Action
May 2005	<i>Building a Health Service Fit for the Future (the Kerr Report)</i> published – a blueprint for service change over the next 20 years.
November 2005	<i>Delivering for Health</i> published – the SEHD's action plan to address the recommendations in the national framework.
February 2006	<i>HDL (2006) 12 Delivering for Health: guidance on implementation</i> – stated what needs to be done, by whom and when, with local, regional and national actions and timescales.
Summer 2006	Boards started to provide quarterly monitoring reports to SEHD on progress against <i>Delivering for Health</i> – these provide high-level information on progress against actions in <i>Delivering for Health</i> . Previously local delivery plans and HEAT targets, which tie in with some of the high-level aims of <i>Delivering for Health</i> , were being used to gauge progress.
February 2007	<i>NHS HDL (2007) 10: CHP Long-term conditions toolkit</i> published – a mandatory tool for CHPs to complete annually, with an action plan to be produced to ensure they are providing systematic support for people with long-term conditions. This was due to be finalised in 2006.

Source: Audit Scotland fieldwork, 2006/07

41 *Our health, our care, our say: a new direction for community services*, Department of Health, January 2006.

42 The four high-level objectives known as HEAT are as follows: Health improvement for the people of Scotland; Efficiency and governance improvements; Access to services; and Treatment appropriate to individuals.

62. 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 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.

63. We found some good examples of CHPs working in partnership with specialist clinicians in hospitals when moving services for a particular condition into the community. Many staff who had been involved in these successful partnerships felt the same principles could be applied to many other long-term conditions. However, generally CHPs were finding it difficult to engage hospital clinicians on a wider basis.

64. There are also some examples of CHPs and social work working well, for example integrated teams and co-location of staff. All of the board areas we visited had joint health and social work teams for preventing hospital admissions and supporting earlier discharges from hospital. However, health and social work staff are still coming up against cultural and organisational barriers, such as budget constraints, a lack of pooling budgets, and different governance arrangements.

65. There is varying engagement by CHPs with voluntary organisations. Usually a local representative from the Scottish Council of Voluntary Organisations (SCVO) sits on individual CHP committees. The level of engagement with voluntary organisations in relation to long-term conditions often depends on what organisations are based in the local area.

66. In our survey of GPs, most reported good working relationships

Exhibit 22

NHS Tayside has an effective system in place to monitor progress against its local strategy for long-term conditions

NHS Tayside was part of a national pilot for the implementation of the principles of citiStat, which is a performance management and improvement system originally developed for the public sector in North America. The resulting system for managing performance (TayStat) is now well established within the board. TayStat is focused around meetings where the board has a key role in monitoring and challenging progress against robust, timely and appropriate indicators focused on key priority areas. At these meetings actions are agreed to resolve any identified problems within agreed timescales.

TayStat includes some of the relevant national and local targets for long-term conditions, for example within *Delivering for Health*, the local long-term conditions plan and several Managed Clinical Networks. Tayside intends to develop this over 2007/08 to include all the relevant objectives and targets relating to long-term conditions and improve monitoring of service improvement against these.

Source: Audit Scotland fieldwork, 2006/07

with secondary care and community pharmacists. Relationships with social work and local charities were not as strong, and the least positive working relationships were reported with the CHPs themselves ([Exhibit 23](#)). Relationships with CHPs were better in some board areas than others, however this is clearly an area where CHPs need to build on improving partnership working.

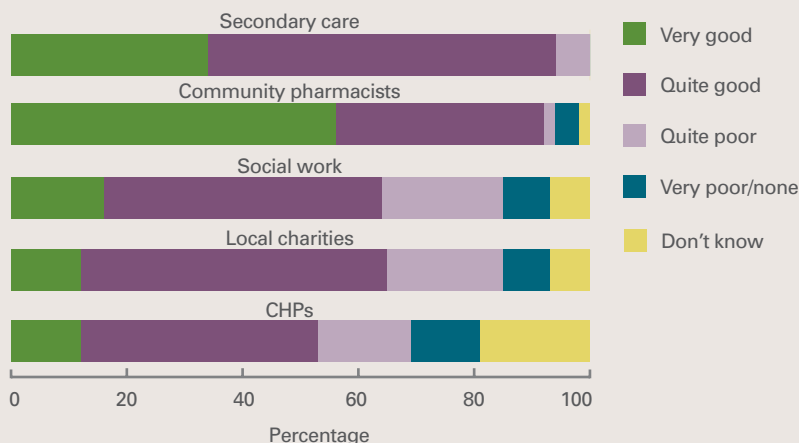
More progress is needed in transferring resources from secondary to primary care

67. The *Kerr Report* predicts, on limited evidence, shifting the balance of care will be cost neutral within the NHS but with more resources directed at services in the community. *Delivering for Health* does not estimate what the cost implications of shifting the balance of care are but states improvements should be made within current spending plans and that the pace of change will depend on efficiency savings and future investment decisions. A national group has now been set up to look at the resource implications of shifting the balance of care.

68. *Delivering for Health* emphasises the need for NHS boards and CHPs to be innovative and redesign

services through collaboration with partners, integrating services and multidisciplinary working. Boards are taking different approaches to shifting the balance of care, for example, redesigning services within existing budgets, increasing investment or development of primary care and closing facilities and reinvesting staff and money into community teams. But there is little evidence so far of any large-scale transfer of resources (including money and staff) from secondary to primary care. Barriers to shifting resources include the significant amount of resources tied up in secondary care and the need to maintain hospital services during periods of change. It is a complex issue that involves more than simply closing wards and freeing up money to spend on community services. This will require guidance and support for NHS boards and councils to develop shared business plans for resource transfer. This may also require some initial development funding.

69. Many of the examples of shifting the balance of care we found across Scotland were pilots or short-term funded projects ([Exhibit 24, overleaf](#)). One of the barriers to securing long-term funding for new services is the lack of proper evaluation of projects which demonstrate their

Exhibit 23**Working relationships between general practice and partner organisations**

Source: GP survey carried out for Audit Scotland, 2006

cost-effectiveness. It is still unclear whether moving services from hospitals into the community affects quality, cost and effectiveness. In the absence of this information, NHS boards are unwilling and unable to make informed decisions on investment in new community services (see Part 2).

To help join up services professionals need access to comprehensive information on patients with long-term conditions but this is not yet available

70. The lack of progress in providing access to comprehensive patient information is seen as a major barrier to developing joined-up services for long-term conditions. If this information was available it would allow general practice staff, other community professionals such as those in community pharmacy, and staff in hospitals to have access to all of the information on care provided to patients.

71. Social work systems are difficult to tie in with NHS systems as they do not collect information by condition or

use the same patient identifier, known as the Community Health Index. There are also issues around data protection and patient confidentiality, for example agreeing what level of social work data that NHS staff should be able to access regarding an individual's social circumstances.

72. Some patient electronic systems for specific conditions – diabetes (SCI-DC) and heart disease (SCI-CHD) – have been developed and rolled out nationally. Local systems are also being developed, for example NHS Tayside is developing its own electronic system for long-term conditions. As electronic systems in Tayside are introduced for individual conditions, these will eventually be linked together into an overall long-term conditions clinical database. In addition to diabetes and CHD, Tayside has an electronic system for COPD. These systems allow both GPs and specialists in hospitals to access more comprehensive information about a patient's care, for example laboratory results, images from scans, and referral letters.

Better links are needed between workforce and service planning

73. As well as affecting how many people are likely to develop a long-term condition, the changing make-up of the future population in Scotland also affects the number of people in the working population who will be available to care for these people. This emphasises the need for effective workforce planning which takes account of how many people will be needed to care for people with long-term conditions, what skills they are likely to require and where they should be located to be most effective.

74. There are a number of new contracts and strategies in place which boards are using to extend and change the roles of some key staff groups to meet the increasing provision of care for people with long-term conditions in the community. These include the nGMS Contract, new Community Pharmacy Contract, Community Nursing Review, and Review of Community Hospitals.^{43 44 45} For example:

- The Chronic Medication Service (CMS) within the new Community Pharmacy Contract will allow community pharmacists to review and manage patients on long-term medication. The CMS was due to be implemented in April 2007 but there were delays in getting the underpinning electronic system in place. The SEHD now estimates that it may not be fully implemented until April 2008.⁴⁶
- A new model is being developed incorporating existing separate community nurse disciplines, for example district nurse and health visitor, into one community health nursing role. This aims to allow nurses working in the community to better address the health needs of the local population.

43 <http://www.communitypharmacy.scot.nhs.uk/documentation.html>

44 *Visible, Accessible and Integrated Care: Report of the Review of Nursing in the Community in Scotland*, SEHD, November 2006.

45 *Developing community hospitals: A strategy for Scotland*, SEHD, December 2006.

46 *NHS Circular: PCA(P)(2007)1: New community pharmacy contract: situation update*, SEHD, January 2007.

Exhibit 24

We found some examples across Scotland of shifting the balance of care.

NHS Ayrshire & Arran

Clinical Decisions Unit (CDU) within A&E at Ayr Hospital – the unit has removed inefficiencies from the investigation process to quickly assess and diagnose emergency patients and discharge them back into the community if possible, rather than admitting them to hospital. This approach has been piloted for patients with eight common presenting symptoms, rather than conditions. There has been a reduced rate of hospital admission for those assessed through the CDU. The unit is to be extended to patients with long-term conditions and COPD will be the first condition piloted.

NHS Borders

Reinvestment of resources into community services – two community hospitals which were no longer fit for purpose were closed. This has allowed NHS Borders to reinvest the money into the community in a more targeted way and transfer the staff from the hospital into community teams where they can more appropriately address the health needs of the local population.

Falkirk Council

Using innovative technology to help people in their own homes – this is being used in the homes of people who may otherwise not be able to live independently. For people with dementia, potential risks can be monitored by fitting sensors and alarms which are linked to a control centre. Similarly for people with epilepsy, tilt monitors and bed monitors can alert the control centre when someone is having a seizure.

NHS Forth Valley

Mental Health Intensive Home Treatment Service – intensive care for people with serious mental illness is provided in patients' homes where possible, and inpatients are discharged earlier with support at home. The development of a community team and new way of working has allowed

NHS Forth Valley to close 15 acute beds in a mental health ward.

NHS Greater Glasgow & Clyde

Community-based COPD services – there is a well established community COPD rehabilitation programme and outreach spirometry service in the city of Glasgow. Unlike other board areas, there is no waiting list for the COPD rehabilitation programme and it is provided in local communities rather than in hospital. The spirometry service is provided by qualified technicians in a number of locations across the city. This ensures good quality testing and diagnosis. In other board areas, general practice staff not confident in carrying out a spirometry test or unsure of diagnosis would have to refer the patient to a respiratory specialist in a hospital clinic.

NHS Highland

Use of local enhanced services in the nGMS contract to develop community services for the diagnosis and management of type 2 diabetes not treated with insulin – almost all GP practices in Highland (excluding Argyll & Bute) have signed up to provide this service. Previously many patients attended clinics held in hospitals, which involved a considerable amount of travel. Work is continuing by specialist staff to provide training to practice staff on the diagnosis and management of patients with type 2 diabetes. The new community service has led to a reduction in waiting times for new referrals to hospital clinics due to a decrease in the overall number of patients attending for regular ongoing review.

NHS Shetland

Specialist staff in the community – Shetland does not have dedicated specialists in the management of many long-term conditions, including COPD and epilepsy. Patients are supported by generic primary care teams, with secondary care input being provided by local consultant physicians who

have a special interest in a number of long-term conditions. Local services in primary and secondary care are supported by specialist services provided by NHS Grampian. Developing the skills of community staff, input from local consultant physicians and close links with colleagues in Grampian has allowed NHS Shetland to fill gaps in care where clinically appropriate, and reduced the need for patients to travel to Aberdeen.

NHS Tayside

Community-based COPD services – specialist COPD nurses provide a community service in GP practices across Dundee. They carry out spirometry, diagnosis and treatment in conjunction with GPs, a dietician and physiotherapists, who all work to a locally developed COPD manual. An electronic management system, which hospital staff can access and add to, is used to record comprehensive information on patients' spirometry readings, medicines and other treatments, and general care. COPD patients in Dundee are now rarely referred to a hospital clinic for diagnosis and hospital admissions have reportedly gone down.

Scottish Ambulance Service

Paramedic – Nurse Practitioner Team – In a nine-month pilot project with NHS Fife, a paramedic and an Emergency Care Practitioner nurse worked together as a team attending 999 calls and out-of-hours home visits. The aim was to reduce the number of people being transferred to hospital using the combined skills of the paramedic and nurse team to treat a wider range of minor illnesses and injuries at the scene. Early analysis suggests that for their cohort of patients, the team managed to reduce the national rate of patients taken to hospital (91 per cent) by more than half, down to 37 per cent. If this service is rolled out across Fife there is scope to reduce the number of hospital attendances by a considerable amount, reducing the pressure on busy A&E departments and treating more patients closer to home.

- There are opportunities for community hospitals to provide a wider range of services to the local population to reduce the need for patients to travel to larger hospitals for specialist care.

75. Some boards have started to think about the workforce planning issues of shifting the balance of care but more needs to be done. Each NHS board is required to produce a local workforce plan which feeds into a national plan for Scotland.⁴⁷ In the national plan, future projections of demands for staff groups are based on figures provided in local plans but not all boards were able to provide all of this information. National estimates for future demand of staff include: a one per cent increase in the medical consultant establishment over the next ten years; a 1.6 per cent increase in Allied Health Professionals (AHPs) and 2.6 per cent increase in assistant AHPs over the same period; and an 8.8 per cent increase in registered nursing and midwifery staff over the next five years. There is no projection for the future requirements for GPs; boards provided little information on this but under the nGMS contract there is no requirement for general practices, as independent contractors to the NHS, to provide data on staffing to NHS boards or to ISD Scotland.

76. In a previous report, Audit Scotland assessed all NHS boards' workforce plans in relation to nursing staff and found that where projections were made there is limited detail on the methods used to calculate them.⁴⁸ Therefore it is unclear to what extent changing demographics have influenced these projections. In the national workforce plan, the SEHD recommends NHS boards improve their forecasting of future demand for staff and that clear links for future demand should be made within local delivery plans.

Exhibit 25

The implications of shifting the balance of care perceived by GPs and practice nurses



77. As more long-term conditions care is provided in the community in the future this will need to be accompanied by a shift in skills and specialist staff, and more training for generalist staff. Boards should start taking these issues into account in their workforce planning.

Not all general practice staff are aware of the current policy for shifting the balance of care

78. Not all GPs and practice nurses are aware of the current policy for shifting the balance of care and improving the management of long-term conditions. We found that only 43 per cent of GPs had read either the *Kerr Report* or *Delivering for Health* compared with 62 per cent of practice nurses; a further 39 per cent of GPs and 27 per cent of practice nurses were aware of at least one of these reports but had not read them; and

18 per cent of GPs and 11 per cent of practice nurses were not aware and had not read the reports. If boards and CHPs are to effectively shift the balance of care, it is important that all staff are aware and supportive of both national and local policies to do this.

Community-based staff need training and support to ensure quality of care is maintained

79. In our surveys, most GPs and practice nurses felt that shifting the balance of care will lead to better quality of care. However, they believe that there will not be an increase in resources to accompany the increased workload this will produce and this will put pressure on practice staff (Exhibit 25). The majority of respondents said that they are treating more patients with long-term conditions in the community;

47 National Workforce Plan for NHSScotland: setting out future supply of staff to meet service needs of NHSScotland, SEHD, December 2006.

48 Planning ward nursing – legacy or design? A follow-up report, Audit Scotland, January 2007.

Exhibit 26

Examples of attempts to maintain the quality of care when shifting services from hospital to community-based services

COPD

During our fieldwork, concerns were raised about the variability of the quality of spirometry carried out in the community by GPs and nurses and that the standard of equipment and level of training varied.

NHS Greater Glasgow and Clyde has overcome this by providing an outreach spirometry service carried out by hospital technicians.

NHS Tayside has set up a community COPD service in Dundee where specialist nurses ensure that spirometry equipment used in GP practices conform to European standards and are calibrated daily. A peer supervision system is in place and graphs showing results of tests can be viewed electronically via the COPD electronic management system. The specialist nurses also carry out regular reviews of people on their COPD registers.

Source: Audit Scotland fieldwork, 2006/07

Epilepsy

There is evidence that lack of specialist knowledge of epilepsy in the community can lead to patients not receiving appropriate treatment or ongoing review.⁴⁹ Epilepsy specialist nurses and voluntary organisation fieldworkers, as well as people with epilepsy, have stressed the importance and value of having specialist advice and support with regards to psychosocial needs. In addition, epilepsy specialist nurses could help to bridge the gap in limited numbers of consultant neurologists, particularly those that specialise in epilepsy.

In the boards we visited in our fieldwork, four had specialist nurses to provide this support (Ayrshire and Arran, Forth Valley, Greater Glasgow and Clyde, and Tayside).

providing early intervention to avoid hospital admissions; and encouraging health promotion among patients with long-term conditions.

80. Specialists in hospitals were generally supportive of providing more care in local settings, however they highlighted training issues for staff in primary care that would need to be addressed in order to maintain good quality care (Exhibit 26).

More community-based staff are being supported to develop special interests

81. Traditionally specialist roles have been based in secondary care. NHS boards are supporting the development of more practitioners (eg, GPs, nurses and AHPs) trained in

an area of special interest so they can provide a wider range of treatments for people with long-term conditions, particularly in community settings. NHS Education for Scotland (NES) is developing an education programme to support the development of these roles across Scotland.

82. Over half of the GPs we surveyed are supportive of the existence and increase in GPs with a special interest. Those not interested in becoming a GP with a special interest said: they enjoy being a generalist and the NHS needs generalist roles; they do not have enough time to study or train to become a specialist; and some said they are too old to become a specialist.

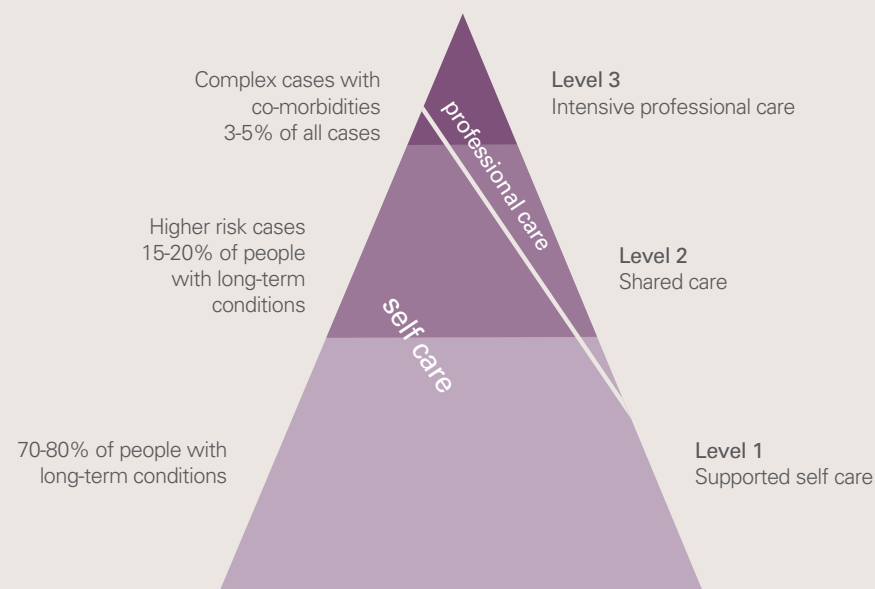
83. From our GP survey, incentives that may attract them to becoming a GP with a special interest include: time to study and learn; funding or resources; adequate or extra training/courses; adequate remuneration; support of practice partners or clinical support; if demand arose from patients in the area; and proven benefits to patient care.

84. The most popular areas that GPs specialise in, or would like to specialise in, are dermatology, diabetes and CHD; and for practice nurses they are diabetes, respiratory conditions and CHD. Practice nurses are much more interested in becoming specialists. NHS boards need to ensure that the development of practitioners with special interests are for conditions where there is local need for specialisation, which should be linked to workforce planning.

The Quality and Outcomes Framework has a role to play in improving the management of long-term conditions

85. In our fieldwork, views varied about the effectiveness of the QOF in improving how long-term conditions are managed. The main points raised were:

- the lack of quality measures, with measures very much focused on clinical outcomes
- argument over what should and what should not be included
- it has helped raise awareness of certain conditions but is not holistic enough
- it does not take into account people with more than one long-term condition
- patients value having regular reviews.

Exhibit 27**Different levels of care for people with long-term conditions**

Source: *Delivering for Health*, SEHD, November 2005

86. Practice nurses are generally more positive than GPs about the impact the QOF has made on managing people with long-term conditions. Around 50 per cent of practice nurses in our survey thought that it has helped to reduce emergency admissions to hospital, compared with just 25 per cent of GPs. The majority of GPs and practice nurses agreed quite strongly that the QOF has a positive impact on the care of people with more than one long-term condition. And most said having a register of patients enables them to monitor patients with long-term conditions, and that providing regular reviews improves their care.

Support for people with long-term conditions needs to be more systematic

87. *Delivering for Health* outlines a model with three levels of care for people with long-term conditions (Exhibit 27):

- **Level 1 Supported self care** (also known as self management)

covers the majority of people with long-term conditions (70-80 per cent). Most of these people are thought to be able to manage their own conditions with appropriate advice and support.

- **Level 2 Shared care** relates to around 15-20 per cent of patients who require additional care and support to manage their conditions.
- **Level 3 Intensive professional care** is a more coordinated and proactive approach known as intensive care management or case management. This approach is required for a small proportion of the population with complex needs, who often have more than one condition (up to 3-5 per cent).

88. In our fieldwork, we examined the extent to which this more systematic approach is being taken in the management of people with long-term conditions. In particular, we looked at progress against self

care programmes, intensive care management and systems for identifying those in most need of intensive care management (known as risk prediction or risk assessment tools). There has been considerable progress in developing risk prediction tools and limited progress in self care and intensive care management approaches.

Patients are being encouraged to take more responsibility for their own care

89. The Long-term Conditions Alliance Scotland (LTCAS) is developing a strategy for self management but this is in early development and there are no clear timescales for completion of this work.⁵⁰ It is expected there will be some generic approaches that can be taken across all long-term conditions, for example good information provided on conditions at diagnosis. However, many conditions have specific issues around self care, for example advice on managing diet to control sugar levels for people with diabetes.

90. We found some examples of small local pilots in self care approaches for specific conditions, for example diabetes, asthma and arthritis, across Scotland. Self care is not happening to a great extent within COPD and epilepsy services. People with COPD taking part in our focus groups and who had attended pulmonary rehabilitation programmes told us they appreciate the education provided which enables them to take more responsibility for their condition.

People with more than one long-term condition are likely to need more intensive care

91. 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. Intensive care management approaches are still being developed and have not

50 LTCAS was formed in May 2006 and is supported by funding from the SEHD. It brings together the hundreds of voluntary organisations across Scotland to address common issues at a national level.

been applied to any great extent in the areas we visited. The SEHD is coordinating the implementation of intensive care management for people with the most complex needs and at risk of hospital admission. The target date in *Delivering for Health* for NHS boards to implement this is 2007.

92. There are a number of small pilots around Scotland testing a model where a key contact in the primary care team (usually a nurse) has responsibility for coordinating the contribution of various professionals involved in a patient's care but this is still in early development. NHS Tayside has piloted a case management approach over the period of a year with each of the three CHPs testing different aspects, such as case finding criteria, comparison with social work care management input, and whether to target patients aged over 40 years or over 65 years. Early findings from the pilot indicate that:

- not all those who benefit from intensive care management are those with high unscheduled hospital admissions
- there are people under 65 who benefit from case management
- patients' quality of life improved and they were more confident about managing their conditions
- the role of coordinating patients' care could be carried out by staff groups other than nurses, eg AHPs or social care staff with sufficient training.

93. Participants in our focus groups reported they now receive regular reviews from their general practice team but the frequency varies. Most told us they find reviews useful as long as they are comprehensive and not just a tick box exercise. For

example, as well as the standard information GPs are required to check for the QOF, patients want to be able to discuss how they are coping generally and discuss any particular issues they may have.

Systems for identifying patients in need of more intensive care are being developed

94. Risk assessment tools are being developed at national and local levels to identify people with long-term conditions in most need of care and support.

95. The Scottish Patients At Risk of Readmission and Admission (SPARRA) tool was developed nationally and can be used at a local level (NHS board, CHP or general practice level) to identify patients aged 65 years and over at greatest risk of emergency inpatient admission.⁵¹ Since this tool was introduced in June 2006, ISD has provided information to almost all CHPs on their patients with regards to their risk of being admitted to hospital based on their previous hospital admission history. Some boards and CHPs are using this information to identify patients suitable for assessment for intensive care management and others are using it to inform service planning.

96. A number of NHS boards have progressed their own risk assessment tools and are currently piloting and testing them (eg, Ayrshire and Arran, Highland and Tayside).

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

97. 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. 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.⁵²

98. The people attending our focus groups described a number of ways their condition had impacted on their lives, wider than the obvious health issues.

99. For those with COPD:

- Most people were no longer able to work.
- Some were unable to do activities they used to enjoy (eg, hill walking, golf).
- Simple activities, such as washing and dressing, take much longer and can be quite tiring.
- Many said they can feel isolated because they are scared to go out on their own in case they become really breathless.

100. For those with epilepsy:

- Many said they have difficulty finding work as some employers were anxious they would have a seizure at work.
- Many are unable to drive because they have had their driving licence withdrawn on medical grounds or they are too scared to drive in case they have a seizure and cause an accident.
- Some felt there was a lot of stigma attached to their condition.
- Some said they lack confidence or experience mood swings because of their seizures.

51 SPARRA: *Scottish Patients At Risk of Readmission and Admission*, Information Services Division, NHS National Services Division, August 2007.

52 *Scottish Household Survey Analytical Topic Report: Characteristics and Experiences of Unpaid Carers in Scotland*, Scottish Executive Social Research, 2006.

101. 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. This condition-specific information should be supplemented with better information about local services. A new approach called Information Prescriptions is being piloted across 20 sites in England: people with long-term conditions or social care needs will receive tailored information which will guide them to relevant information about their condition, for example information about conditions and treatments, care services, benefits advice and support groups. The Department of Health plans to roll out Information Prescriptions across England in 2008.⁵³

Recommendations

- 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 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.
- 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.
- NHS boards should link changing demographics and the impact of shifting the balance of care to workforce projections in their workforce plans.
- NHS boards and CHPs should ensure that all staff are aware and supportive of both national and local policies for 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.

Appendix 1.

Project advisory group membership

Member	Organisation
John Alexander	Senior Manager (Adult Services), Fife Council and Association of Directors of Social Work
Professor Martin J Brodie	Director, Epilepsy Unit, Western Infirmary, NHS Greater Glasgow and Clyde
Hilary Davison	Team Manager, Standards Development Unit, NHS Quality Improvement Scotland
Susan Douglas-Scott	Chief Executive, Epilepsy Scotland
Martin Hill	Modernisation Director, NHS Lanarkshire
Dr Steve Kendrick	Information Services Division, NHS National Services Scotland
Fiona Lornie	Practice Development Nurse for Long-term Conditions, NHS Tayside
Sandra MacNaughton	Primary Care Pharmacy Coordinator, Royal Edinburgh Hospital, NHS Lothian
Gill McVicar	General Manager, Mid Highland CHP and Chair of the Association of Community Health Partnerships
Professor Jillian Morrison	Section of General Practice and Primary Care, Division of Community Based Sciences, University of Glasgow
Helen Mosson	Operational & Performance Improvement Manager, East Ayrshire CHP
Dr Bill Mutch	Medical Director for Board, NHS Tayside
Andrew Powrie-Smith	Head of British Lung Foundation Scotland
Will Scott	Scottish Executive Health Directorates
Dr Soong Tan	Consultant Physician Respiratory Medicine, NHS Lanarkshire
Accounts Commission sponsors	
Owen Clarke	Accounts Commission
Alyson Leslie	Accounts Commission
Peter McKinlay	Accounts Commission

Appendix 2.

Overview of economic analysis

We commissioned health economists at the University of Glasgow to conduct economic modelling to estimate the costs of our two tracer conditions, COPD and epilepsy. The objectives were to estimate:

- the costs of COPD and of epilepsy to the NHS in Scotland at present

- how these would change over time with particular regard to the implementation of *Delivering for Health*, including estimates of how the quality of care may change as a result.

Method used to estimate cost of current service

In [Part 2](#) we provide a breakdown of the estimated direct cost of COPD and epilepsy to the NHS in Scotland. The items included are shown below with a description of how the estimates were obtained.

Day cases and bed days	Day cases where either COPD or epilepsy was the main cause (source ISD). Inpatient bed days where either COPD or epilepsy was the main cause of admission: data were available on admissions, bed days, specialty, NHS board of residence of the patient (source ISD).
Primary care	Costs include estimates of the cost to treat people by a GP or other members of the primary care team, including nurse practitioners and community physiotherapists. Previous research studies were used for this: <ul style="list-style-type: none"> • For COPD – <i>The burden of COPD in the UK: results from the Confronting COPD survey</i>, Britton M, Respiratory Medicine 2003; 97 (Supplement C): S71-S79. • For epilepsy – <i>Uptake and costs of care for epilepsy: findings from a UK regional study</i>, Jacoby A, Buck D, Baker G, McNamee P, Graham-Jones S and Chadwick D, Epilepsia 1998; 39: 776-786. This is an older study conducted in England. The assumption is that the results can be generalised across place and time.
Outpatients and A&E	Recent data were not available for the review and so the studies referred to in relation to primary care (above) were used.
Prescribing	Drugs prescribed for COPD generally could have been prescribed for other conditions. Only one, Tiotropium (Spiriva), is licensed solely for use in COPD and data refer to it. No drug is used solely for epilepsy. The estimate of epilepsy prescribing was done using a research study in Tayside where an examination of GP lists found that 62 per cent of patients taking drugs that could be prescribed for epilepsy were taking it for that condition. ⁵⁴ The data include children, whereas our review concentrated on adults, and the rate of prescribing may differ for adults and children. Unfortunately it was not possible to separate adult and children's prescribing data. The data have been applied to total epilepsy prescribing in Scotland and to each board.
Other	This mainly includes laboratory and diagnostic tests. The cost of scans and tests for epilepsy were estimated using the same study that provided our estimates of epilepsy data (above).
Population estimates and average costs	Estimates of the number of people with COPD and epilepsy in Scotland were done using ISD data on prevalence – defined as the number of people registered as having a condition. Since not everyone is registered with a GP or registered as having long-term conditions such as COPD or epilepsy, the data were adjusted accordingly.
Cost per patient	The unit costs used (eg, for cost per bed day, cost per GP contact) were not specific to each board, instead standard unit costs for Scotland were applied. ⁵⁵ For example, the Scottish average cost per bed day for all boards was multiplied by the number of bed days specific to that board. The differences in cost per patient across boards result from differences in use of services and the number of patients.

54 *Implementation strategies for a Scottish national epilepsy guideline in primary care: results of the Tayside Implementation of Guidelines in Epilepsy Randomized (TIGER) trial*, Davis J, Roberts R, Davidson DL, Norman A, Ogston S, Grimshaw JM, Davey P, Grant J, Ruta D. Epilepsia. 2004 Jan;45(1):28-34.
55 *Unit Costs of Health and Social Care 2006*, Personal Social Services Research Unit, University of Kent, 2006.

Appendix 3.

Focus groups with people with COPD or epilepsy

The following qualitative research was conducted with patients in the sample board areas.

NHS board area	Condition	Format	No. of participants	Date
Ayrshire & Arran	COPD	Focus group	16	November 2006
Borders	Epilepsy	Focus group	13	December 2006
Forth Valley	COPD	Focus group	16	November 2006
Greater Glasgow & Clyde	COPD	Pilot focus group	14	May 2006
	Epilepsy	Focus group	9	December 2006
Highland	Epilepsy	Telephone interviews	2	January 2007
Tayside	COPD	Focus group	17	November 2006
Shetland	Epilepsy	Pilot focus group + individual interviews	4 + 4	May 2006

Research Ethics Committee approval was obtained to contact people on GP registers in the six main NHS board areas that we sampled; we asked CHPs to help enlist the support of GPs, and participating general practices sent out packs on our behalf to people on their COPD or epilepsy registers.⁵⁶ The packs contained information about the work, along with a consent form and a pre-paid envelope for patients to reply to us if they were interested in attending. Exceptions to this included:

- The COPD focus group held in Glasgow, where participants were recruited through the British Lung Foundation: seven were from Greater Glasgow and Clyde; others came from Kilmarnock, Fife (four people), Midlothian, and Perth.
- The epilepsy focus group in Glasgow was supplemented with contacts obtained through Epilepsy Scotland, which asked callers to its helpline if they would be interested in taking part.
- The epilepsy focus group on Shetland was recruited through the local patient support group.
- We were unable to get sufficient support to recruit a focus group in Highland and instead used two contacts supplied by the North of Scotland Epilepsy MCN.

⁵⁶ There are a number of Research Ethics Committees across Scotland, and the rest of the UK, overseen by the National Research Ethics Service and regulated by the UK Ethics Committee Authority.

Appendix 4.

Overview of surveys with GPs and practice nurses

As part of our review of the management of long-term conditions, we commissioned a market research organisation, BMRB, to carry out a telephone survey among GPs and practice nurses to find out the following with reference to *Delivering for Health*:

- current ways of working
- how these ways of working are changing
- attitudes towards proposed new models of care for people with long-term conditions.

The survey was carried out in the same six NHS board areas in which we carried out fieldwork. A total of 258 GPs were interviewed across the six NHS board areas. The response rate varied between 31 per cent and 37 per cent by NHS board area. The overall response rate among GPs was 33 per cent.

NHS board	No. of practices	No. of practices with 5 or more GPs	Total no. of GPs available for GP sample ⁵⁷	Number of GPs interviewed	Response rate
Ayrshire & Arran	57	35	92	34	37%
Borders	24	13	37	12	32%
Forth Valley	57	22	79	26	33%
Greater Glasgow & Clyde	256	86	342	106	31%
Highland	101	33	134	42	31%
Tayside	67	42	109	38	35%
Total	562	231	793	258	33%

The response rate among practice nurses varied between 19 per cent in Highland and 70 per cent in Tayside: a total of 200 were interviewed across the six sample NHS board areas, giving an overall response rate of 36 per cent.

NHS board	No. of practices	Number of practice nurses interviewed (one per practice)	Response rate
Ayrshire & Arran	57	27	47%
Borders	24	9	38%
Forth Valley	57	22	39%
Greater Glasgow & Clyde	256	76	30%
Highland	101	19	19%
Tayside	67	47	70%
Total	562	200	36%

More detail on the methods and results for the surveys are included in the supplement to this report.

57 The total number of GPs available for the GP sample is the sum of the previous two columns: BMRB attempted to interview one GP in practices with less than five GPs and two in practices with five GPs or more.

Appendix 5.

Self-assessment checklist for NHS boards

The checklist on the next few pages sets out some high-level statements about managing long-term conditions based on issues raised in this report. Boards (with their CHPs) should assess themselves against each of the statements and consider which statement most accurately reflects their current situation:

- not in place and action needed
- not in place but action in hand
- in place but needs improving
- in place and working well.

This approach will enable boards to identify what action needs to be taken forward.

Self-assessment of managing long-term conditions

The last column in the checklist can be used to record sources of evidence, supplementary comments to support your assessment or to highlight areas of interest, etc.

Issue	Assessment of current position				Comment to support or explain your statement
	No – action needed	No – but action in hand	Yes – in place but needs improving	Yes – in place and working well	
<p>Is the full cost of long-term conditions available? If not:</p> <ul style="list-style-type: none"> Where are the major gaps, eg within primary care, hospitals, prescribing data, and how can these be addressed? Can systems being developed in other board areas be adapted for use locally? 					
<p>Is there information on the activity, cost and quality of services for people with long-term conditions?</p> <p>Are new service developments being properly evaluated, including assessing cost-effectiveness?</p>					
<p>Is progress being made in shifting the balance of care with regards to:</p> <ul style="list-style-type: none"> CHPs identifying measurable service improvements, according to local needs? CHPs completing the long-term conditions toolkit and producing an action plan? 					

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	No – action needed	No – but action in hand	Yes – in place but needs improving	Yes – in place and working well	
<p>Is the NHS board prioritising:</p> <ul style="list-style-type: none"> • shifting the balance of care? • long-term conditions? <p>Have CHPs within the board addressed the key issues around managing long-term conditions? For example:</p> <ul style="list-style-type: none"> • Do all CHPs have long-term conditions plans in place? • Do all CHPs have a lead person for long-term conditions? • Are sufficient systems in place to monitor progress against national and local strategies for long-term conditions? <p>Is partnership working being used effectively to help shift the balance of care? For example:</p> <ul style="list-style-type: none"> • Have CHPs made good links with other parts of the organisation and other partners? • Are there good practice examples of partnership working for long-term conditions that can be used to improve the management of other conditions? 					

Managing long-term conditions

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ISBN 978 1 905634 62 0 AGS/2007/3

This publication is printed on uncoated paper, made from 100% post consumer reclaimed material.