



SCOTTISH DIABETES SURVEY 2002

SCOTTISH DIABETES SURVEY MONITORING GROUP

April 2003



FOREWORD

The challenge for NHS Scotland is to provide high quality diabetes care to all patients with diabetes. The SIGN guidelines have clearly documented the evidence base for good clinical care. Improved outcomes for patients with diabetes can be achieved by lifestyle modification and other interventions to lower raised blood glucose, blood pressure and cholesterol. These interventions, together with effective screening programmes will have a major impact on reducing coronary heart disease, stroke, kidney disease and visual impairment in people with diabetes. This challenge needs to be met not only for the estimated 153,000 patients who currently have diabetes, but also for the people developing diabetes in the future; it is estimated that the number of people with diabetes will double within the next 10 to 15 years.

With publication of the Scottish Diabetes Framework and more recently HDL(2002)81 (Developing services for people with diabetes), the Scottish Executive has demonstrated its commitment to improving the health of people with diabetes. One of the key steps in achieving improved care is to improve the quality and availability of data by establishing regional clinical information systems that support high quality clinical care. The creation of an accurate picture of diabetes care at regional and national level presents a considerable challenge.

There is no doubt that in the absence of effective IT to support clinical care, the task of compiling data is time consuming and difficult. The sometimes heroic efforts of clinical and administrative staff to collate the data necessary for the Diabetes Survey submission is both the reason why Scotland has been able to make such progress with diabetes register development and a testament to the enthusiasm and commitment amongst the diabetes community to improve diabetes care in Scotland. The implementation of the SCI-DC clinical and network systems in each NHS Board area will greatly reduce the effort involved in data collection and analysis. The burden of data collection will continue until SCI-DC is implemented. This will not be wasted effort however, if the systems used to collect the information in each area is designed with SCI-DC in mind. The use of up to date information collected for the survey to populate the SCI-DC system will expedite and ease implementation of this new system.

On behalf of the Monitoring Group I would like to thank all those who have helped to make this report possible. I would like particularly to thank David Cline the Secretary of the Group who has worked very hard to prepare this report and Professor Andrew Morris who chaired the Scottish Diabetes Survey Monitoring Group until his appointment as Chairman of the Scottish Diabetes Group in March 2002. I have greatly appreciated their continuing support and advice.

Dr John McKnight

John A Makinght

On behalf of the Scottish Diabetes Survey Monitoring Group

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Executive Summary

- This report presents the results of the 2002 Scottish Diabetes Survey. This survey provides important information on progress towards our goal of improving diabetes care across all of Scotland.
- Care of people with diabetes spans the primary and secondary care health care sectors. It is therefore an exemplar of a disease where multi-disciplinary, integrated care is essential.
- There is evidence from large randomised controlled trials in Type 1 and Type 2 diabetes that good diabetes treatment (e.g. control of blood pressure, glycaemic control and cholesterol) reduces the risk of complications.
- Considerable effort has been devoted to developing the infrastructure necessary to deliver high
 quality diabetes care in Scotland. Key planks of this work include the Scottish Diabetes
 Framework, clinical standards for diabetes published by NHS Quality Improvement Scotland,
 clinical guidelines published by SIGN, the Scottish Diabetes Core Dataset, and the work of SCI-DC
 to implement a national diabetes IM&T solution.
- In this Scottish Diabetes Survey 2002 we report:
 - □ 14 of 15 NHS Boards submitted data for the Survey.
 - There are 103,835 patients with known diabetes in Scotland recorded on local diabetes registers. This represents 2.03% of the population.
 - Registered prevalence ranged from 0.46% to 3.53% over health board areas. The explanation for this variance is that many NHS Boards do not as yet have comprehensive diabetes registers that cover their whole population. A number of areas have embarked on a major process of validating register data; these exercises were incomplete by the 2002 Survey submission deadline. It is anticipated that the widespread introduction and use of the SCI-DC Network system will enable the development of comprehensive registers.
 - 84% of records were associated with use of the Postcode, and Community Health Index Number (CHI) was recorded in over 90% of records in eleven areas.
 - There appears to be an excess of Type 1 and Type 2 diabetes in males. The reasons for this need to be explored but could include excess cardiovascular risk in females with diabetes.
 - 81% of patients had an HbA1c test recorded.
 - 60% of patients had a record of eye screening recorded on the register in the preceding 15 months and a further 14% were screened greater than 15 months ago. This is a significant increase compared to the provisional survey of 2001.
 - Prevalence of blindness was 1% and recorded renal failure 0.5%.
 - 8,374 registered patients (NHS Board range 4.5-9.9%) have suffered a previous myocardial infarction and 3,848 (0.6-7.2%) have undergone revascularisation.
- The results of this Survey demonstrate the enormous amount of work being undertaken to provide diabetes care in Scotland. There is clear evidence of positive developments in diabetes care occurring in most NHS Boards in Scotland.
- As with the 2001 Survey, the 2002 Survey shows an information system in transition.
 Comprehensive, robust data at the touch of a button is not here yet. In the interim, the reality for
 most services is ad hoc data collation and partial returns. Improving the quality of data and the
 ability to collect information easily is largely dependent on the SCI-Diabetes Collaboration, an IT
 system that will support integrated diabetes care in NHS Scotland. The full implementation of this
 system is eagerly awaited.

Targets

The Survey Report highlights a number of targets for the 2003 Survey. Whilst the expectation is that the quality and quantity of data will improve across all areas, the Monitoring Group wishes to draw particular attention to a few areas where it is considered there is scope to make significant progress.

At least 90% of records include a CHI number. (paragraph 22)

At least 95% of records include a full postcode. (paragraph 24)

All records include a record of HbA1c. (paragraph 36)

At least 65% of records include a recording of BMI. (paragraph 38)

The Scottish Diabetes Framework identifies eye care as one of the 'first stage priorities' and has set a target that all people with diabetes should have their eye status (retinopathy) recorded by September 2003. (paragraph 40)

INTRODUCTION

Background

- 1. The importance of robust data to support clinical care was recognised in the *Scottish Diabetes Framework* ⁽¹⁾ which included 'IM&T and Diabetes Registers' as one of the first stage priorities. In addition, the clinical standards for diabetes care in Scotland developed by NHS Quality Improvement Scotland (formerly the Clinical Standards Board for Scotland) included as the first standard the requirement for areas to have "an up to date electronic population clinical management system of all people with a recorded diagnosis of diabetes in the area". ⁽²⁾
- 2. An agreed dataset provides a 'common currency' to ensure consistency of definitions and allow data to be shared between different IT systems. The significance of this has been acknowledged by the diabetes community in Scotland for a number of years and concerted efforts have been made to develop an appropriate dataset since the mid-1990s. In March 1996, the Scottish Intercollegiate Guidelines Network (SIGN) published "a recommended minimum data set for collection in diabetic patients" (SIGN 4). This was updated in June 1998 (SIGN 25). Recognising that the SIGN minimum dataset focused largely on outcomes of diabetes care, a CRAG Working Group on IT to Support Shared Care in Diabetes extended the dataset to include items for clinical management. This dataset was published in September 2000. Building upon this work, the SCI-DC team, in conjunction with ISD, developed *the Scottish Diabetes Core Dataset* which was published at the start of 2003.
- 3. The Diabetes Registers and Diabetes IT Systems Steering Group, (a CRAG working group which reported in 1999) recommended the establishment of a national diabetes register. The CRAG Working Group on IT to Support Shared Care in Diabetes, which followed in 2000, strongly supported this proposal both as a mechanism to monitor progress against the St Vincent targets ⁽⁷⁾ and also as a spur to the establishment of local diabetes registers. The work of these groups led, in September 2000, to the Scottish Executive issuing a Health Department Letter-HDL (2000)12 *Scottish Diabetes Survey*. ⁽⁸⁾ This stated:-

"The Scottish Executive remains committed to improving the health of patients with diabetes. One of the key steps in achieving this objective is to improve the availability of data, particularly as many of the complications of diabetes can be prevented or delayed by effective monitoring of diabetic patients. This Circular outlines plans to compile a national picture of diabetes in Scotland through the central collation of information on diabetic patients and sets out the actions required by Health Boards, Trusts and individual clinicians."

- 4. In order to oversee the development and to evaluate the output of the national survey a Scottish Diabetes Survey Monitoring Group was established; (the membership is detailed in Annex A). The Group's remit is to:
 - (a) Monitor and provide advice on the establishment and development of the Scottish Diabetes Survey. Comment on the quality of (i) the data; and (ii) the systems used by Health Boards and Trusts to provide the data.
 - (b) Ensure that data submitted for inclusion in the national diabetes register conforms to all data protection and data security requirements.
 - (c) Evaluate, on the basis of the Scottish diabetes survey, the progress of Health Boards in delivering diabetes services to their population and monitor Scotland's performance in meeting the St Vincent Declaration targets.
 - (d) Report to the Chief Medical Officer.
- 5. The Scottish Executive established the Scottish Diabetes Group in March 2002 to support and monitor the implementation of the *Scottish Diabetes Framework*. At this time, in order to ensure integration of national diabetes initiatives, the Scottish Diabetes Survey Monitoring Group became a subgroup of the Scottish Diabetes Group.

6. A 'provisional' Survey was undertaken in 2001 and a report published in November 2001. (9) This 2002 Survey demonstrates some significant improvements on 2001, but again the Survey represents 'work in progress'. The intention to implement effective IT as part of the SCI-DC programme (Scottish Care Information Diabetes Collaboration) is widely welcomed and will significantly ease with burden upon those charged with collating data for the Diabetes Survey.

The Purpose of the Scottish Diabetes Survey

- 7. The purpose of the survey was set out in HDL(2000)12:-
 - (a) To improve patient care by encouraging better monitoring of diabetic patients in order to provide a more effective response to the complications of diabetes.
 - (b) To allow Scotland's progress towards achieving the St. Vincent Declaration Targets to be monitored and provide evidence to show whether or not Scotland is achieving the targets.
 - (c) To enable the standards of care of patients with diabetes to be monitored between Health Boards and over time.
 - (d) To allow analysis of the Scottish diabetic population by, for example, age or deprivation category.
 - (e) To provide data to support and encourage the implementation of best practice, for example as set out in SIGN guidelines.
 - (f) To provide data to inform clinical governance.
- 8. The intention remains to undertake the survey on an annual basis. However, as the HDL noted:
 - "IT developments may provide more effective solutions than an annual snapshot survey and service developments may demand other approaches. Evaluating the technology, methodology and the content of the survey will be a part of the Scottish Diabetes Survey Monitoring Group's remit." (8)
- 9. It is worth underlining that a key intention of the Survey is to promote the development of local diabetes systems and that one of the most important roles of the Survey is to monitor progress towards this objective.
 - A key driver for the Scottish Diabetes Survey is the wish to support and encourage the establishment of effective local diabetes systems which work to improve patient care and assist service delivery. To this end, the national survey is envisaged as a collation of returns from local area registers. However, it is acknowledged that some Health Board areas have more developed systems than others. The expectation is that the survey will fill out over time, i.e. it may take a number of years before the survey is comprehensively populated. (8)
- 10. The HDL also highlighted that the short-term goal of delivering data for the Survey should not detract from the longer term goal of implementing an effective clinical management system. This should ensure that NHS Boards do not feel compelled to divert resources from the implementation of clinical systems in order to capture data manually for the Survey. However, it also means that during this transition phase, (until comprehensive clinical systems are in place and populated with data), the Scottish Diabetes Survey will be a measure of the completeness of coverage of effective IT at least as much as a measure of the outcomes of diabetes care. The encouraging progress of SCI-DC in the development and roll out of SCI-DC Clinical (a hospital clinic system) and SCI-DC Network (a population register) will help significantly to ensure that effective diabetes clinical management systems are available throughout Scotland.

Data confidentiality and consent issues 2002

11. The 2002 Survey has not been hampered by concerns or doubts about the context of consent because, in accordance with a decision made in 2001, the data are, once again, anonymised and aggregated with no raw data being submitted for analysis.

12. Since the publication of the 2001 Diabetes Survey, the Confidentiality and Security Advisory Group Scotland (CSAGS) has produced guidance in relation to consent. In essence, implied consent is sufficient to share data for purposes of direct clinical care but further consent would be required to utilise named data beyond this boundary. There is an intention to develop a system of acceptable anonymisation (psueudonymisation) so that linkage analysis will remain possible but without the need to transmit identifiers. However, this mechanism has not been established. Until this is in place – and is proven to work satisfactorily – the Scottish Diabetes Survey will not collect individual data.

Shetland (22.4)Orkney (19.5)WI (27.2)Gramp High (523.4)(208.6)Tay Fife A&C (350.4)(423.5)Loth (783.6)**GGHB** (904.4)Lan Bord 562) (106.9)D&G A&A (373.4)

Figure 1: Map of Scotland showing NHS Board populations (000s)

RESULTS

Overview

13. Each NHS Board was asked to submit data to the Monitoring Group by 30 September 2002. Data was submitted by 14 boards. No data was submitted from Orkney and so 2001 survey data has been used throughout. It is clear that during 2002 most areas were in a period of

development - establishing registers, implementing clinical systems and collating and validating data. The net result is that the 2002 Survey is a record of consolidation rather than significant advance. Nevertheless, it is encouraging that the data which were submitted for the 2002 Survey are more robust than the data available in 2001.

14. All figures shown in this report represent percentage information for those patients registered and included in the survey. The percentage information shown therefore overestimates the actual screening performance in any area. The amount of this overestimate is determined by the prevalence of registered diabetes compared to the true prevalence of diabetes in any area. Thus, those areas which have a high prevalence of registered diabetes may seem to have similar screening performance to those of other areas when in fact they are covering their population in a far more robust way. In the 2003 survey the Monitoring Group intend to use the estimated prevalence of diabetes in each area, corrected for population demographics, and use these figures to produce more meaningful comparisons across Scotland.

Prevalence of diabetes and prevalence of registered diabetes

- 15. The 2002 Scottish Diabetes Survey identified 103,835 people with diabetes in Scotland.
- 16. The prevalence of diabetes and the number of people reported on local diabetes systems and reported to the Scottish Diabetes Survey are not yet synonymous. The gap between these two figures will not begin to close until diabetes clinical management systems are implemented and in use throughout Scotland. Even then, there are always likely to remain some people with diabetes who have not been diagnosed and therefore are not known to the health service. Clinical management systems can only ever be a record of diagnosed diabetes; it is a matter of research to calculate how many people remain undiagnosed. As noted in last year's report, estimates of the overall prevalence of clinically diagnosed diabetes in Europe based on published studies suggested a prevalence of approximately 3% in 1997. Projections indicated an increase to around 3.6% by 2000 and to over 4% by 2010. (11)
- 17. Acknowledging that the true prevalence may be around 3.6%, using figures from Tayside, which is recognised in Scotland as having the most accurate diabetes register, it is estimated that about 3% of the Scottish population have been diagnosed as having diabetes; that is, over 150,000 people. Table 1 looks at the picture across Scotland if this estimate (3%) is correct. The expected figures for individual areas has been calculated by applying national age-specific rates for diabetes to NHS Board populations. Differences in the expected rate between NHS Boards reflects differences in age structure only. This expected rate does not take account of sex, ethnicity or deprivation which will also have an influence on the prevalence. Table 1 shows that two areas have already exceeded this expected prevalence. This is perhaps evidence that our estimate of 3% is too low. It is recognised that more sophisticated estimates of prevalence are required and the Monitoring Group recommends that work be commissioned to develop more accurate ways of deriving figures.
- 18. The box below summarises the ways in which registers may over- or under-estimate the number of patients.

Potential reasons for incorrect ascertainment

Possible reasons for **highe**r than expected figures:-

- Duplicate entries/patients with multiple records (perhaps due to name change or moving house)
- Inclusion of patients who have moved out of the area
- Inclusion of patients who have died

Possible reasons for **lower** than expected figures:-

- People with diabetes undiagnosed
- Patient data in patient record not included on local register

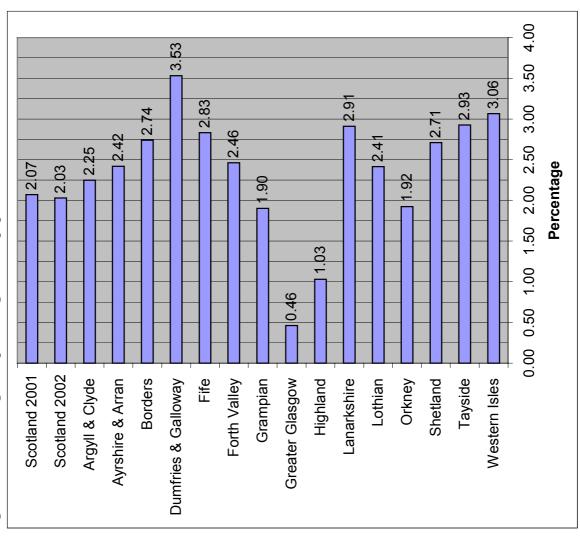
Table 1: Expected prevalence of diabetes in Scotland 2002

	Population (a)	% of Scottish population	Expected pop. with diabetes Age std rate/100 pop (b)	Expected pop. with diabetes Age std (Number)	Registered people with diabetes (2002 SDS)	Estimated pop. with diabetes registered by September 2002
Scotland	5,114,600	100.0%	3.00	153,438	103,835	%L'. 12%
1 Argyll & Clyde	423,500	8.3%	3.06	12,940	9,522	73.6%
2 Ayrshire & Arran	373,400	7.3%	3.16	11,802	9,026	76.5%
3 Borders	106,900	2.1%	3.44	3,678	2,929	%9.67
4 Dumfries & Galloway	145,800	2.9%	3.47	5,057	5,150	101.8%
5 Fife	350,400	%6.9	3.06	10,724	9,920	92.5%
6 Forth Valley	278,000	%5.5	2.99	8,318	6,845	82.3%
7 Grampian	523,400	10.2%	2.92	15,309	5,726	37.4%
8 Greater Glasgow	904,400	17.7%	2.87	25,984	4,191	16.1%
9 Highland	208,600	4.1%	3.16	6,590	2,156	32.7%
10 Lanarkshire	562,000	11.0%	2.85	16,027	16,358	102.1%
11 Lothian	783,600	15.3%	2.84	22,268	18,917	85.0%
12 Orkney	19,480	0.4%	3.24	631	377	29.7%
13 Shetland	22,440	0.4%	2.83	634	809	%6.56
14 Tayside	385,500	7.5%	3.25	12,546	11,277	%6.68
15 Western Isles	27,180	%5.0	3.42	930	833	%9.68

^a Estimated population figures at 30 June 2000

^b expected figure has been calculated by applying national age-specific rates to NHS board population. Differences in expected rate between NHS boards reflects differences in age structure only. The rate does not take account of sex, ethnicity or deprivation which will also have an influence on the prevalence.

Figure 2: Diabetes register: percentage of total population



in ascertainment have been identified by NHS Boards it is population have been identified as having diabetes. As gaps unsurprising that this recorded percentage is less than the certain areas have only been able to identify cases in subsections of their populations. A number of Boards are currently providing data predominantly for patients seen in 3lasgow reflects the fact that these data are based on three In the 2002 Scottish Diabetes Survey 2.03% of the Scottish predicted prevalence of diabetes in Scotland. In particular, secondary care. The very low percentage of cases in Greater Local Health Care Co-operative areas; figures for Grampian exclude significant areas of the region; and Highland data ncludes only patients seen in secondary care. The Scottish Diabetes Survey is intended to be a survey of NHS Board oppulations, as each board is responsible for the diabetes care of all patients in their areas. Results are therefore presented based for populations. However, it is anticipated that over ime ascertainment will improve and the survey will more accurately reflect population prevalence. 19.

20. The proportion of the population identified as having diabetes in the Survey ranged from 0.46% to 3.53% in different health board areas. By standardising for age the effects of different age structures in the populations of different health board areas can be taken into account (figure 3). This still shows considerable variation in proportion of the population recorded as having diabetes throughout the country. Most of this variation is likely to be due to differences in case ascertainment and the maturity of the register in each area. These marked variations between areas should reduce over time as registers develop.

3.50 3.00 2.50 Prevalence rate 2.00 1.50 1.00 0.50 0.00 A & A Lothian A&C Lan D & G Grampian Highland Orkney Tayside <u>×</u> Fife ₹ ලි Shetland Borders Scotland

Figure 3: Diabetes register: age-standardised prevalence by NHS Board

Note: Glasgow - prevalence has been calculated using the population of the 3 LHCC's.

21. Differences in the completeness of local registers inevitably impacts on the registered prevalence for Scotland as a whole. As the largest board in Scotland, the impact of Greater Glasgow is particularly marked. The figures submitted by Greater Glasgow for the 2002 Survey only include data from three LHCC's in South Glasgow, which together provide care to a little over a fifth of the Glasgow total (192,374 out of 904,400). These data have been collected in the course of implementation of the Glasgow Diabetes Project, and therefore the data currently available reflects the current stage of the project. The project is now being extended to the North of Glasgow and data will be collected from practices in the north for the first time. It is anticipated that the submission in 2003 will include data for the south and a large part of the north of Glasgow. The registered prevalence in South Glasgow 2.18%. However, adding in the population for the rest of Glasgow reduces the registered prevalence to only 0.46%. If the figures for South Glasgow were reflected across the whole board area the registered prevalence for Scotland would be 2.36%.

Community Health Index (CHI)

- 22. The Community Health Index (CHI) is a unique patient number that enables records and results to be linked to produce a single patient record. Widespread use of the CHI has significant benefits in terms of administrative efficiency and patient safety. The CHI is also essential for the development of clinical management systems.
- 23. Because of the importance of CHI, the Monitoring Group in its last report set a target that all areas should aim to achieve at least 90% of records including a CHI number. We report this year that 11 areas reached the target; eight areas achieving over 95%. The overall percentage increasing from 66.6% to 82.4%. The target of 90% remains for 2003.

100 90 80 70 percentage 60 50 40 30 20 10 A & C Borders A & A D & G Scotland 2002 Fife Lan Lothian Tayside GG Orkney Scotland 2001 ₹ Grampian Highland Shetland

Figure 4: Diabetes register: percentage with CHI

Note: Shetland - No data submitted

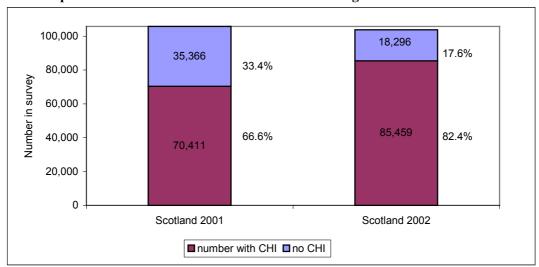


Figure 5: Comparison - Scotland 2001 & 2002. Number on register with CHI

Table 2: Diabetes register - number on register with CHI

	Total no.	% with CHI
Scotland 2001	70,411	66.6%
Scotland 2002	85,459	82.4%
Argyll & Clyde	9,522	100.0%
Ayrshire & Arran	8,541	94.9%
Borders	2,897	98.9%
Dumfries & Galloway	4,721	91.6%
Fife	9,786	99.0%
Forth Valley	6,845	100.0%
Grampian	5,570	97.3%
Greater Glasgow	4,061	96.9%
Highland	1,481	68.7%
Lanarkshire	3,208	19.6%
Lothian	16,395	86.7%
Orkney	377	100.0%
Shetland	0	0.0%
Tayside	11,266	99.9%
Western Isles	789	94.7%

Table 3: Diabetes register - number included in survey with postcode

	Full po	stcode	Partial _J	postcode	Missing	postcode
Scotland 2001	93,682	88.6%	3,301	3.1%	8,794	8.3%
Scotland 2002	91,689	88.3%	907	0.9%	11,187	10.8%
Argyll & Clyde	9,518	100.0%	0	0.0%	4	0.0%
Ayrshire & Arran	8,811	97.9%	0	0.0%	187	2.1%
Borders	2,929	100.0%	0	0.0%	0	0.0%
Dumfries & Galloway	4,787	92.8%	42	0.8%	327	6.3%
Fife	8,998	91.1%	28	0.3%	855	8.7%
Forth Valley	6,385	93.3%	389	5.7%	71	1.0%
Grampian	5,218	91.1%	7	0.1%	501	8.7%
Greater Glasgow	0	0.0%	0	0.0%	4,191	100.0%
Highland	2,156	100.0%	0	0.0%	0	0.0%
Lanarkshire	12,325	75.3%	303	1.9%	3,730	22.8%
Lothian	18,242	96.4%	112	0.6%	572	3.0%
Orkney	377	100.0%	0	0.0%	0	0.0%
Shetland	0	0.0%	0	0.0%	608	100.0%
Tayside	11,134	98.7%	14	0.1%	129	1.1%
Western Isles	809	97.1%	12	1.4%	12	1.4%

Postcode

24. At individual patient level, accurate collection of postcode data is important for ensuring that patients receive their clinic letters. For planning and epidemiological purposes, postcodes are also used to calculate deprivation categories. The Survey found that 88.4% of records include the full postcode, with eight areas achieving over 95%. Disappointingly, these figures are little changed from 2001. Given the importance of postcode, particularly in relation to the calculation deprivation (see Annex B) the Monitoring Group is suggesting a target for the 2003 Survey that 95% of all records should have a full postcode.

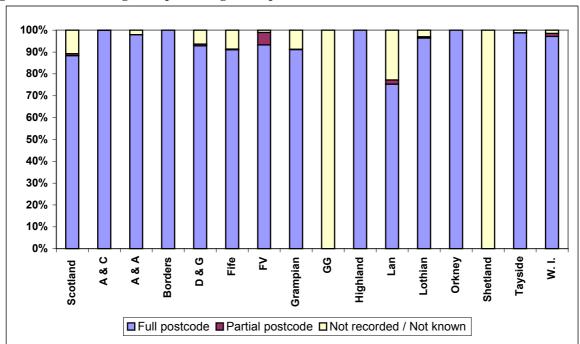


Figure 6: Diabetes register: percentage with postcode

Note: Lanarkshire - data only available for secondary care. Shetland - no data submitted

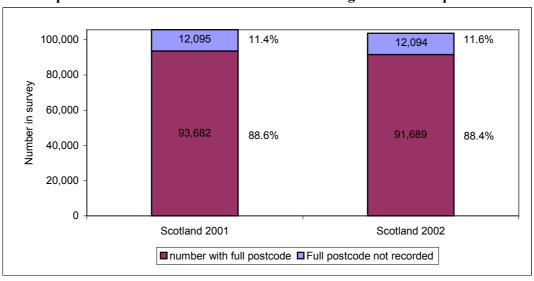


Figure 7: Comparison - Scotland 2001 & 2002. Number on register with full postcode recorded

25. People in poorer areas tend to have more ill-health and less access to health services than people from more affluent areas; for example, socio-economic deprivation in Scotland is associated with an increased prevalence of Type 2 diabetes. In order to explore these issues it is proposed that submissions for the 2003 Survey should include deprivation categories for the registered diabetic population in comparison to the population as a whole.

Sex

26. There are significantly more men than women with diabetes in Scotland. This pattern is repeated across all areas of Scotland apart from Orkney. Unfortunately, six boards were unable to provide a sex breakdown for a significant number of their patients, consequently, sex is not known for over 8% of the registered population in this year's Survey.

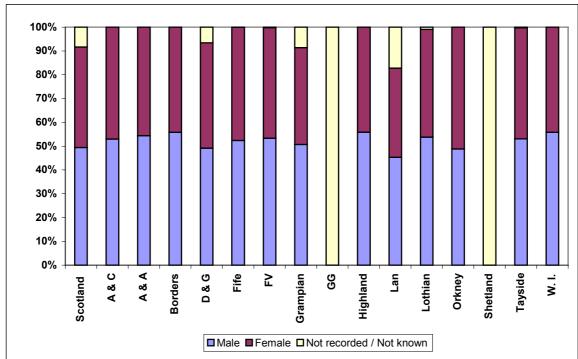


Figure 8: Diabetes register: percentage sex breakdown

Note: D&G - not recorded/not known data includes all paediatric patients. Lanarkshire - data only available for secondary care. Shetland - No data submitted

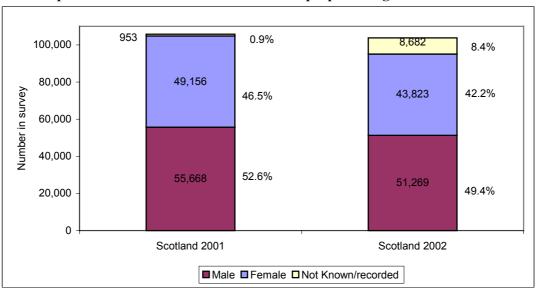


Figure 9: Comparison - Scotland 2001 & 2002. Sex of people on register

Age

27. Over 80% of those included in the Survey are aged 45 or over, and nearly half (47.9%) are aged 65 or over. The registered population is older in 2002 than in 2001. There has been a fall in the number of registered patients aged 85 or older. This is likely to represent improved data validation with people who have died being removed from the register.

100% 90% 80% 70% 60% 50% 40% 30% 20% 10% 0% Lothian A & A D & G 9 Lan Tayside Grampian Highland Orkney Borders Fife Shetland ₹ Scotland **0**-14 **■**15-44 **45-64 65-84** ■85+

Figure 10: Diabetes register: percentage age breakdown

Note: Lanarkshire - data only available for secondary care. Shetland - no data submitted

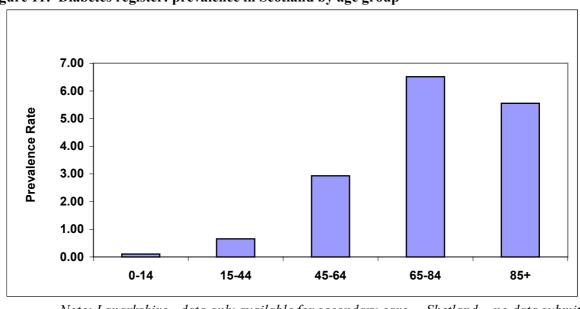


Figure 11: Diabetes register: prevalence in Scotland by age group

Note: Lanarkshire - data only available for secondary care. Shetland - no data submitted

28. It is widely recognised that much of the increased prevalence of diabetes is related to an increase of Type 2 diabetes, which tends to occur in older people. However, there is an increasing incidence of Type 1 diabetes in children. This group of patients have very specific care needs. Annex B describes the work of the Scottish Study Group for the Care of Diabetes in the Young.

Ethnic Group

- 29. Studies in the UK have shown diabetes prevalence rates of 11-20% in Asian Indian, 15% in Afro-Caribbean and 1-5% in white Caucasians. The age distribution of the disease also varies significantly, with Type 2 diabetes presenting in Asians at a younger age than in Europeans. Generally, Type 2 diabetes is up to four times more common in British south Asians than in the indigenous white population. South Asians develop diabetes up to ten years earlier and are more likely to develop renal and cardiac complications. Generally, 15% and 16% are more likely to develop renal and cardiac complications.
- 30. The 2002 Survey asked for the first time whether the ethnicity of the people on local registers had been identified. In part this item was included as a means of highlighting this issue and to encourage all areas to collect this important piece of information. As anticipated, few areas have been recording ethnicity routinely. The Survey shows that by September 2002 only six boards had made a start in collecting ethnicity data. Overall, ethnic group has been recorded for 30.9% of those included in the Survey.

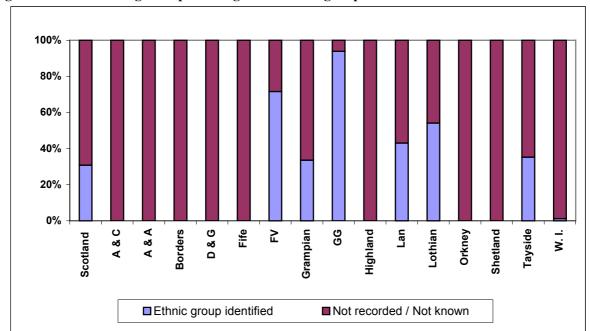


Figure 12: Diabetes register: percentage with ethnic group identified

Note: D&G and Fife - do not record ethnic group Lanarkshire - data only available for secondary care Orkney - this information was not collected in 2001 Survey

- 31. In general, despite some examples of good practice, relatively little attention was paid to the specific health care needs of black and minority ethnic groups by the NHS in Scotland until the publication of Fair for All. This deficiency is now being addressed. An important project is currently being undertaken by the National Resource Centre for Ethnic Minorities (NRCEM) to look at the issues in the context of diabetes, (see box below).
- 32. The Scottish Diabetes Core Dataset ⁽⁶⁾ includes within it the ethnic groupings used by the Census and which should be adopted throughout Scotland. Ethnicity can be a sensitive issue and people should be asked to self-identify their own ethnic group. Guidance about capturing ethnicity data will be included as part of the NRCEM report.

Epidemiology of Diabetes amongst Black Minority and Ethnic Groups in Scotland

The National Resource Centre for Ethnic Minorities (NRCEM), funded by the Scottish Executive Health Department, has been set up within NHS Health Scotland (formerly the Public Health Institute of Scotland) to support NHS Boards meet their responsibilities to deliver culturally competent services and promote race equality. The NRCEM has five core principles that underpin its activities: community development, competence, openness, reliability and equity. The resource centre works as a catalyst encouraging open discussion on the race agenda between participants to foster trust, offer practical advice and facilitate a creative and an innovative environment.

As part of its work short term networks will be set up to address specific areas of work. These networks will be inclusive, recognising the wide range of professions, statutory and voluntary organisations and community groups which have the capacity to influence the health of black minority and ethnic groups in specific targeted areas. The networks will aim to develop and strengthen practice, by encouraging working across traditional boundaries. When appropriate networks will include informed patient/s who would be willing to contribute their personal experiences to the specific work. Themed networks will contribute to the overall national development of black minority and ethnic groups health policy by acting as reliable and respected source of advice and in the provision of reports.

In response to a recommendation in the Scottish Diabetes Framework the NRCEM has established a Diabetes Themed Network. Its main aim is to actively support the work of NRCEM in the production of a report on the epidemiology of diabetes amongst Scotland's ethnic minorities by providing expertise, strategic direction and approval of the Report for the Scottish Executive. The report is scheduled to be published in September 2003.

Diabetes type

- 33. There are two main types of diabetes: Type 1 diabetes and Type 2 diabetes.
 - Type 1 is an autoimmune condition in which the body's own immune system destroys the insulin-producing cells in the pancreas. This deficiency needs to be treated with insulin injections. People with Type 1 diabetes are by definition insulin dependent who in the absence of insulin treatment would suffer fatal diabetic ketoacidosis. Type 1 usually occurs in people under the age of 30, often in childhood, although it can occur at any age. Virtually all people with diabetes under the age of 30 years have type 1 diabetes
 - Type 2 diabetes develops when the body is unable to produce enough insulin, or cannot use the insulin the body produces properly (insulin resistance). This type of diabetes usually appears in people over 40 and depending on its stage of development can be treated by a combination of diet and drugs, although insulin may also be required. The development of Type 2 diabetes is strongly linked to obesity and lack of physical exercise which explains the recent dramatic increase in the incidence of Type 2 diabetes, including the worrying trend of Type 2 diabetes being identified in ever younger patients.
- 34. European studies generally report that Type 1 diabetes accounts for around 10% of the diabetic population and type 2 for about 90%. The Survey data show 18.2% have Type 1 diabetes, 74.1% Type 2 diabetes, 0.8% have other types of diabetes (e.g. gestational) and 6.9% not known or not recorded. This would suggest that people with Type 2 diabetes are under-represented in the Survey sample.

Figure 13: Diabetes register: diabetes type

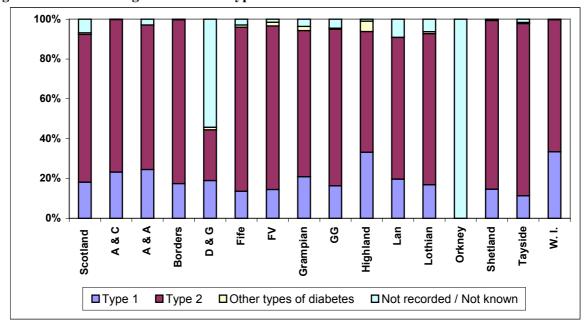
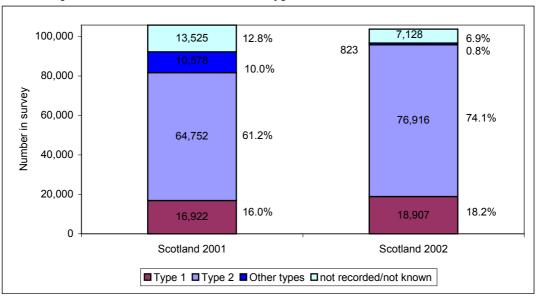


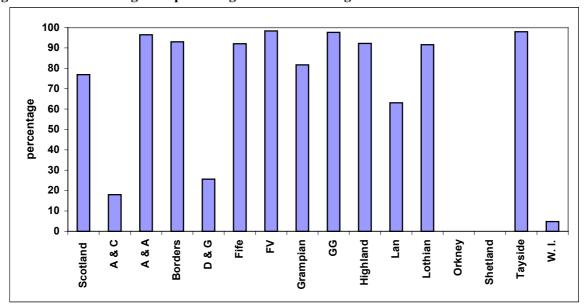
Figure 14: Comparison - Scotland 2001 & 2002. Type of diabetes



Date of diagnosis

35. The date of diagnosis is known for three quarters (76.9%) of registered patients. This data item was collected for the first time in this year's Survey. Date of diagnosis is useful because it enables duration of disease to be calculated, although Type 2 diabetes may be present for a number of years before diagnosis.

Figure 15: Diabetes register: percentage with date of diagnosis recorded



Note: Lanarkshire - data only available for secondary care. Orkney - this information was not collected in 2001 Survey Shetland - No data submitted

HbA1c

36. The Scottish Diabetes Framework recommended that all people with diabetes should have had an annual HbA1c measurement by September 2002. However, in this year's survey, 81.2% of those registered with diabetes have had an HbA1c recorded; 70.8% within the last 15 months. It is disappointing that these figures fall short of the recommendation and show no improvement on last year. However, it is not known how many of the remaining patients (18.9%) have been tested but the information has not been collected for the Survey. In the absence of generally available effective IT, these and other figures can only remain an indication of service provision rather than a definitive judgement. Notwithstanding these caveats, in light of the importance of HbA1c measurement to effective diabetes care, the target of all records including an HbA1c measurement is retained for next year's survey.

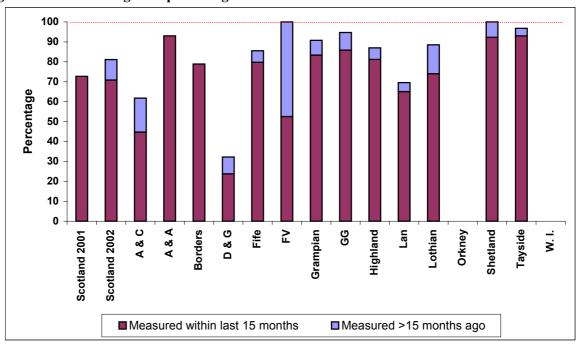


Figure 16: Diabetes register: percentage with HbA1c measurement

Note: A&C - data is incomplete as one laboratory's data is missing. D&G - data is from out-patient clinic workloads only and does not include primary care patients. W.I. - no data submitted

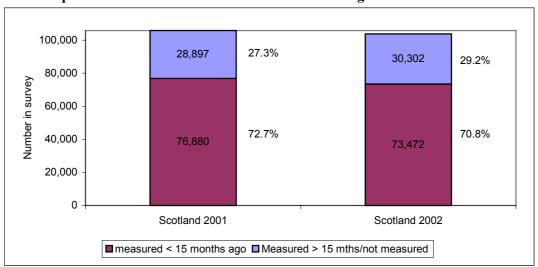


Figure 17: Comparison - Scotland 2001 & 2002. Number on register with HbA1c measurement

Table 4: Diabetes register - HbA1c measurement

	< 15 mon	ths ago	> 15 mor	nths ago	Not me	asured
Scotland 2001	76,880	72.7%	(Not req	uested)	28,897	27.3%
Scotland 2002	73,472	70.8%	10,737	10.3%	19,565	18.9%
Argyll & Clyde	4,260	44.7%	1,623	17.0%	3,639	38.2%
Ayrshire & Arran	8,366	93.0%	0	0.0%	632	7.0%
Borders	2,311	78.9%	0	0.0%	618	21.1%
Dumfries & Galloway	1,226	23.8%	434	8.4%	3,496	67.8%
Fife	7,883	79.8%	568	5.7%	1,430	14.5%
Forth Valley	3,594	52.5%	3,251	47.5%	0	0.0%
Grampian	4,774	83.4%	421	7.4%	531	9.3%
Greater Glasgow	3,600	85.9%	370	8.8%	221	5.3%
Highland	1,750	81.2%	126	5.8%	280	13.0%
Lanarkshire	10,643	65.1%	741	4.5%	4,974	30.4%
Lothian	14,014	74.1%	2,733	14.4%	2,170	11.5%
Orkney	0	0.0%	0	0.0%	377	100.0%
Shetland	561	92.3%	47	7.7%	0	0.0%
Tayside	10,490	93.0%	423	3.8%	364	3.2%
Western Isles	0	0.0%	0	0.0%	833	100.0%

37. The interpretation of HbA1c data in relation to outcomes of care is difficult because of the number of methods of measurement currently used. Thus, different laboratories use different methods for measuring HbA1c each with its own reference range. Until there is Standardisation, any comparison of HbA1c between different centres must be treated with caution. The Monitoring Group strongly recommend that steps be taken to explore the potential to move towards a National Standardised HbA1c, linking with International Recommendations. (19)

Body mass index (BMI)

38. Body mass index (BMI) is calculated by dividing a person's weight (in kilograms) by the square of their height (in metres). An increase in body mass index (BMI), is known to be strongly linked with the development of Type 2 diabetes. Overweight is an increasing problem in Scotland.

BMI	Classification
<18.5	Underweight
18.5-24.9	Healthy weight
25-29.9	Overweight
30-39.9	Obese
>40	Morbidly obese

39. Overall, BMI recording is improving - rising from 39.8% in 2001 to 52.3% in 2002. Several boards have made significant progress, for example, Borders reported only one in five patients (21.6%) with a BMI record in 2001, but this had risen to nearly three quarters (73%) in 2002. However despite this encouraging progress is it is disappointing that more areas were not able to reach the target level of 60% suggested in the 2001 report. It is recommended that areas aim to include a BMI measurement in 65% of records in the 2003 Survey.

100 90 80 70 Percentage 60 50 40 30 20 10 0 Lothian Shetland Tayside Scotland 2002 A&C A & A Borders D & G Fife 99 Lan Orkney Scotland 2001 ₹ Grampian Highland

Figure 18: Diabetes register: percentage with BMI calculated

Note: D&G - data is from out-patient clinic workloads only and does not include primary care diabetes

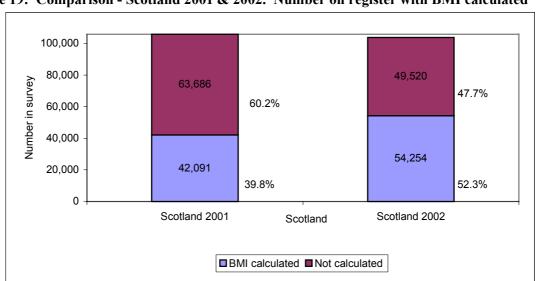


Figure 19: Comparison - Scotland 2001 & 2002. Number on register with BMI calculated

Table 5: Diabetes register - percentage with BMI calculated

	BMI cal	culated		BMI cal	calculated	
Scotland 2002	54,254	52.3%	Greater Glasgow	2,991	71.4%	
Argyll & Clyde	1,506	15.8%	Highland	1,879	87.2%	
Ayrshire & Arran	0	0.0%	Lanarkshire	8,751	53.5%	
Borders	2,138	73.0%	Lothian	13,410	70.9%	
Dumfries & Galloway	1,012	19.6%	Orkney	0	0.0%	
Fife	4,735	47.9%	Shetland	436	71.7%	
Forth Valley	3,131	45.7%	Tayside	9,533	84.5%	
Grampian	4,732	82.6%	Western Isles	0	0.0%	

Diabetes and the eye

40. There has been an increase in the percentage of patients screened for diabetic retinopathy compared to the 2001 survey. This is mainly due to an increase of recorded screening during the last 15 months. This is a significant improvement but much work is still required. The Scottish Diabetes Framework set a target that all people with diabetes should have their eye status (retinopathy) recorded by September 2003. The introduction of a national system for diabetic retinal screening as proposed by the Health Technology Board for Scotland should see these figures improve in future surveys. (20, 21)

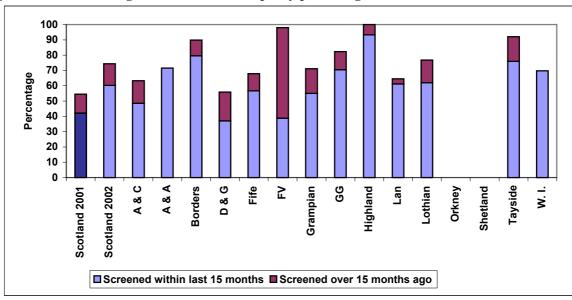


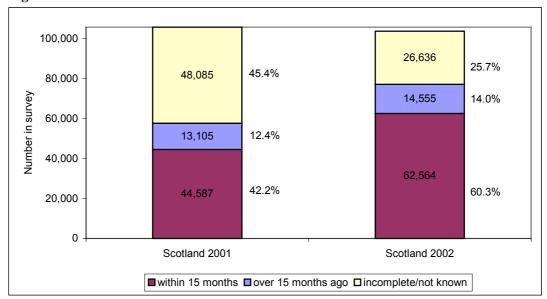
Figure 20: Diabetes register: diabetic retinopathy percentage screened within last 15 months

Note: A&A - excludes 288 patients who are under 12 years old or who are registered blind/partially sighted. Grampian - data is from 38 practices only. Lanarkshire - data only available for secondary care. Orkney - no data submitted. Shetland - no data submitted. W.I. - Not recorded/Not known includes 162 patients who were not eligible for screening.

Table 6: Diabetes register - diabetic retinopathy screening

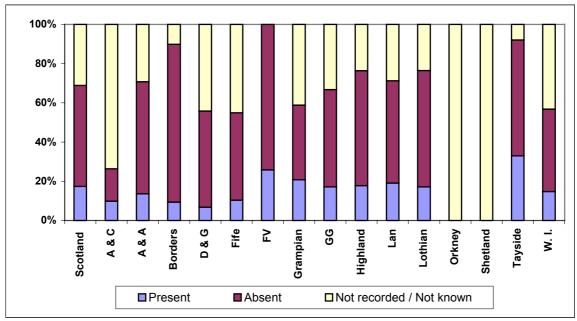
	Screened v		Screened month		Not recor	
Scotland 2001	44,587	42.2%	13,105	12.4%	48,064	45.4%
Scotland 2002	62,564	60.3%	14,555	14.0%	26,636	25.7%
	1					
Argyll & Clyde	4,618	48.5%	1,411	14.8%	3,493	36.7%
Ayrshire & Arran	6,436	71.5%	0	0.0%	2,562	28.5%
Borders	2,332	79.6%	301	10.3%	296	10.1%
Dumfries & Galloway	1,911	37.1%	969	18.85	2,276	44.1%
Fife	5,601	56.7%	1,108	11.2%	3,172	32.1%
Forth Valley	2,659	38.8%	4,052	59.2%	134	2.0%
Grampian	3,150	55.0%	924	16.1%	1,652	28.95
Greater Glasgow	2,953	70.5%	497	11.9%	741	17.7%
Highland	2,012	93.3%	144	6.7%	0	0.0%
Lanarkshire	10,018	61.2%	532	3.3%	5,808	35.5%
Lothian	11,731	62.0%	2,799	14.8%	4,382	23.2%
Orkney	0	0.0%	0	0.0%	377	100.0%
Shetland	0	0.0%	0	0.0%	608	100.0%
Tayside	8,562	75.9%	1,818	16.1%	897	8.0%
Western Isles	581	69.7%	0	0.0%	238	30.3%

Figure 21: Comparison - Scotland 2001 & 2002. Number on register having Diabetic retinopathy screening



- 41. The 2002 Survey asked about all patients with any record of diabetic retinopathy in left or right eye. This simplified the request made in 2001 when diabetic retinopathy in both left eye and right eye was requested.
- 42. Of those screened for diabetic retinopathy, the highest prevalence of retinopathy is recorded in Tayside, an area which has used retinal photography as the screening method for a number of years. The HTBS report has recommended this methodology for Scotland. At this stage the Survey cannot define what interventions (e.g. specialist referral and/or laser therapy) are being undertaken to limit progression of disease in those with sight-threatening retinal changes.

Figure 22: Diabetes Register: Diabetic retinopathy - left or right eye



Note: A&A - excludes 288 patients who are under 12 years old or who are registered blind/partially sighted. Orkney - this information was not collected in 2001 Survey. Lanarkshire - data was submitted for Left and Right eye separately therefore the highest figure of the two was used.

Shetland - no data submitted

43. The prevalence of permanent blindness is reported at just under 1%. However, there are some problems about how 'permanent blindness' is defined and this may impact on this figure. Blindness may not be due to specific diabetic eye disease in a significant number of cases. Work in Fife has suggested that many of the people who lose their sight as a result of diabetic retinopathy have not made use of diabetes services. This finding should be examined in other areas and if confirmed, work should be commissioned to explore why such people chose to avoid diabetes services.

2.5 2.0 Percentage 1.5 1.0 0.5 0.0 D & G 9 A&C A&A Highland Lothian Fife ₹ Grampian Lan Tayside Shetland Scotland Borders Orkney ■ Diabetic cause ■ Non-diabetic cause

Figure 23: Diabetes register: permanent blindness - percentage diabetic/non diabetic cause

Note: Shetland - no data submitted. Orkney - no data submitted

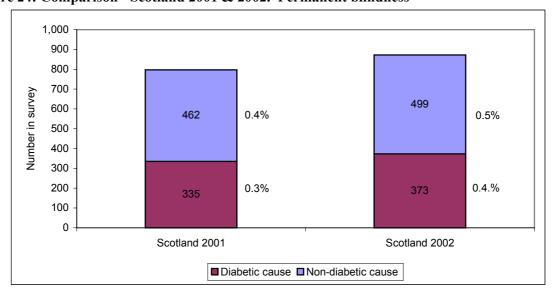


Figure 24: Comparison - Scotland 2001 & 2002. Permanent blindness

Diabetes and the kidney

44. Diabetes mellitus is now one of the major causes of renal failure. The UK Renal Registry <<u>www.renalreg.com</u>> (which covered 72% of the UK adult population in 2001) reported that diabetic nephropathy was seen in 18% of new patients. This remains low in comparison to figures reported for Europe and USA. (22) Chronic renal failure is an important complication of diabetes as renal replacement carries a high morbidity and mortality especially in patients with diabetes. It also uses considerable health service resource.

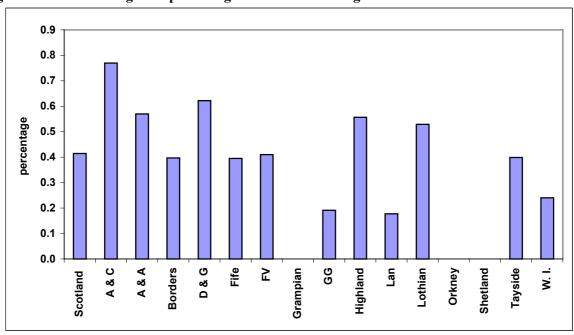


Figure 25: Diabetes register: percentage recorded as having chronic renal failure

Note: Lanarkshire - data only available for secondary care. Shetland - no data submitted Orkney - no data submitted

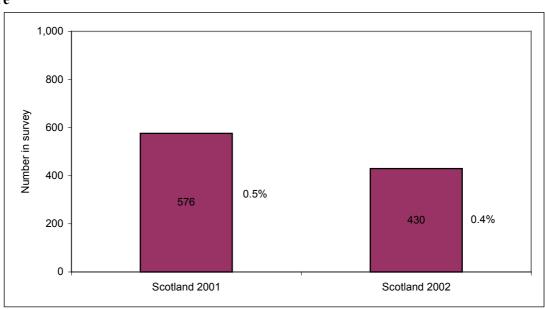


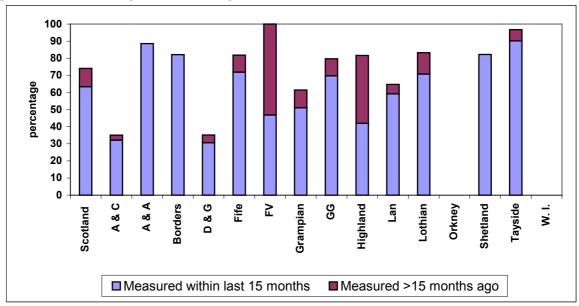
Figure 26: Comparison - Scotland 2001 & 2002. Number on register having end stage renal failure

45. It is difficult to compare figures in 2002 to those of last year's survey as the definition of chronic renal failure has been clarified and this could have resulted in reclassification of some individuals. The definition of chronic renal failure is taken to be: "Either serum creatinine was chronically greater than 500 mmol/l (i.e. >500 mmol/l on two occasions three months apart), or the patient was placed on permanent dialysis or received a renal transplant". The wide range between different boards is more likely to points to different stages of register development than to real differences in the prevalence of chronic renal failure.

Risk factors: Serum creatinine and urinary microalbumin

46. A recorded serum creatinine measurement was a new request for the diabetes survey this year. More than 60% of registered patients have had a creatinine measured within the last 15 months. This is a good start. We would anticipate a higher figure in next year's survey.

Figure 27: Diabetes register: Percentage with serum creatinine measured



Note: A&A - data excludes 53 patients who are under 12 years old. A&C - data is incomplete as one laboratory's data is missing. D&G - data is from out-patient clinic workloads only and does not include primary care diabetics. Orkney - no data submitted. W.l. - no data submitted

47. A recorded urinary microalbumin measurement was another addition to the diabetes survey in 2002. Microalbuminuria is defined by a rise in urinary albumin loss to between 30 and 300 mg/day. Urinary microalbumin screening is important in Type 1 diabetes as it indicates early diabetic renal disease. Intervention is believed to delay the deterioration of renal function. Microalbuminuria in Type 2 diabetes also indicates diabetic renal disease but is more important as a marker of increased risk of vascular disease. Aggressive management of vascular risk factors is required in this group of patients. A disappointing 22% of patients with diabetes have had a recorded urinary microalbumin assessment during the last 15 months. Assessment of urinary microalbumin is recommended by SIGN and is part of the Scottish Core Diabetes Dataset.

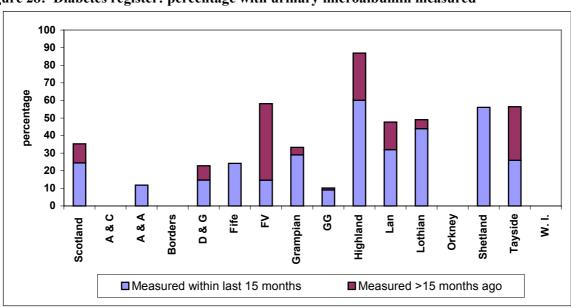


Figure 28: Diabetes register: percentage with urinary microalbumin measured

Note: A&A - data excludes 53 patients who are under 12 years old. D&G - data is from out-patient clinic workloads only and does not include primary care diabetics. Borders and Fife - data not submitted as only routinely screen type 1. Lanarkshire - data only available for secondary care.

Orkney - no data submitted. W.l. - no data submitted

Diabetes and the heart

48. Diabetes Mellitus increases the relative risk of coronary death by 2.6 for women and 1.8 for men. In the 2002 Scottish Diabetes Survey, 8.1% of individuals are recorded as having had a myocardial infarction, 3.7% are recorded as having undergone previous cardiac revascularisation. The corresponding rates in the 2001 Survey were 6.7% and 2.1% respectively. The impression of the Monitoring Group is that the increased prevalence most probably reflects improved quality of diabetes registers nationally, thus an increase in ascertainment of these previous events has led to a better picture of the prevalence of these diseases across Health Boards. This is encouraging, as the figure of 8.1% is approaching that of 9.9% in Boards where there is validation of clinical diagnoses. In future years, we hope to look at the incidence rates of myocardial infarction and revascularisation, which are a better indicator of the effectiveness of primary and secondary preventative measures.

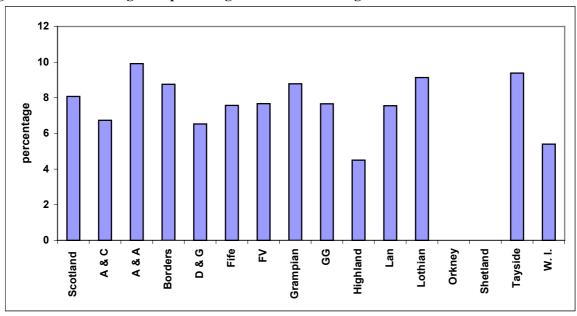


Figure 29: Diabetes register: percentage recorded as having had an MI

Note: Lanarkshire - data only available for secondary care. Shetland - no data submitted Orkney - no data submitted

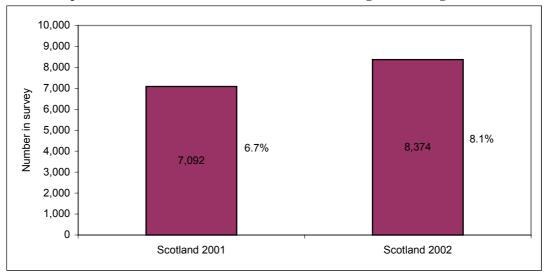


Figure 30: Comparison - Scotland 2001 & 2002. Number on register having had an MI

8 7 6 percentage 5 4 3 2 1 A & A D & G Highland Lothian Tayside A&C Borders Lan × -99 Shetland Grampian Orkney ₹ Scotland

Figure 31: Diabetes register: percentage recorded as having undergone cardiac revascularisation

Note: Forth Valley - data is the sum of CABG & Angioplasty. Lanarkshire - data only available for secondary care. Shetland - no data submitted. Orkney - no data submitted

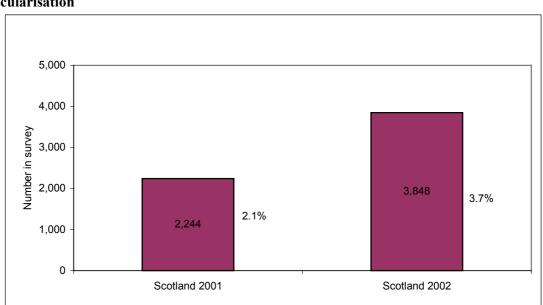


Figure 32: Comparison - Scotland 2001 & 2002. Number on register having undergone Cardiac revascularisation

49. Cardiac revascularisation was not tightly defined for this year's survey but is taken to mean all forms of revascularisation including stents and angioplasty.

Risk factors: Blood pressure, cholesterol and smoking status

- 50. There is very strong evidence in people with diabetes that lowering blood pressure, cholesterol and stopping smoking are highly effective primary and secondary prevention methods. Lifestyle modification to stop smoking, and measurement and treatment of blood pressure and cholesterol are essential components of modern diabetes care. These risk factors have been recorded in over 70% of people with diabetes. This is a major achievement, especially as two factors, blood pressure and cholesterol were requested for the first time in this 2002 survey.
- 51. Unlike HbA1c, both blood pressure and lipids are measured across Scotland using methods that may be compared between Health Board areas. The survey, to date, has concentrated on quantitative information rather than qualitative data. It should be possible in further years to analyse actual blood pressure and cholesterol results from important subgroups (e.g. patients aged 50 to 60 years) to look for population differences. This type of analysis will be dependent on the recording methods used within each Board area, but should be supported for those using SCI-DC systems in the future.

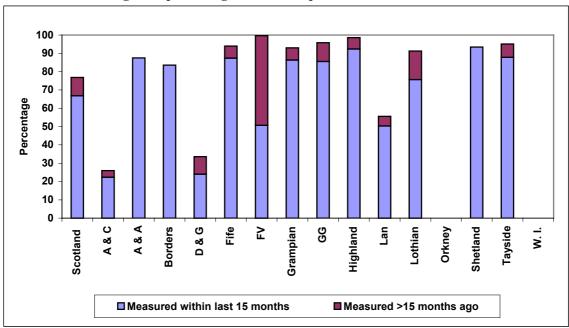


Figure 33: Diabetes register: percentage with blood pressure measured

Note: A&A - excludes 53 patients who are under 12 years old. D&G - data is from out-patient clinic workloads only and does not include primary care diabetics. Orkney - no data submitted. W.I. - no data submitted.

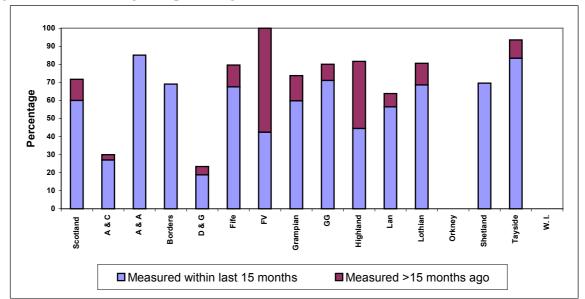


Figure 34: Diabetes register: percentage with cholesterol measured

Note: A&A - data excludes 53 patients who are under 12 years old. A&C - data is incomplete as one laboratory's data is missing. D&G - data is from out-patient clinic workloads only and does not include primary care diabetics. Orkney - no data submitted. W.l. - no data submitted

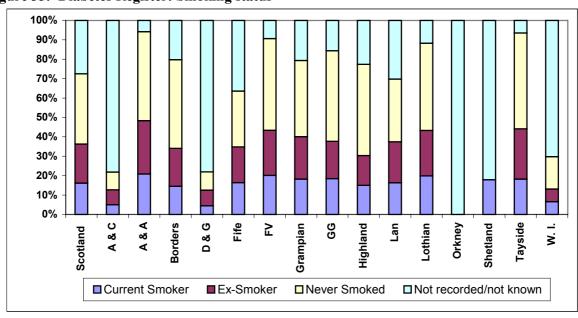


Figure 35: Diabetes Register: Smoking status

Note: A&A - data excludes 53 patients who are under 12 years old. D&G - data is from out-patient clinic workloads only and does not include primary care diabetics. Lanarkshire - data only available for secondary care.

52 It is disappointing that 16% of registered patients with diabetes continue to smoke. This is a national problem, not only relating to those with diabetes. The recent SIGN guideline on diabetes includes a useful review of methods to encourage smoking cessation. (23)

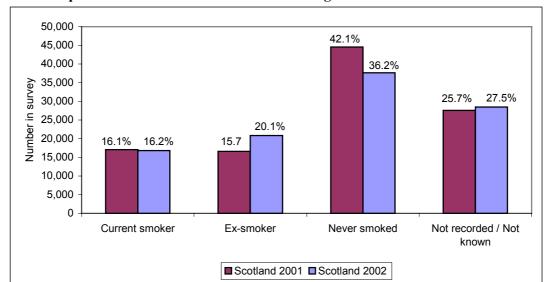


Figure 36: Comparison - Scotland 2001 & 2002. Smoking status

Diabetes and cerebrovascular disease

The survey data again emphasises the impact of stroke on people with diabetes. Guidance was 53. provided for the 2002 survey to clarify the definition of stroke: "Stroke (cerebrovascular accident) - defined as rapidly developing signs of focal (and/or global) disturbance of cerebral function lasting more than 24 hours or leading to death with no apparent cause other than vascular origin." Against a background of improving data recording and data quality (e.g. the exclusion of transient ischaemic attacks) the overall percentage of patients who have had a stroke rose from 3.4% to 4.9%.

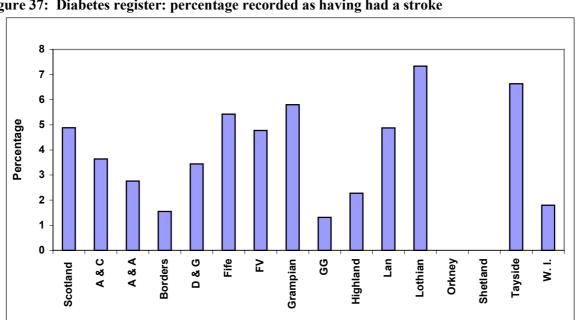


Figure 37: Diabetes register: percentage recorded as having had a stroke

Note: Borders - only clinic form records stroke. Lanarkshire - data only available for secondary care Shetland - no data submitted. Orkney - no data submitted

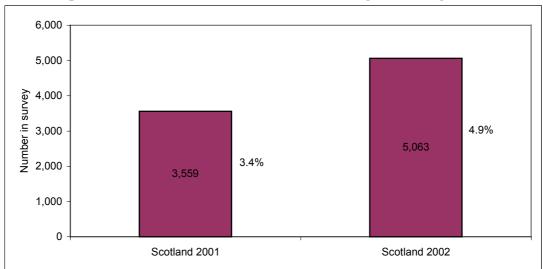


Figure 38: Comparison - Scotland 2001 & 2002. Number on register having had a stroke

Diabetes and the foot

54. As in 2001, the survey found different rates of recorded foot ulcer and amputation across each NHS Board. The increasing rate in most areas is likely to indicate improved data capture.

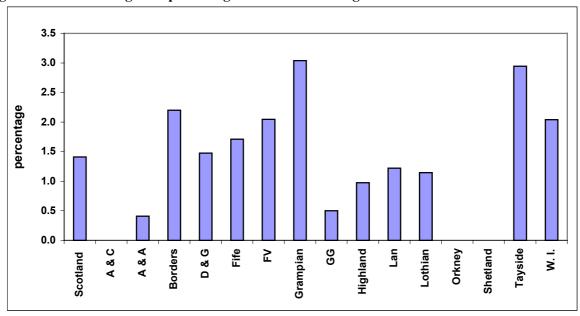


Figure 39: Diabetes register: percentage recorded as having had a foot ulcer

Note: Lanarkshire - data only available for secondary care. Shetland - no data submitted.

Orkney - no data submitted

Figure 40: Comparison - Scotland 2001 & 2002. Number on register having had a foot ulcer

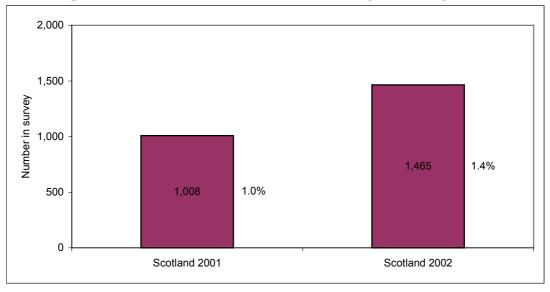
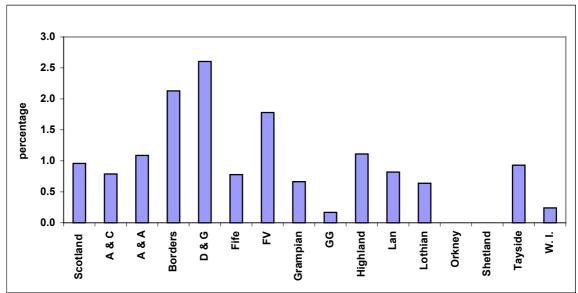


Figure 41: Diabetes register: percentage recorded as having had an amputation



Note: Lanarkshire - data only available for secondary care. Tayside - data previously included digits.

Shetland - no data submitted. Orkney - no data submitted

1,400 - 1,200 - 1,000

Figure 42: Comparison - Scotland 2001 & 2002. Number on register having had lower limb amputation

DISCUSSION

The 2002 Survey

- 55. The 2002 Survey demonstrates that NHS Boards have made significant progress in recording information that may be used to measure and understand the quality of diabetes care in Scotland. It is clear that considerable work is still required to capture information for all people with diabetes in each area. It is perhaps a little disappointing that the number of registered patients is slightly reduced in this survey compared to the provisional survey of 2001, but the reasons for this are understood and it is anticipated that numbers will increase as NHS Boards provide information for all the patients in their area rather than for subgroups of patients.
- 56. The Scottish Diabetes Survey Monitoring Group believe the quality of information has improved significantly compared to that of the provisional survey. There is increased recording of CHI, diabetes retinopathy screening and recorded myocardial infarction. Information about modifiable vascular risk factors (blood pressure and cholesterol) is now available for many patients.
- 57. The introduction of the SCI-DC Clinical and Network systems will enable timely collection of information and greatly ease analysis of data in each NHS Board. As these systems become fully integrated into diabetes services, data quality should improve, thereby creating an increasingly valuable resource.

Future developments

- 58. In order to provide information which can be more easily compared across different NHS Boards, it is proposed that in the 2003 Survey report some (and perhaps all) of the data items will be presented in relation to the estimated prevalence. It is acknowledged that at present such estimates are rather crude. However, it is hoped that by next year it will be possible to improve upon the estimates included in this year's report.
- 59. In addition to improving the estimate of current prevalence, there is a need to produce a more accurate prediction of future trends. The suggestion that the prevalence of diabetes will double in the next 10-15 years is frequently repeated, but to date no work has been carried out to confirm the relevance of this projected increase to the Scottish context. The Monitoring Group will bring forward plans to produce figures for the estimated future prevalence of diabetes in Scotland.

- 60. The Monitoring Group suggest that a number of additional data items should be added to the Survey in 2003. These will be confirmed before the end of June 2003. We welcome comment on the relevance and practicality of these items.
 - <u>Incident data</u>. Number of patients newly diagnosed in 2000, 2001 and 2002.
 - Number of patients with **Type 2 aged under 35 years**.
 - Number and percentage of patients aged 45-64 achieving a Blood Pressure target of 140/80.
 - Number and percentage of patients achieving **cholesterol** target of <5.
 - Number and percentage of patients falling within different **<u>BMI</u>** ranges->18; 18-25; 25-30; 30-35; 35-40, 40+; not recorded.
 - <u>Deprivation</u>. Depcat scores of the registered diabetes population in comparison to the total NHS Board population.
- 61. In the absence of effective clinical management systems the collection of data for the Survey is time-consuming and difficult. Nevertheless, it should be possible for NHS Boards to submit data by the requested date. Starting in the 2003 report, the date when data are submitted will be published.

CONCLUSION

- 62. The 2002 Survey provides information for about two thirds of the patients with diabetes in Scotland. One NHS Board did not provide data and many others provided data only for subgroups of their population. It is anticipated that the implementation of SCI-DC will facilitate the development of more comprehensive diabetes registers in each Board area.
- 63. There has been an improvement in the quality of data recorded for those on registers. This survey has concentrated on whether or not data is available on a local register rather than analysing data accuracy, or clinical interpretation. In future surveys the Diabetes Survey Monitoring Group wish to begin to analyse clinical information, rather than monitor only the collection of data.
- 64. The Diabetes Survey Monitoring Group consider that the use of expected diabetes prevalence (corrected for age and, where possible, other attributes) would be more illuminating than the presentation of data based only on registered patients. This will be explored in more detail in the 2003 Survey.
- 65. The Diabetes Survey Monitoring Group has no concerns about data protection, because the data are anonymised and aggregated with no raw data being submitted for analysis.
- 66. Finally, the Monitoring Group wishes to acknowledge the commitment and hard work of all those who have contributed to the 2002 Scottish Diabetes Survey and to the development of local clinical management systems upon which this Survey is based.

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Scottish Study Group for the Care of Diabetes in the Young

The Scottish Study Group for the Care of Diabetes in the Young was established in 1985 to encourage co-operation amongst paediatricians and adult physicians responsible for the care of young people with diabetes. The original and still primary aim of the SSG is to improve the care of, and outcomes for, young people with diabetes. To do this, it has the following objectives:

- To provide a programme of continuing medical education.
- To provide a forum in which paediatricians and physicians can have informal discussions of problems and solutions, for example relating to the transition from paediatric to adult clinics.
- The maintenance of an informal but effective clinical network covering all the main centres in Scotland.
- A research programme which is internationally credible and which achieves publications in respected journals.
- To provide a non-threatening but stimulating training setting for guest presentations by junior medical staff and colleagues from other disciplines.
- To create a pressure group to press for improvements in diabetes services in Scotland in liaison with Diabetes UK and the Royal Colleges of Physicians and Paediatrics and Child Health.
- To provide for informal debates with the pharmaceutical industry.
- To provide a confidential setting for collaborative audits such as DIABAUD.
- To be a source of professional advice and statistics in relation to matters concerning the care of young people with diabetes in Scotland.

An important part of the SSG's work has been to maintain a central register of all existing and newly presenting patients <15 years with Type 1 diabetes. Using this data, supplemented by other sources, the SGG have been able to calculate the incidence of Type 1 diabetes in children. This study showed that incidence has trebled over the last 30 years and that incidence is highest in northern rural areas highest. Review of the literature shows that Scottish incidence is high in international terms.

Age-standardised incidence rate per 100,000 by Health Board 1984-2000

NHS Board	%	No.
Greater Glasgow	22.6	660
Dumfries & Galloway	22.8	106
Borders	23.3	74
Tayside	23.5	287
Lothian	24.4	551
Fife	24.4	279
Forth Valley	24.9	223
Ayrshire & Arran	25.3	315
Grampian	25.9	438
Lanark	26.2	510
Argyll & Clyde	27.9	402
Shetland	30.5	26
Highland	33.4	234
Western Isles	36.7	37
Orkney	39.1	26

Scottish Diabetes Survey 2002

[NAME] HEALTH BOARD

	Number	%
1. Total population		
Source: Registrar General for Scotland (mid-year estimates at 30 June 2000)		
2. Area diabetes register		
(a) People registered on area diabetes register		
(b) People not included due to non consent		
(c) Number of people included in survey (a-b)		
3. Use of CHI number		
Records with CHI		
4. Postcode		
Full postcode		
Partial postcode		
Not recorded / Not known		
5. Type of diabetes		
Type 1		
Type 2		
Other types of diabetes		
Not recorded / Not known		
6. Age of people on register		
0-4		
5-14		
15-24		
25-34		
35-44		
45-54		
55-64		
65-74		
75-84		
>=85		
Age not recorded / missing or incomplete data		
Age not recorded / missing or incomplete data		
7. Date of diagnosis	[
Recorded		
Not recorded / Not known		

8. Sex	of people on register		
	Male		
	Female		
	Not recorded / Not known		
	Not recorded / Not known		
9. Ethn	ic group		
	Ethnic group identified		
	Not recorded / Not known		
	Not recorded / Not known		
10. BMI	(where weight recorded within last 15 months)		
	Calculated		
	Not calculated / Data incomplete / Not known		
	·	!	
11. HbA	1c measurement	ĺ	
	Measured within last 15 months		
	Measured >15 months ago		
	Not calculated / Data incomplete / Not known		
		ļ	
12. Bloo	d pressure measurement	 1	
	Measured within last 15 months		
	Measured >15 months ago		
	Not calculated / Data incomplete / Not known		
	The concentration of Batta mooniplete / Not the min	ļ	
13. Cho	esterol measurement		
	Measured within last 15 months		
	Measured >15 months ago		
	Not calculated / Data incomplete / Not known		
	The calculated / Bata moonplete / Not known		
14. Seru	m creatinine measurement		
	Measured within last 15 months		
	Measured >15 months ago		
	Not calculated / Data incomplete / Not known		
	Not calculated / Data incomplete / Not known		
15. Urin	ary microalbumin measurement		
	Measured within last 15 months		
	Measured >15 months ago		=
	-		
	Not calculated / Data incomplete / Not known	ļ	
16. Smo	king status		
	Current smoker		
	Ex-smoker		
	Never smoked	ļ	
	Not recorded / Not known		

17. Dia	betic Retinopathy Screening		
	Screened within last 15 months		
	Screened over 15 months ago		
	Screening status not recorded / Not known		
18 Dia	betic Retinopathy - Left or right eye		
IO. DIA	Present		
	Absent		
	Not recorded / Not known		
19. Pei	manent blindness		
	Diabetic cause		
	Non-diabetic cause		
	Cause not recorded / not known		
20. Mv	ocardial infarct		
. ,	Recorded as having had an MI		
21. Ca	rdiac Revascularisation		
	Recorded as having undergone cardiac revascularisation		
22. Str	oke		
	Recorded as having had a stroke		
23. Fo	ot ulceration		
	Recorded as having had a foot ulcer		
24. Lo	wer limb amputation		
	Recorded as having had an amputation		
25. En	d stage renal failure		
	Recorded as having chronic renal failure		
	Date of data extraction	n:	
	Date of data extraction	•••	

Scottish Diabetes Survey 2002

The following guidance was issued with the 2002 Survey.

1. Total population

Final estimated population at 30 June 2000 should be used. Source: Registrar General for Scotland

June 2000	Estimated population
Scotland	5,114,600
Argyll & Clyde	423,500
Ayrshire & Arran	373,400
Borders	106,900
Dumfries & Galloway	145,800
Fife	350,400
Forth Valley	278,000
Grampian	523,400
Greater Glasgow	904,400
Highland	208,600
Lanarkshire	562,000
Lothian	783,600
Orkney	19,480
Shetland	22,440
Tayside	385,500
Western Isles	27,180

2. Area diabetes register

This allows prevalence to be calculated. The number of patients who have opted not to include their data on the register or for the Survey should be recorded.

3. Use of CHI number

The Community Health Index (CHI) is a population register used for health care purposes. The CHI number uniquely identifies a person on the index.

4. Postcode

Full postcode | Partial postcode | Not recorded/Not known.

The postcode is a basic unit for identifying geographic locations. A postcode has two component parts: part one is the outcode, and part two is the incode. Refer to Defs Manual for more details.

5. Type of diabetes

Type 1 | Type 2 | Other types of diabetes | Not recorded/Not known.

'Other' should include Gestational Diabetes Mellitus or Maturity onset diabetes of youth (MODY), but should exclude Impaired glucose tolerance.

6. Age of people on register

0-4 | 5-14 | 15-24 | 25-34 | 35-44 | 45-54 | 55-64 | 65-74 | 75-84 | >=85 | Not recorded/Not known. Age at date of survey (i.e. September 2002).

7. Date of diagnosis

Recorded | Not recorded/Not known.

8. Sex of people on register

Male | Female | Not recorded/Not known.

Phenotype at birth.

9. Ethnic group

Ethnic group identified | Not recorded/Not known.

An ethnic group is a group of people having racial, religious, linguistic and/or other cultural traits in common. The ethnic group to which a patient belongs is judged by the patient. The standard OPCS classification of ethnicity is used here - 0 = White; 1 = Black Caribbean; 2 = Black African; 3 = Indian; 4 = Pakistani; 5 = Bangladeshi; 6 = Chinese; 30 = Other.

10. BMI

Calculated | Not calculated.

Refers to BMI based on a weight recorded within last 15 months.

11. HbA1c measurement

Measured within last 15 months | Measured > 15 months ago | Not measured/Not known. Glycated haemoglobin refers to measurement of HbA1c (not HbA1).

12. Blood pressure measurement

Measured within last 15 months | Measured > 15 months ago | Not measured/Not known.

13. Cholesterol measurement

Measured within last 15 months | Measured > 15 months ago | Not measured/Not known.

The Scottish Diabetes Core Dataset includes data fields for Serum total cholesterol, Serum HDL Cholesterol and Triglycerides. Measurements can be either fasted or unfasted. For the purposes of the 2002 Survey, any one of these is sufficient.

14. Serum creatinine measurement

Measured within last 15 months | Measured > 15 months ago | Not measured/Not known.

15. Urinary microalbumin measurement

Measured within last 15 months | Measured > 15 months ago | Not measured/Not known.

Urine specimen tested for presence of microalbuminuria by any method is sufficient for the purposes of the 2002 Survey (Albustix, albumin concentration, albumin: creatinine ratio, timed overnight albumin excretion rate or 24 hour albumin excretion rate.

16. Smoking status

Current smoker | Ex-smoker | Never smoked | Not recorded/Not known.

17. Diabetic Retinopathy Screening

Screened within last 15 months | Screened > 15 months ago | Screening status not recorded.

18. Diabetic Retinopathy - Left or Right eye

Present | Absent | Not recorded.

Present means any degree of retinopathy recorded as present in left and/ or right eye; Absent means 'no retinopathy' recorded for both eyes.

19. Permanent blindness

Diabetic cause | Non-diabetic cause | Cause not recorded/not known.

Permanent blindness is defined as permanent visual acuity corrected (i.e. wearing corrective lenses) of <3/60 (I.e. CF, HM or PL) in the better eye.

20. Myocardial infarct

Recorded as ever having had an acute myocardial infarction.

21. Cardiac Revascularisation

Recorded as having undergone cardiac revascularisation.

22. Stroke

Recorded has having had a stroke.

Stroke (cerebrovascular accident) - defined as rapidly developing signs of focal (and/or global) disturbance of cerebral function lasting more than 24 hours or leading to death with no apparent cause other than vascular origin.

23. Foot ulceration

Recorded as ever having had a foot ulcer.

Foot ulcer is defined as any break in the epithelium greater than a crack below the level of the malleoli.

24. Lower limb amputation

Recorded as ever having had a lower limb amputation.

Amputation is defined as recommended in the SIGN guideline on management of diabetic foot disease as 'removal of forefoot or part of the lower limb'. This excludes loss of toes or single metatarsals.

25. End stage renal failure

Recorded as having chronic renal failure.

Either serum creatinine was chronically greater than 500 mmol/l (i.e. >500 mmol/l on two occasions three months apart), or the patient was placed on permanent dialysis or received a renal transplant.

NOTES

It is recommended that all patients with diabetes should be seen at least annually. However, in a number of the survey responses a period of 15 months has been used. This is to allow "confidence limits" around the annual review.

All aspects of the Survey remain under review. The Monitoring Group will be commenting upon any possible changes to definitions or format in the report of the 2002 Survey.

Seven new items have been added to the Survey since 2001:-

- 7. Date of diagnosis
- 9. Ethnic group
- 12. Blood pressure measurement
- 13. Cholesterol measurement
- 14. Serum creatinine measurement
- 15. Urinary microalbumin measurement

In addition, the item for diabetic retinopathy has been changed to:

18. Diabetic retinopathy – left or right eye

This replaces 'diabetic retinopathy – left eye' and 'diabetic retinopathy – right eye'. These items (which were used in the 2001 Survey) reflect the data as they are captured by SCI-DC for clinical purposes. For the purpose of the 2002 Survey, the number of patients who have any retinopathy is of interest, hence the amalgamation of the two fields.

Three other items have been amended:

- 2. Area diabetes register
- 5. Type of diabetes
- 20. Permanent blindness





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