

Health

National report



 **audit**  
commission  
in wales

# Diabetes services in Wales

A baseline review of service provision

**The Audit Commission in Wales** is an independent body responsible for ensuring that public money is spent economically, efficiently and effectively, to achieve high-quality local and national services for the public. Our work covers local government, housing, health and criminal justice services.

As an independent watchdog, we provide important information on the quality of public services. As a driving force for improvement in those services, through inspection, audit, research and other methods, we provide practical recommendations and spread best practice. As an independent auditor, we monitor spending to ensure public services are good value for money.

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## Preface

Previous research has indicated that diabetes<sup>1</sup> affects about 3.5 per cent of the adult population in Wales, with many more people remaining undiagnosed. Every year the number of people living with diabetes increases. The disease can have a major impact on the physical, psychological and material well-being of individuals and their families. Moreover, failure to detect and treat complications can have a devastating effect on individuals' quality of life.

Treating complications associated with diabetes also represents a major health service cost. Diabetes accounts for around 9 per cent of all hospital costs across England and Wales, and there are additional costs associated with the management of the disease in general practice and the community. Diabetes thus accounts for a significant and growing proportion of NHS spend.

There is sound evidence that good management of diabetes can reduce the risks of developing serious complications and lengthen life. However, not all patients receive the best care and services can vary enormously.

A National Service Framework (NSF) for Diabetes has been developed across the UK to help improve the standard of care for people with diabetes and their carers. The Welsh Assembly Government (the Assembly) in partnership with the Department of Health has developed 12 new standards aimed at improving diabetes services in Wales and has recently published a Delivery Strategy for the Diabetes NSF in Wales.

The Assembly commissioned the Audit Commission in Wales to undertake a baseline review of diabetes services to inform the implementation of the Diabetes NSF in Wales. The key all-Wales findings from the baseline review are presented in this national overview report. It will be of interest to all involved in the planning and delivery of diabetes services, and also to individuals with diabetes and their carers. This report will be accompanied by the production of 22 local health board-level reports that will help identify the local priorities for the planning and delivery of diabetes services.

The Audit Commission in Wales is grateful to members of the Assembly's Diabetes NSF Implementation Group who contributed to the design of the study and to the numerous staff in health authorities, local health groups/boards (LHGs/Bs) and NHS trusts who provided information to support the review. Special thanks are also due to the people with diabetes who responded to our surveys and the assistance provided by local diabetes service advisory groups. As always, however, responsibility for the contents and conclusions rests solely with the Audit Commission.

<sup>1</sup> Throughout this report reference to diabetes refers to Diabetes Mellitus

# Introduction and background

## What is diabetes?

- 1 Diabetes<sup>1</sup> is a chronic, lifelong condition, characterised by the body's inability to control the amount of sugar in the blood. There are two forms of diabetes – Type I, where the pancreas fails to produce insulin, with onset occurring early in life and requiring injections of insulin; and Type II, which is much more common, with later onset and treatment by diet, oral medication and, sometimes, insulin injections. Without proper management, diabetes can lead to premature death and long-term complications such as an increased risk of coronary heart disease and stroke, kidney failure, foot ulceration and amputation, neuropathy, diabetic retinopathy and blindness (**Exhibit 1**).

## The burden of diabetes in Wales

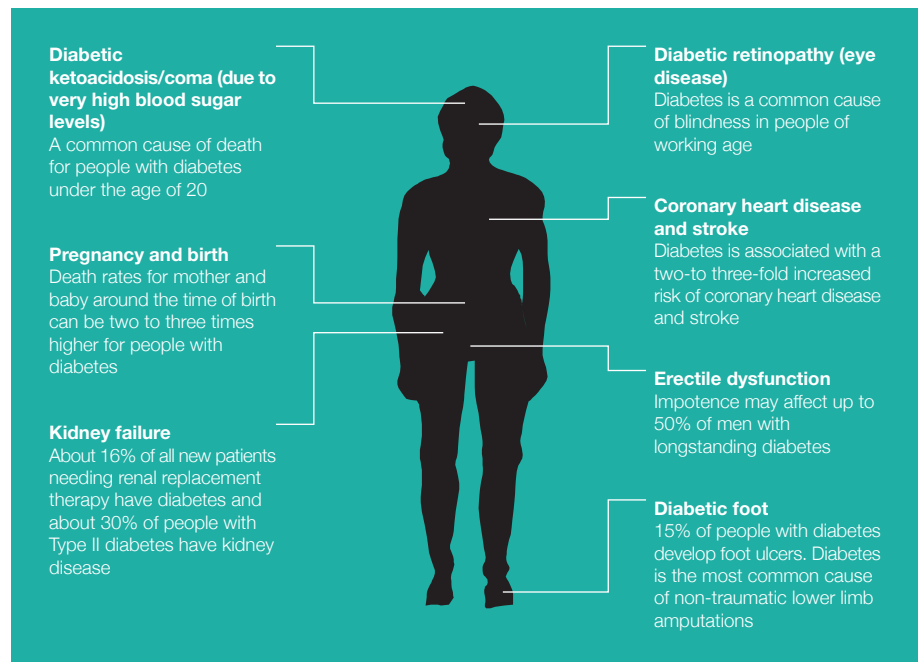
- 2 Data taken from our survey of general practices in 2002 indicated that the prevalence rate of diabetes in Wales is 3.2 per cent. Based on 2001 population census data this would indicate that just under 93,000 people in Wales have diagnosed diabetes.

<sup>1</sup> Throughout this report reference to diabetes refers to Diabetes Mellitus

### Exhibit 1

#### Complications of diabetes

Diabetes is associated with a range of serious complications.



**Source:** *Testing Times: A Review of Diabetes Services in England and Wales (Ref 1)*.

- 3 There are predictions that the overall number of people with diabetes is likely to double over the next ten years, due to rising levels of obesity and an ageing population. The National Service Framework (NSF) for Diabetes is also likely to bring an increased emphasis on early detection with the likelihood that this will further inflate the number of people that are formally diagnosed.
- 4 Statistics taken from the Patient Episode Database for Wales (PEDW) for 2001 give an idea of the burden of diabetes on the individual and the health service (**Table 1**).
- 5 Many of the complications of diabetes can be averted through good management of blood glucose. However, Wales has a relatively poor record in this area and examination of hospital statistics shows that the number of hospital admissions for hyperglycaemia rose by 70 per cent between 1995 and 2001 (see caveats on clinical coding in Table 1).

## Care settings

- 6 Patterns of care for patients with diabetes in Wales vary according to the type of diabetes they have, their age and where they live. The baseline review found that children with diabetes will typically receive all their care from specialist hospital teams. The majority of adults requiring insulin to manage their diabetes (all Type I and some Type II patients) will also receive all, or most of, their care from hospital-based teams, although this varies across Wales.

**Table 1**  
**Hospital admissions in Wales for diabetes related conditions during 2001**

Condition	Number of admissions
Diabetes as principal diagnosis	5834
Hypoglycaemia	704
Hyperglycaemia	31284*
Diabetic ketoacidosis	1218
Lower limb amputations among diabetic patients	385
Congenital abnormalities	52
Diabetic renal failure	225
Coronary heart disease and myocardial infarction associated with diabetes (morbidity and mortality)	1668

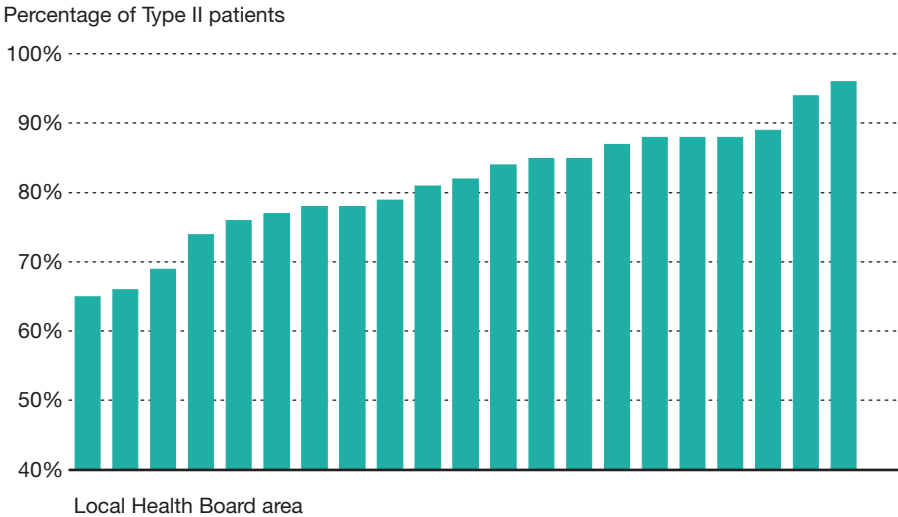
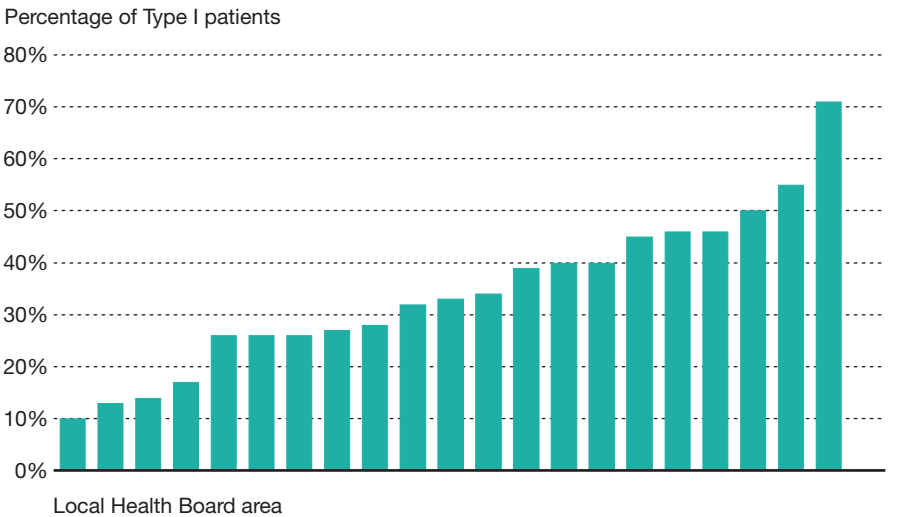
**Source:** PEDW data, 2001

There is no specific clinical code to identify hyperglycaemia, this would be coded under diabetes without complications, therefore figures are highly inflated

7 The majority of adults with Type II diabetes now receive most of their routine care from general practice, indicating the increasing role that primary care is playing in the management of diabetes in Wales. These patterns of care do, however, exhibit geographic variation (**Exhibit 2**).

**Exhibit 2**  
**Proportion of patients receiving all or most of their care from general practice**

The number of people with diabetes receiving all or most of their care from general practice can vary considerably between LHB areas.



Source: Audit Commission in Wales survey of general practice, 2002 (see Appendix)

8 Depending on people's individual complications, a range of professionals can be involved in providing support and care for people with diabetes. Someone with diabetes can receive routine support and care from a GP, a practice nurse, a diabetic specialist nurse, a diabetologist or general physician, podiatrist/chiroprapist, dietician or ophthalmologist/optician. For patients this can represent a complex and potentially confusing series of interactions with the health service. Careful co-ordination is therefore required to ensure that the services patients receive are timely and appropriate and that they know where to go when they need support to help them manage their diabetes.

## Context and scope of the review

9 There is no clear evidence of what model of care is most effective for people with diabetes. The NSF focuses on improving standards of care across all settings and instigating 'real change in the way the NHS delivers care to people with diabetes'. *The National Service Framework for Diabetes (Wales): Standards* document (Ref. 2) sets out national standards to drive up service quality and tackle variations in care. It also identifies key interventions based on research evidence, including the previous Audit Commission publication, *Testing Times: A Review of Diabetes Services in England and Wales* (Ref. 1). The second stage of the NSF is a Delivery Strategy, which identifies key actions, targets and milestones together with underpinning programmes to support local delivery (Ref. 3).

10 The baseline review has been designed to provide evidence on service delivery in the key areas covered by the NSF standards. As such, it provides a 'gap analysis' of current services to inform implementation of the NSF. The review built on methodology and research techniques developed during previous Audit Commission work on diabetes that led to the publication of *Testing Times*. It has drawn on extensive surveys of general practices and people with diabetes in Wales. It has also involved site visits to all health authorities (now demised), LHGs/Bs and NHS trusts in Wales; with associated data collection from all these bodies. Data from an NHS trust survey by the All-Wales Podiatry Diabetic Subgroup was also used to inform our findings (see Appendix).

## Structure of this report

11 This report summarises the key messages at the all-Wales level that need to be considered as part of the implementation of the NSF. It provides an overview of current services for people with diabetes in Wales and highlights where action is needed to ensure progress against specific NSF standards.

12 Our findings have been organised into five chapters:

- The prevention and early detection of diabetes.
- Empowering patients and carers.

- Delivering effective clinical care.
- Supporting vulnerable patient groups.
- Planning, co-ordinating and monitoring diabetes services.

13 The report's final chapter, Meeting the challenge, considers the key issues that will need to be addressed in order to ensure successful delivery of the NSF standards over the coming years.

# 1



## Prevention and early detection of diabetes

Raising awareness of the symptoms and signs of diabetes among the public and health care professionals can help to ensure that diabetes is identified and diagnosed as early as possible. Moreover, the incidence of the most common form of diabetes, Type II, can be reduced by preventative healthcare strategies.

### Case study 1

#### Linking diabetes with the CHD NSF

General practices in **Flintshire** have included both patients at risk of developing diabetes and known diabetic patients over 18 years of age on their CHD registers. Patients on the register are offered a review with the GP or practice nurse, which includes blood sugar analysis. As a result:

- new diabetics are being identified;
- prevention activities are better co-ordinated; and
- the initiative provides the basis to develop comprehensive chronic disease registers.

Primary care development funds and CHD monies have been devolved to general practices, with practice action plans developed to improve the care of patients on the CHD registers. Action plans include links to the Diabetes NSF standards, and some practices have developed joint CHD and diabetes clinics.

*Source: Audit Commission in Wales fieldwork visit*

## Introduction

- 14 The incidence of the most common form of diabetes, Type II, can be reduced by preventative healthcare strategies. In addition, many people with Type II diabetes remain undiagnosed this can increase the risk of people having developed complications by the time of diagnosis. The prevention and early detection of diabetes is the responsibility of all those professionals who deliver diabetes care in the community and in hospitals, as well as LHBs, which have a strategic role in shaping and commissioning services.
- 15 This chapter examines:
- the steps that are being taken to reduce the risk of people within Wales developing Type II diabetes; and
  - how health bodies are tackling the challenge of identifying people with undiagnosed diabetes.

## Reducing the risk of developing diabetes

- 16 The baseline review indicated that much remains to be done in this area. To date, there has been little or no progress across Wales in developing strategies specifically aimed at reducing the risk of developing Type II diabetes. There is a need to apply primary prevention initiatives across the whole population, as well as targeting groups of patients who already have risk factors.
- 17 Within the demised LHGs and health authorities (HAs), initiatives around improving diet and nutrition, promoting physical activity and tackling obesity fell within the remit of health promotion specialists. In the main, these staff had not been part of the HA/LHG teams that were taking forward implementation plans for the Diabetes NSF. This clearly represents a challenge for the new LHBs and one which will need to be tackled within the statutory framework of health, social care and well-being strategies, in partnership with unitary authorities. Policy guidance from the Assembly indicates that one of the key aims of local health, social care and well-being strategies is to 'enhance the prevention role of both local authority services and health care services'. An important role for the national public health service is also indicated.
- 18 There are opportunities to make use of work already underway as part of the Coronary Heart Disease (CHD) NSF. The review indicated that there has been encouraging progress in some parts of Wales in using CHD disease registers to identify patients who are at risk of developing diabetes. These registers provide an opportunity to record key measures such as blood pressure, smoking status, fasting blood glucose, lipid profiles and family history and can be used to target interventions at patients who are at risk of diabetes, but who have not yet developed symptoms (**Case study 1**).

## Case study 2

### Lifestyle changes for high risk patients

At **Ceredigion and Mid Wales NHS Trust** the Diabetic Specialist Nurse works closely with the Cardiac Rehabilitation Nurse. They have jointly developed a course that encourages and supports patients with diabetes in reducing their risks of developing coronary heart disease through making changes to their lifestyle.

Selected patients attend a 12 week course based at a leisure centre.

They undergo an exercise programme and set and review goals on diet and exercise.

Baseline tests are taken at the start of the programme and progress is measured over time. The success of the initiative is not yet able to be fully assessed, as the long-term benefits of lifestyle changes will take time to emerge, however, early signs of take-up are encouraging.

*Source: Audit Commission in Wales fieldwork visit*

- 19 A key gap at present is the lack of focus on lifestyle factors when developing preventative strategies as part of both the Diabetes and CHD NSFs. Given the importance of physical activity and diet in relation to developing diabetes, this is an area that requires attention. The difficulties of encouraging patients to change their lifestyles was one of the key problems identified by healthcare professionals during the baseline review.
- 20 Tackling this requires an imaginative and committed approach, with evidence of emerging good practice in some areas (**Case study 2**). Some patients may benefit from a simple intervention, such as a prescription for physical exercise at a local leisure centre. Others may require more intensive support to motivate them to change their lifestyle that includes input from a number of professionals, such as dieticians and, possibly, even psychologists. However, accessibility to these healthcare professionals can be problematic (this is discussed further in Chapter 4). Moreover, staff who are in day to day contact with patients may benefit from specific training in order for them to be able to stimulate, encourage and support lifestyle change.
- 21 A key theme that emerged from the review was the fact that there is much unexploited data, particularly within primary care, that could be used to help target advice and support to people at risk of developing diabetes. However, a number of important issues need to be addressed in order to begin to make use of this information:
- there needs to be a co-ordinated approach to the delivery of separate, but linked NSFs, such as Diabetes and CHD (and subsequent NSFs for children's and renal services);
  - a flexible approach to sharing patient based data will be required and the support and advocacy of Caldicott guardians<sup>1</sup> will be vital; and
  - initiatives aimed at sharing information and patient data will need to be supported by the appropriate information technology.

## Identifying people with undiagnosed diabetes

- 22 Reviewers found limited evidence of any strategic approach to identify patients with undiagnosed diabetes, which is not surprising in the absence of any national screening guidelines. To date, effort has mainly been directed to opportunistic interventions, ad hoc awareness raising initiatives and campaigns by Diabetes UK.
- 23 Over half of practices (52 per cent) responding to the Audit Commission primary care survey indicated that they had developed some sort of processes to raise awareness of diabetes and its complications amongst their practice population.

<sup>1</sup> The Caldicott Committee's report on the *Review of Patient Identifiable Information*, published in December 1997, included a requirement for NHS organisations to appoint Caldicott Guardians to be responsible for agreeing and reviewing internal protocols governing the protection and use of patient identifiable information.

- 24 In the main, this awareness raising initiative was limited to placing posters and display material in waiting areas. However, there were also examples of opportunistic testing at CHD screening appointments (see Case study 1) and at new patient and well person 'health checks'. There was also evidence of more targeted 'screening' for patients based on age group, ethnic background or those with a family history of diabetes.
- 25 Interestingly, over half the practices responding to the primary care survey indicated that they had a 'screening policy' in place. Although this is encouraging, and could provide the basis for a model for primary prevention and screening of diabetes, care must be taken not to draw overly positive conclusions from this response. Screening is only likely to be fully effective when it is properly researched, standardised and funded. Evidence from the baseline review indicated that current 'screening' activity is ad hoc, unstandardised and opportunistic.
- 26 Currently there is no clear guidance on which high risk groups should be offered screening, which screening tests should be used and the costs and benefits of screening programmes. To address this, the UK National Screening Committee is to provide advice on targeted screening in 2005. This advice will be informed by additional research and pilot projects. Diabetes UK has developed a helpful guidance document (**Ref. 4**) on the early identification of people with Type II diabetes, which can be used by healthcare professionals to inform screening initiatives.
- 27 During the review it was noted that some high street pharmacy chains had been promoting 'free diabetes checks'. Whilst there is an undoubted opportunity to make better use of the professional skills and knowledge of pharmacists, this should be done as part of a co-ordinated initiative and with appropriate quality control measures to ensure that patients receive appropriate advice and signposting to local NHS services.
- 28 Strategies to improve patient awareness of risk factors, and the early signs of diabetes, need to be complemented by strategies that ensure the healthcare professionals with whom they come into contact are also aware of the signs and symptoms of the disease. The baseline review indicated that variable progress has been made in this area.
- 29 Many hospital based diabetes teams had organised awareness raising events for staff groups such as ward nurses, practice and district nurses and care home staff. However, there was a general absence of co-ordinated strategies and work programmes that had identified which staff groups needed to be targeted and what sort of information they needed. A lack of protected time for staff to attend awareness raising sessions and study days on diabetes was often a problem that limited take-up of this training.

## Recommendations

To improve the prevention and early detection of diabetes...

LHBs and local diabetes service advisory groups (LDSAGs) need to:

- ensure healthy living and diabetes awareness raising strategies are developed as an integral part of local Health, Social Care and Well-Being Strategies;
- ensure greater involvement of health promotion specialists with the local groups tasked with implementing the Diabetes NSF;
- co-ordinate the implementation of the Diabetes, CHD and other NSFs and use data that is available locally to target advice, support and treatment at people at risk of developing diabetes;
- ensure that appropriate continuing professional development and education programmes are in place to raise awareness of risk factors associated with the development of diabetes;
- ensure that healthcare professionals who come into regular contact with people who have diabetes have appropriate training in behaviour change techniques;
- promote a flexible and positive approach to the sharing of patient data, within the principles and guidelines of Caldicott; and
- ensure that initiatives aimed at sharing information and patient data are supported by the appropriate information technology.

The Assembly needs to:

- ensure guidance on development of Health, Social Care and Well-Being strategies promotes appropriate links to the Diabetes NSF; and
- develop an all-Wales approach to screening patients for diabetes based on the findings of the National Screening Committee when it reports in 2005.

# 2



## Empowering patients and carers

Diabetes is a lifelong condition and robust self management is key in minimising its effects and the risk of developing long-term complications. The provision of information, education and psychological support to facilitate self management is therefore a crucial element of effective diabetes care.

## Introduction

- 30 From the point of diagnosis, people with diabetes need structured and appropriate programmes of care with a strong focus on education and self management. Diabetes is a lifelong condition and self management is the key to minimising its effects.
- 31 This chapter covers the measures that can be taken to empower patients and carers, and reviews:
- **patient education programmes** – the ways in which community and hospital services provide education for patients and evaluate its effectiveness;
  - **promoting self management** – the range of information that is available to help people with diabetes understand their condition and its management, and the use of personal care planning, patient held records and other initiatives to assist in empowering patients; and
  - **patient satisfaction** – patients’ views on the care they receive and an indication of which aspects of care they believe need to be improved.
- 32 The results presented in this chapter are drawn from fieldwork at NHS trusts, the survey of general practices in Wales and a survey of 1,467 people with diabetes in Wales (see Appendix).

## Patient education programmes

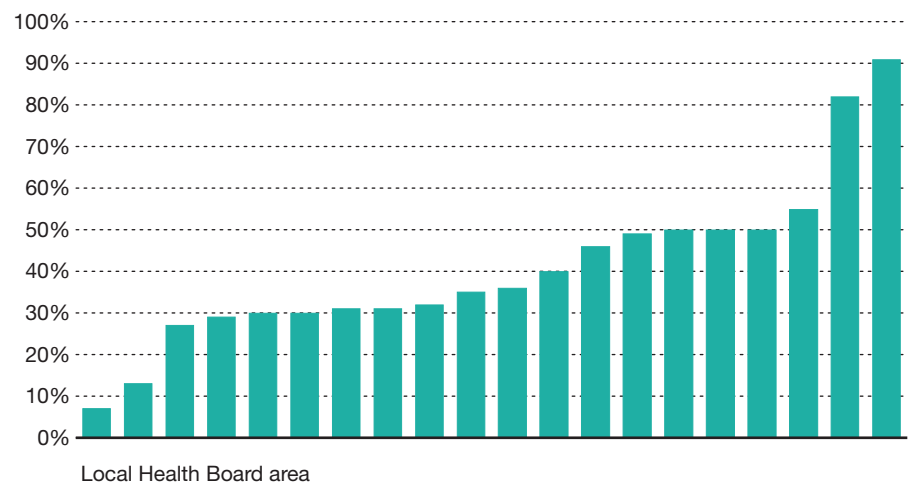
- 33 Reviewers found that all trust-based specialist diabetes teams in Wales had developed some form of structured education programmes, supported by a range of literature and information for patients. However, the content of education programmes varied within and between trusts and, in general, there was a lack of standardisation.
- 34 The review found that specialist diabetes nurses were invariably the key instigators of patient education programmes and played a particularly important role in the education of newly diagnosed patients. The variations observed in approaches to patient education were often linked to the different levels of staff resources. Examples of well-developed programmes for patient education were noted during the review, but there is a need to spread this good practice more widely.
- 35 General practices felt less confident that they had developed a ‘curriculum’ for patient education. Overall, fewer than half the practices in Wales (43 per cent) indicated that they had gone down this route, with much variation between LHB areas (**Exhibit 3**).

### Exhibit 3

#### Proportion of general practices who have developed a structured curriculum for patient education

There is significant geographical variation in the extent to which patient education programmes have been developed in primary care.

Percentage of practices with structured education



**Source:** Audit Commission in Wales survey of general practices, 2002

- 36 Where practices had indicated that they had developed a curriculum for patient education, they appear to include all, or most, of the key elements of a structured education programme, such as information on:
- the nature of diabetes;
  - its day to day management;
  - special problems and complications;
  - its effect on everyday living; and
  - preventative measures (for example, good foot care).
- 37 Exhibit 3 indicates that patient education in primary care was more developed in some parts of Wales than others. Links can be made to investment in specific roles, for example, in Newport, the LHG/B secured funds to employ a diabetes nurse facilitator to strengthen processes for the management of diabetes in primary care. This included the development of structured education programmes. Good progress is evidenced by the fact that over 90 per cent of general practices in the Newport area stated that they had developed an education curriculum for diabetes. **(Case studies 3 and 10).**

### Case study 3

## Structured education programme for patients

Newport LHG had developed a comprehensive set of guidelines for the management of diabetes in primary care. These included a structured education programme that comprised an extensive list of topics covering all the key elements of information that patients with diabetes need to receive. A simple proforma had been designed to allow a record of when particular topics had been addressed, together with space to record specific comments against each element.

*Source: Audit Commission in Wales fieldwork visit*

- 38 Patient education is not easy and staff in both primary and secondary care cited time, facilities and space as barriers to providing effective patient education. Healthcare professionals also felt that getting patients to change their lifestyle was a major impediment to successful management of diabetes.
- 39 Formal education programmes are important within specialist services, such as podiatry and dietetics. The all-Wales podiatry survey indicated that, generally, formal education programmes are not well developed, although some areas have introduced group education sessions for patients and carers.
- 40 Disappointingly, our review has indicated that there has been very little evidence of any formal evaluation of education programmes within either primary or secondary care. Even though such evaluation is likely to be time consuming, done properly it can provide invaluable information on which methods of education offer the greatest potential for improving outcomes for patients.
- 41 The effectiveness of education programmes can be judged, at least in part, by patients' awareness about their diabetes. Our survey of patients with diabetes in Wales indicated good levels of general awareness of diabetes and the importance of maintaining good diabetic control:
- only 2 per cent of patients responding to the survey did not know which type of diabetes they had;
  - over 98 per cent of respondents felt it was either worthwhile or very worthwhile to maintain good control over their diabetes;
  - about 83 per cent were aware that their general health was at greater risk because of their diabetes; and
  - over 70 per cent of respondents were either confident or very confident that good control of their blood glucose levels would prevent them from developing complications.
- 42 The National Institute for Clinical Excellence (NICE) has recently issued guidance on the use of patient education models for diabetes (**Ref. 5**). These should help standardise practice and ensure that education programmes are based on clearly defined good practice principles.

## Promoting self management

- 43 A key challenge is to encourage patients to 'take ownership' of their diabetes and provide them with appropriate information and professional support to manage the condition and minimise the risk of complication.
- 44 Responses to the survey of people with diabetes indicate that, overall, they are getting a lot of information on important areas such as:
- controlling their blood glucose levels;

- keeping to an ideal weight;
- benefits of exercise;
- how diet can affect diabetes;
- the importance of regular check ups, including eye checks; and
- the importance of foot care.

45 However, a more mixed response was obtained from respondents in relation to information on:

- the effects of smoking and alcohol on diabetes;
- what can happen when blood glucose levels get too low;
- what to do if you start to feel unwell; and
- the potential long-term complications of diabetes.

46 The development of agreed personal care plans are one way of helping patients to take greater responsibility for the management of their diabetes. The review indicated that the approach to the development of personal care planning for people with diabetes is ad hoc and extremely variable. Reviewers struggled to find any explicit examples of good practice in relation to personal care planning and this remains a major area for development.

47 Isolated examples of the use of patient-held records were identified but, in the main, these are absent. This impedes joined up care across professional groups and the ability to give the patient some ownership of the management of their diabetes.

48 Different approaches to patient empowerment were noted across Wales. These included:

- routinely copying patients in on letters from the hospital to the GP;
- using email and mobile phone text messaging to stay in contact with younger patients;
- peer support schemes;
- patient-held records that included patient objectives; and
- clinics specifically aimed at the management of risk factors.

Case study 4 provides details of several of these schemes.

49 At the time of the baseline review, the Assembly was piloting a Chronic Disease Self Management Programme at two LHB areas in Wales, as part of a commitment to build a network of 'expert patients' in Wales. Although involvement of diabetes patients in the pilot was not extensive, the initiative does offer the opportunity to identify and evaluate good practice approaches to self management of chronic diseases such as diabetes. It will be important to ensure that lessons learnt from the pilot are rolled out and applied to diabetes patients across Wales.

## Case study 4

### Promoting self management

**Peer support scheme in Merthyr** — The Diabetes Peer Support Programme is a layperson led self management programme delivered by, and to, people with diabetes. The programme aims to provide participants with non-medical advice and support, enabling them to build confidence in their ability to manage their health and maintain active and fulfilling lives.

**Patient-held record in secondary care** — Patients under the care of the diabetes team at the Princess of Wales Hospital in Bridgend are given an A5 diabetes record card to bring with them each time they attend the clinic. The card provides a record of appointments, key biochemical tests and clinical measurements, together with an education checklist. Members of the hospital diabetes team indicated that they felt the card, which is used by around 80 per cent of patients, assisted them in tracking trends in the management of individuals' diabetes and discussing with patients where key actions were needed.

**Patient-held record in primary care** — A patient-held diabetes record has been introduced by the Arwystli Medical Practice in Powys. The patient-held record is in the form of an A5 booklet in a hard backed file. The record provides a summary of appointments and attendances covering all clinics and health professionals; details the patient's goals for the next review (including HbA1c, diet, exercise and smoking); and details the results of tests, investigations and medication. The booklet also provides information on the condition, review process and medication, and why the various tests and investigations are needed. There is also advice on healthy eating, exercise and alcohol consumption.

**Risk factor control clinic at Prince Phillip Hospital, Llanelli** — A risk factor control clinic has been developed at Prince Phillip Hospital. The clinic targets support to high risk diabetes patients and has led to improved glycaemic and blood pressure control by patients.

The clinic is led by a diabetes nurse specialist. Diabetic patients with poor glycaemic or blood pressure control are referred to the risk factor clinic for a programme of three visits, at three monthly intervals. At the clinics:

- diabetes education and lifestyle factors are assessed;
- advice on lifestyle changes is provided; and
- therapeutic changes according to detailed evidence based guidelines are instituted.

A pilot study of the scheme found that the nurse led clinics resulted in better glycaemic and blood pressure control by patients, as evidenced by a higher proportion of patients meeting treatment goals for HbA1c and BP. An audit is now underway to assess this approach fully.

*Source: Audit Commission in Wales fieldwork visits*

- 50 The majority of people responding to our survey (75 per cent) felt that they had good control over their diabetes, although many also felt that the condition prevented them from leading a normal life.
- 51 The survey indicated that, in the vast majority of cases, patients felt that they were able to discuss their diabetes with someone who spoke their preferred language. Many patients felt that they did not need help in this area. The survey highlighted a few isolated cases of problems in terms of patients not being able to communicate in their language choice, but these constituted a very small proportion of overall responses. *[NB this was not a survey targeted specifically at groups of patients from different ethnic backgrounds.]*
- 52 Overall, 47 per cent of respondents were aware of support groups in their area to help them understand and manage their diabetes. The response to this question was patchy and exhibited much geographical variation, indicating more activity in some parts of Wales than others.

## Patient satisfaction

- 53 Overall, people with diabetes responding to our survey were complimentary about the care they received from both general practice and hospital clinics in terms of:
- its convenience;
  - the extent of information they received;
  - the quality of that information; and
  - having a feeling of being listened to.
- 54 However, the survey also highlighted areas of common concern, with the following issues being the most frequently cited:
- access to chiropody/podiatry services (most frequently mentioned);
  - waiting times for a hospital appointment;
  - ability to have all routine check ups in the same place;
  - waiting times at hospital clinics;
  - getting consistent advice from different healthcare professionals;
  - access to an eye clinic/specialist;
  - better written information; and
  - timing of clinics.
- 55 Many patients did not feel able to give a view of whether the care they received was good or not, indicating that there is still a need to raise patients' awareness of what constitutes a good diabetes service.

- 56 In addition, variations in responses were obtained from different LHB areas, indicating that different areas face different challenges. For example, all respondents within some LHB areas felt that they received good quality information on diabetes from their GP surgery whereas, in others, the figure was only 65 per cent.
- 57 Respondents were invited to use the survey to provide additional comments on their diabetes. A wide and varied range of responses was received. The following are some notable examples:

*'I have had diabetes since 1967 and have always felt very well looked after by the health service. Recently doctors have begun to explain the results of various tests. I feel this is helpful as it helps me to achieve better control. However, not all doctors and nurses do this.'*

*'I am very pleased with the level of care that I receive from my GP and diabetic nurse. The only thing that I feel is that your eyes should be checked every 12 months and not 18 months.'*

*'I am at present taking Gliclazide to control my diabetes. I feel that my blood sugar levels are so high that I need to take insulin. I am under the care of [two consultants]. One says that I do not need insulin, the other says I do. Where do I stand?'*

*'I have been a diabetic for at least five years and have not yet seen a diabetic specialist, neither have I has any annual check ups.'*

## Recommendations

To support self management in diabetes...

Specialist diabetes services staff should work with staff in primary care to:

- develop standardised and structured programmes of patient education based on recognised good practice, which are periodically evaluated for effectiveness;
- review the patient information that is available and agree when this information is to be provided to people with diabetes;
- develop patient-held records and personal care plans as a mechanism for promoting patient involvement in the management of their diabetes; and
- gather views on patient experiences systematically as a part of their routine service monitoring exercises.

The Assembly should:

- take steps to ensure that the core contents for patient education programmes are based on the recently issued NICE technical guidance; and
- use the results from the Chronic Disease Self Management Programme pilot exercises to develop an evidence based approach self management programme for diabetes across Wales.

# 3



## Delivering effective clinical care

Structured diabetes care programmes that include the provision of regular recall and review of people with diabetes can improve the quality of diabetes care and result in better diabetic control, lower risk of long-term complications and a higher quality of life.

- 58 This chapter examines the nature and content of services for people with diabetes provided by general practices and specialist hospital teams and, in particular, whether:
- **guidelines for diabetes care** have been developed – using guidelines based on the best, and most recent evidence is a good way of ensuring consistency of care for patients;
  - people with diabetes have speedy **access to specialist services** – following referral, patients should not have to wait too long to be seen;
  - **regular surveillance** is in place – systematic reviews can help detect complications at an early stage, to highlight problems of diabetes control and to identify people who are at risk of coronary heart disease and kidney failure;
  - services are **responding to complications** effectively – good preventative care can minimise the effects of diabetes, but services will always be needed to treat complications; or
  - services are **managing emergencies** effectively – steps need to be taken to help manage emergencies when they arise, from provision of appropriate information to people with diabetes through to access to hospital care.

## Defining best practice through guidelines and protocols

- 59 Guidelines for diabetes care have been developed in most localities and are generally based upon accepted good practice from previous research, such as the United Kingdom Prospective Diabetes Study (UKPDS) (**Refs. 6 and 7**). In most localities, however, these guidelines need updating to reflect the NSF and recent guidelines from NICE (**Ref. 8**).
- 60 In some localities, the guidelines have only been developed for one care setting, for example, hospital based care. Others do not specify criteria for referral to specialist care. Across Wales as a whole, there was little evidence of routine audit to check on whether services are being delivered in line with the prescribed guidelines and protocols.

## Access to specialist services

- 61 There was wide variation in the waiting times reported by trusts in Wales for first appointments to see a variety of key professionals (**Table 2, overleaf**).

**Table 2**  
**Waiting times for first appointments**

	Shortest wait	Longest wait
<b>First appointment:</b>		
In diabetes clinic following GP referral	1 week	1 year
Photocoagulation following referral to ophthalmic surgeon	2 weeks	8 to 16 weeks
With dietician following referral as an inpatient	4-8 days	2 weeks
With dietician following referral as outpatient	<1 week	4 months
With podiatrist following referral as an inpatient	1 week	4-6 weeks
With podiatrist following referral as outpatient	<1 week	3-4 weeks

Note: Times are those stated by trusts in response to the Audit Commission questionnaire; some trusts provided a range of waiting times.

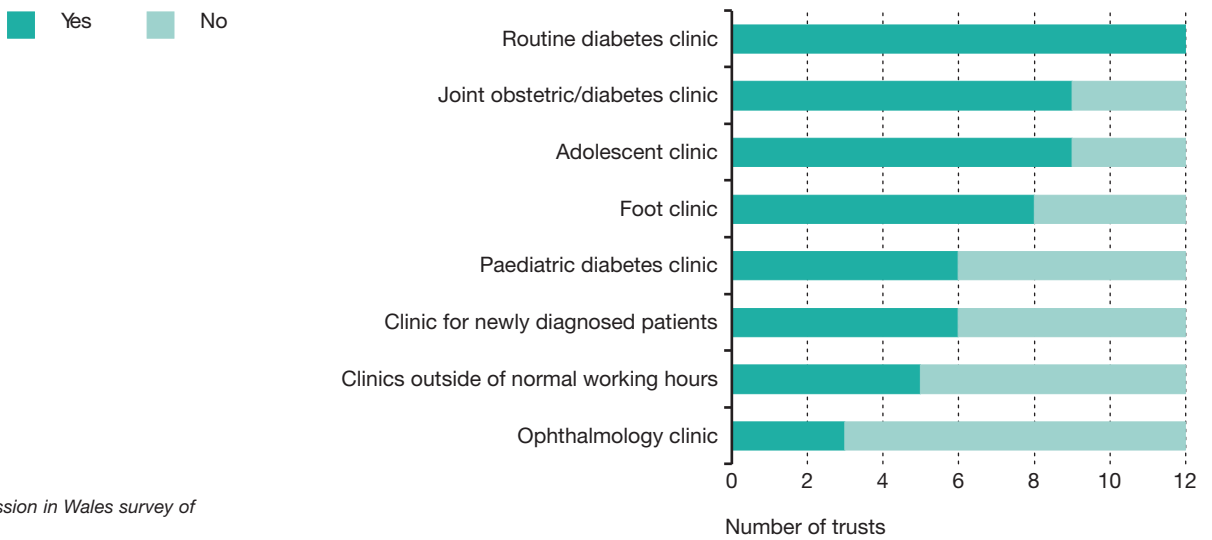
Source: Audit Commission in Wales survey of NHS Trusts, 2002

- 62 Although trust mergers took place in Wales at least two years ago, many trusts are still operating separate diabetes services in different acute hospital sites within the same trust. The waiting times shown in Table 2 can vary significantly between different hospital sites, within the same trust. In addition, some trusts were able to provide waiting times data by consultant. These can also show large variations, for example, one trust reported that waiting times for first appointments by consultant vary from 6 to 36 weeks.
- 63 There is also a significant degree of variation in the range and timing of clinics that are run in trusts across Wales. Dedicated clinics for the newly diagnosed patients are only available in half of Welsh trusts, whilst fewer still run clinics outside of normal working hours (**Exhibit 4**).
- 64 Large variations also exist in the numbers of new patients seen as a percentage of all outpatient consultations (**Exhibit 5**). This indicates differing practices across Wales in relation to:
- how long patients are supported by the specialist team;
  - approaches to discharging patients to primary care; and
  - the frequency of follow-up contacts.
- 65 Some hospital based teams are more confident about discharging patients to primary care than others. The lack of development of primary care services for diabetes in some areas, to some extent, justifies concerns about discharging back to primary care. However, it may also reflect historical practice that now needs to be reviewed. The consequence of retaining patients within the acute sector is an ever increasing workload that hospital based teams will find increasingly difficult to manage.

### Exhibit 4

#### Range of diabetes clinics in Welsh trusts

There is variation in the type and timing of diabetes clinics.

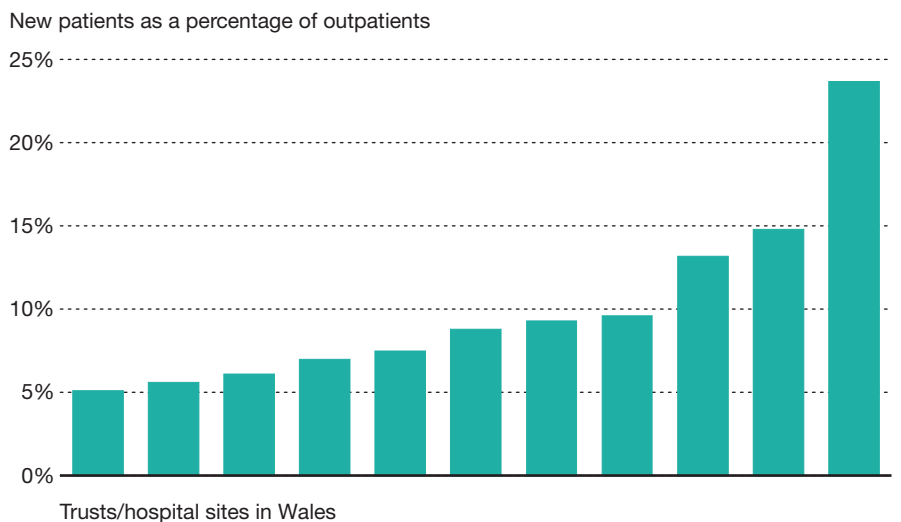


Source: Audit Commission in Wales survey of NHS Trusts, 2002

### Exhibit 5

#### New patients as a proportion of all outpatient consultations

The proportion of new to follow up patients varies significantly across Welsh trusts. A lower overall proportion of new patients indicates that patients are retained longer under the care of the specialist hospital team.



Source: Audit Commission in Wales survey of NHS Trusts, 2002

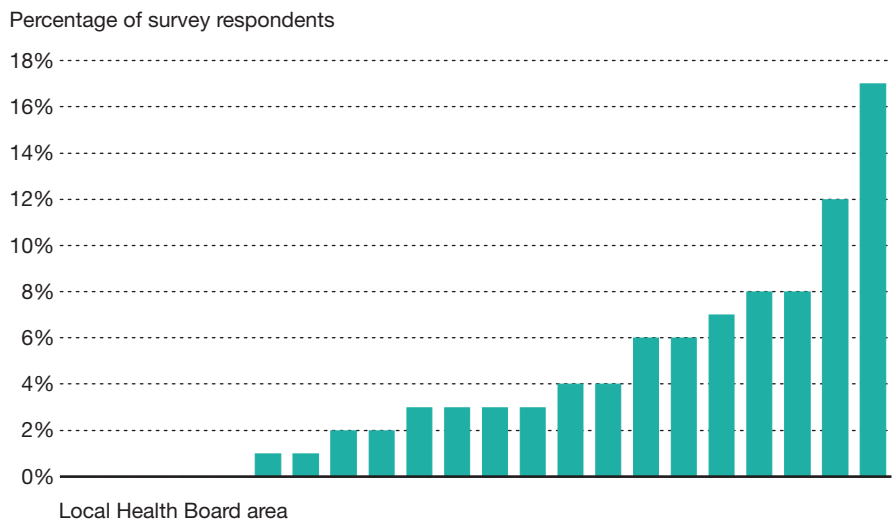
## Regular surveillance

- 66 Patients with diabetes can receive regular surveillance from either hospital based teams, or from their general practice, or from both. This review’s survey of people with diabetes covered people receiving care from all settings. The majority of respondents indicated that they always received an annual check up with a doctor. However, some geographical variation across Wales was noted, with some LHB areas having a higher proportion of patients who did not have annual check ups with a doctor (**Exhibit 6**).
- 67 The majority of respondents indicated that they saw someone about their diabetes between one and five times a year. Thirty-two patients (out of a total of 1,481 respondents) indicated they had not seen anyone in the last year.
- 68 When asked about the content of their structured/annual review, a varied picture was obtained across Wales. These differences are attributable to a number of factors:
  - differences in clinical practice of consultants and GPs;
  - availability of healthcare professionals such as dieticians and podiatrists;
  - facilities and equipment;
  - clinic workload; and
  - access to specialist services such as retinopathy screening.

### Exhibit 6

#### Proportion of survey respondents who do not have an annual check up with a doctor

The proportion of respondents indicating that they do not receive at least annual check ups with their doctor varies across Wales.



Source: Audit Commission in Wales survey of people with diabetes, 2002

- 69 Overall, it appears that most people with diabetes are getting a number of key examinations and tests on a regular basis:
- weight;
  - blood pressure;
  - HbA1c; and
  - blood cholesterol.
- 70 More variable responses were recorded for foot pulse examinations and kidney function tests. But more worrying was the relatively low number of patients who indicated that they received regular testing of their visual acuity and fundi through dilated pupils.

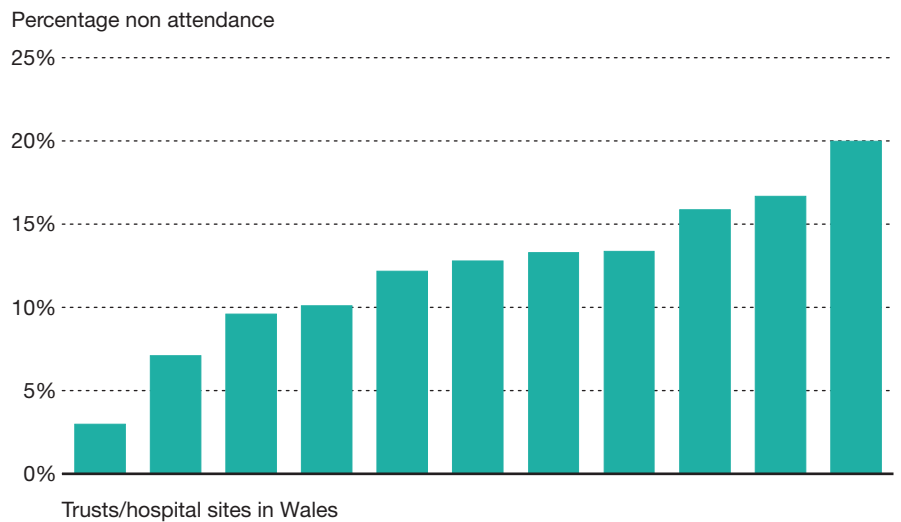
## Regular surveillance by hospital based teams

- 71 A review of a sample of casenotes in each trust indicated that the completeness of hospital based annual reviews appears to have improved since the Audit Commission last reviewed diabetes some three to four years ago.
- 72 Typically, annual or structured reviews included measurement of key parameters such as blood pressure, Hb1Ac and lipid profile. Weight was commonly recorded, but calculation of body mass index, a more informative parameter, was less frequently noted. A variable picture was also obtained in relation to kidney function tests, foot and eye examination, smoking status and dietary advice. This largely correlated with results obtained from the survey of people with diabetes.
- 73 Many trusts have developed documentation and proformas to help standardise the conduct and content of their annual reviews, and to record the results obtained. However, their design and use can vary significantly both within and between trusts.
- 74 Workload and staff resource pressures can often contribute to the problems with the timeliness and content of patients' structured reviews. As an example, patients who are unable to attend a clinic on a specified day may have to wait many months for another appointment.
- 75 Different approaches to the call, and recall, of patients were observed between trusts. Many patients receive automatic reminders about annual review and other clinic appointments, but this is not necessarily the norm and, often, the onus is put on patients to make, and keep, their next appointment. These differences in approaches are reflected in varying attendance rates at clinics, and several trusts also reported worryingly high non-attendance rates at their diabetic clinics. The rates of non-attendance at clinics varied between trusts and ranged from 3 per cent up to 20 per cent (**Exhibit 7, overleaf**).

## Exhibit 7

### Non-attendance rates at hospital clinics

There are high rates of non-attendance at diabetes clinics in some trusts.



Source: Audit Commission in Wales survey of NHS Trusts, 2002

- 76** The management and organisation of diabetes outpatient clinics can vary significantly across Wales. In several trusts patients did not routinely have bloods taken in advance of their structured review, which undermined the usefulness of the consultation. Many patients also miss out on important eye examinations because they have driven to the clinic and cannot have drops administered to dilate their pupils. This can be overcome by provision of better information to patients ahead of their clinic appointment.
- 77** For adult patients, telephone access to specialist staff is limited to normal working hours, with no evening, night or weekend telephone access in most Welsh trusts. However, the review did find examples of diabetic specialist nurses giving patients their mobile phone numbers to enable contact outside working hours in the case of an emergency.
- 78** The review also highlighted concerns about some arrangements for biochemical testing. Whilst quality assurance procedures for laboratory based HbA1c testing appear to be sound, there are much less robust quality assurance measures in place for point of care testing for the measurement of both HbA1c and blood glucose. Moreover, not all trusts in Wales have the facilities to undertake measurement of urinary microalbuminuria, an important marker of renal function.

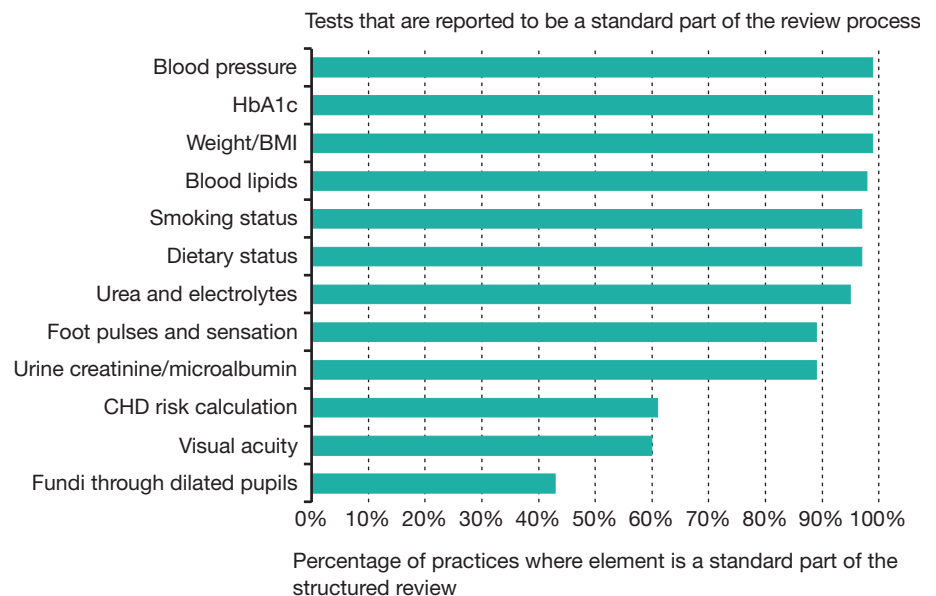
## Regular surveillance by primary care teams

- 79 Over 83 per cent of practices responding to the baseline review survey indicated that they routinely offered all their patients with diabetes an annual review. A further 14 per cent said that 'most' of their diabetes patients received this type of structured check up at least annually.
- 80 Practices indicated that the majority of the important tests and examinations were undertaken as a standard part of annual reviews. However, once again, a lower proportion of practices indicated that foot and eye examination and kidney function tests were a standard part of the review process (**Exhibit 8**).
- 81 The lower figures for eye screening tests may reflect the fact that many patients will be seen in specialist eye clinics or by their optician. However, there is also a risk that many patients are currently missing out on this important part of their structured check-up. The lower figure for urinary creatinine and microalbumin is also a concern.

### Exhibit 8

#### Routine surveillance in primary care

Some important elements of structured reviews can be absent.



Source: Audit Commission in Wales survey of general practices, 2002

- 82 Validation of survey results obtained during the baseline review has indicated the need to interpret some self reported results with caution. For example, in one part of Wales, all practices responding to our survey stated that HbA1c was a standard part of the annual review process, but a local primary care audit indicated that only 76 per cent of patient records contained such a test result in the previous 13 months.
- 83 Practices across Wales provide a range of different types of diabetes care. Most commonly, this takes the form of diabetes clinics run by GPs and practice nurses together, although it is also common to see clinics run by practice nurses only. The all-Wales picture is largely replicated within individual LHB areas. The majority of practices in Wales (66 per cent) hold clinics weekly, although in many practices clinics are less frequent. On average, around eight patients per clinic are seen, although, again, this can vary significantly.

## Other specialist staff

- 84 The ability to provide routine professional support to general practices from practitioners such as podiatrists and dieticians is patchy and varies considerably across Wales. This raises concern that patients in some parts of Wales, who receive the bulk of their care from general practice, are not getting sufficient access to these important support services. Particular concerns were raised about access to podiatry services in primary care in many parts of Wales, with 34 per cent of practices indicating that they do not have routine access to a podiatrist at their diabetes clinics.
- 85 Problems are largely related to limited staff resources in these specialist areas. However, the review also indicated that, in some parts of Wales, historical service provision that dated back to GP fundholding had resulted in an uneven access to dietician and podiatrist support across general practices.
- 86 Problems in getting access to dieticians and podiatrists were also a concern at a number of trusts. As a result, clinics in some trusts need to run without dietician and podiatrist support.
- 87 Access to psychological support for patients with diabetes was routinely identified as a major problem across all parts of the service in Wales. All trusts indicated that it was virtually impossible to refer patients for specialist psychological treatment. In the main, psychologists with a special interest in diabetes were simply not in post. In the minority of trusts that do have this staff resource, workload pressures significantly restrict access to these healthcare professionals.
- 88 Most healthcare professionals interviewed during the review saw access to psychological support as particularly important for adolescents and young people. However, problems are not just confined to this age group, since a diagnosis of

diabetes can have a major psychological impact for any patient. Appropriate support can facilitate better self management and motivation to make the necessary changes to lifestyle.

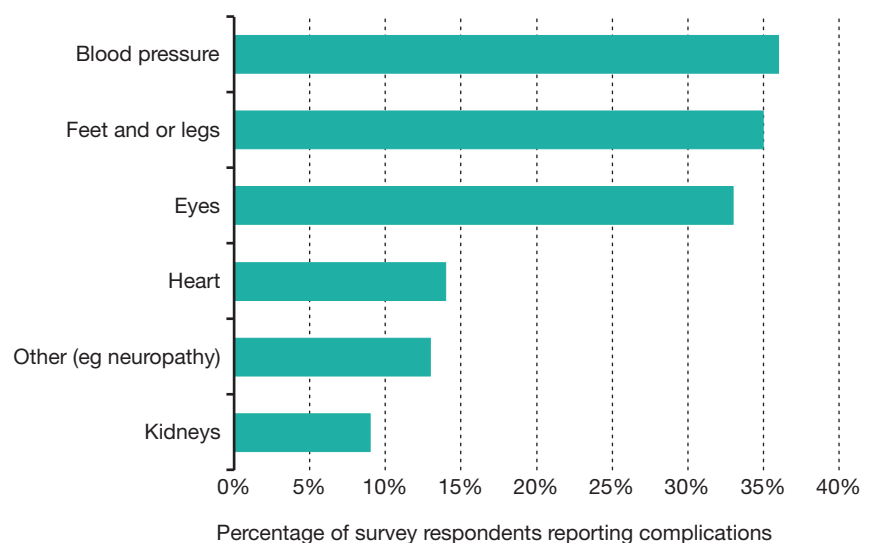
## Responding to complications

- 89 Many patients responding to the Audit Commission survey reported suffering complications as a result of their diabetes (**Exhibit 9**).
- 90 Encouragingly, most respondents indicated that it was relatively easy to get the right care to manage these complications. However, more than one in five patients indicated that they had some difficulties in getting such help, whilst 70 patients across Wales (6.5 per cent) felt they had experienced 'real difficulties'.
- 91 Success in detecting complications at an early stage depends on a high degree of awareness both among patients and healthcare professionals. Patients may not recognise complications and so may delay seeking treatment. Similarly, professionals may fail to detect early complications which are amenable to treatment, particularly in relation to the eyes, feet and kidneys.

### Exhibit 9

#### Incidence of complications associated with diabetes

A significant proportion of respondents to the Audit Commission survey reported complications with their diabetes, particularly in relation to blood pressure and feet or legs.



Source: Audit Commission in Wales survey of people with diabetes, 2002

## Complications affecting the eyes

- 92 There are currently considerable gaps in the provision of screening services for diabetic retinopathy in Wales. This was a significant cause for concern amongst many of the health professionals we spoke to during the review. The all-Wales retinopathy screening programme, launched in July 2002, provides an excellent opportunity to redress this problem, although its implementation will take time and will require an investment in equipment and training staff to use it. Specific action aimed at raising awareness of the screening programme and its benefits will help to ensure that as many patients as possible benefit from the initiative.
- 93 The all-Wales programme is based on the current retinopathy screening service at Bro Taf, which has had a positive impact in detecting problems and helping get early treatment to prevent serious complications. However, the review did indicate that current screening services in Bro Taf can often have long waiting times and problems with non-attendance.
- 94 Not all trusts were able to provide information on waiting times for photocoagulation treatment following referral. Where data was provided, it showed that waiting times varied from two to sixteen weeks.
- 95 The ability to monitor outcomes of eye screening is significantly limited by a lack of information. Current information systems in NHS Wales do not permit rates of new blindness attributable to diabetes to be measured. Registers created through the all-Wales screening programme will hopefully provide an opportunity to improve this information gap, provided that protocols for the sharing of clinical data can be agreed.

## Complications of the feet

- 96 Access to specialist care for diabetic foot problems was a concern in many parts of Wales. Many general practices raised the lack of access to podiatry services as one of the main barriers to delivery of effective diabetes services.
- 97 Access to specialist services when urgent problems occur can occasionally be a concern. The frequency of foot clinics varies significantly across trusts in Wales, meaning that some patients can face long waits to be seen by specialist staff. Some trusts run several foot clinics a week, others do not run any. Many trusts will aim to see urgent referrals as quickly as possible, but staff resources can limit the speed at which this occurs.
- 98 The organisation of foot clinics also varies significantly, both within and between trusts, in terms of the staff present and the policy on foot screening. One hospital site indicated that it includes foot screening in its annual review only for patients aged 50 and over.

## Case study 5 Management of complications

**Co-ordinated detection and management of retinopathy and foot complications in Conwy** — A 'one stop shop' has been developed by Conwy and Denbighshire NHS Trust for retinopathy and foot screening. Service users need only attend one appointment for both checks, and the mobile van service reduces the distance that people have to travel to be seen.

The service is led by a nurse for retinopathy and a diabetes specialist podiatrist for foot screening. There are agreed local protocols and standards for the quality and coverage of the service, and the effectiveness of the service is audited.

A local register is maintained by the LHB and cross checking with practices has ensured that all Conwy patients are on the programme. A screening co-ordinator at the LHB sends out a letter to patients asking them to contact her and book an appointment for the combined checks. All Conwy patients are offered an annual appointment.

*Source: Audit Commission in Wales fieldwork visit*

- 99 Encouragingly, many trusts are moving to having dedicated diabetes sessions with podiatrists who specialise in diabetes. This is having a positive impact on service provision. Most trusts also report good links between vascular surgery and diabetes teams, even though joint clinics are rare.
- 100 A minority of podiatry services (five out of thirteen trusts) offer annual checks to all diabetics. A number of trusts stated that podiatry staff resources restrict, or do not allow, full annual review provision. Elsewhere, podiatry based annual reviews can be offered:
- to those referred by primary care specifically for an annual check; and
  - on an ad hoc basis or for patients under the podiatrists direct care.
- 101 There is also variation between podiatry services in Wales in the neurological, vascular and subjective testing that is routinely performed as part of the diabetic patient assessment process.
- 102 Awareness of diabetic foot complications amongst other health professionals is another issue that requires attention. Although specialist nurses and podiatrists reported that awareness amongst staff groups, such as district nurses, is improving, there is still room for improvement in recognising early signs of ulceration and other foot problems amongst staff groups such ward nurses and care home staff.
- 103 Poor quality information is, again, an issue in managing and monitoring foot services, and reliable data on lower limb amputations associated with diabetes within Wales is limited.
- 104 There is, however, encouraging evidence that some parts of Wales have developed patient focused approaches to the management of complications, based upon having a single point of contact with a range of specialist staff (**Case study 5**).

## Complications of the kidneys

- 105 The review indicated that frequency of testing for renal problems as part of diabetic annual reviews has improved since the Audit Commission published *Testing Times* in 2000 (**Ref. 1**). However, there are still gaps in this screening and lack of access to specialist laboratory assay for microalbuminuria in some trusts is a worry.
- 106 Statistics on the proportion of patients with end stage renal disease who are diabetic are patchy across Wales, and many trusts did not have this information. Where data was provided, the proportion varied from 2 per cent to 35 per cent.
- 107 No trusts reported that they ran joint renal/diabetes clinics, although fieldwork in most trusts indicated that clinical communication between these specialties was generally good.

## Managing emergencies

- 108 Reviewers found that, although guidelines and protocols for the management of diabetic emergencies had been produced in many parts of Wales, they were often old and in need of updating.
- 109 Overall, there was good evidence to suggest that educational material provided to patients contains information to help recognise the signs of diabetic emergencies and what to do if they arise. However, our survey of people with diabetes indicated that many patients in Wales are still unclear about what symptoms are associated with a drop in blood glucose, or what to do if they generally start to feel unwell. This suggests the need to review these aspects of patient education.
- 110 Data from PEDW suggests that the number of hospital admissions for hyperglycaemia is increasing, although anomalies with clinical coding systems make this data difficult to interpret clearly. More reliable data is available for the number of admissions for diabetic ketoacidosis. There are typically around 600 plus admissions per year in Wales for this condition. The level since 1995 has been fairly constant, suggesting neither an escalation nor a reduction in this problem.
- 111 The review did not highlight any specific problems with urgent access to hospital care when diabetic emergencies arise, although patients in rural parts of Wales, such as Powys, can experience long journeys when they need to be admitted to hospital. Prompt ambulance response times can be important in the effective treatment of patients experiencing a diabetic crisis, but separate studies have shown that ambulance response times vary significantly across Wales and, typically, do not meet the prescribed emergency response target (**Ref. 9**).

## Recommendations

To help deliver more effective clinical care...

Specialist diabetes services, together with primary care, need to:

- ensure comprehensive guidelines are in place, covering all care settings, are regularly kept up to date with periodic review, to ensure their implementation;
- review what steps can be taken to reduce the waiting times to be seen, following initial referral to specialist services, where lengths of wait are high;
- ensure patients receive a full structured review at least annually (including foot and eye examinations and dietary advice), with results being recorded in a standard format which is shared across primary and secondary care and is subject to regular audit;
- take action to address problems with access to podiatry and dietetic services in localities where the baseline review has identified problems;
- ensure that laboratory assays for microalbuminuria are available at all NHS trusts in Wales;
- ensure that information and advice for patients is available on retinal screening procedures to ensure attendance; and
- review the adequacy of arrangements for patient education relating to managing emergencies and ensure that there is appropriate access to specialist advice out of hours.

The Assembly should:

- agree the key outcome measures associated with diabetic complications and arrange for this data to be collected and shared across Wales; and
- agree waiting time targets for access to specialist services.

# 4



## Supporting vulnerable patient groups

Some groups of people with diabetes have particular needs. These include children, pregnant women, hospital inpatients and minority ethnic groups. It is important that diabetes services are properly organised to meet the specific needs of these patients.

- 112** Some groups of people with diabetes have specific and particular needs which diabetes services need to address. This chapter examines the services available for:
- children and young people;
  - pregnant women;
  - patients requiring a stay in hospital;
  - minority ethnic groups; and
  - people who are housebound, in care homes or residential settings.

## Services for children and young people

- 113** The baseline review highlighted several encouraging aspects of the care for children and young people with diabetes. In general terms, care provided for this patient group was proactive, user-friendly and focused towards patient empowerment.
- 114** Care for children and young people with diabetes is provided primarily by specialist staff based in acute hospitals. Most, but not all, trusts in Wales (ten out of the twelve responding trusts) have a paediatrician with a special interest in diabetes, who oversees the clinical care of children and young people with diabetes. This specialist physician resource is a crucial element in delivering effective paediatric diabetes services.
- 115** Specialist paediatric diabetic nurses play an equally crucial role in the delivery of diabetes services to children and young people. They are usually the main point of contact for the patient and often make themselves available out of hours to provide advice and support, both to children and their parents. Three trusts in Wales do not have a paediatric diabetic specialist nurses (DSNs) in post and, as a result, services are not always as responsive as they could be.
- 116** Baseline review findings indicated that structured or annual reviews for paediatric patients across Wales were generally complete and timely. As with adult services, the structure and content of the annual review in some trusts would benefit from a degree of standardisation and use of proformas to capture results from key examinations and tests.
- 117** There was good evidence that hospital based teams were using innovative mechanisms to engage with patients. For example, making use of mobile phone text messaging to remind patients of appointments, or writing to the child with clinic results to encourage more active involvement in their care.

## Case study 6

### Engaging young people at diabetes clinics

At Conwy and Denbighshire NHS Trust, a young people's clinic is run three times a year. The clinic is led by the adult diabetologist and involves podiatry, dietetics and the DSN. Family planning advice is provided by the family planning consultant.

To ensure that the service met user needs, a consultation exercise was carried out, involving focus groups and surveys of young people. Following the patient consultation the service was reorganised and now includes special facilities such as music, videos and magazines for young people. Text messaging to remind patients of their appointments is in place and email links are being explored.

Involving young people in redesigning services is expected to both increase ownership and develop patient empowerment. It is hoped that this will lead to higher levels of attendance and compliance. The impact on non-attendance rates will be assessed once the new clinic has been in operation for a longer period. Early anecdotal evidence indicates that the changes are leading to positive results.

*Source: Audit Commission in Wales fieldwork visit*

- 118 Liaison with nurseries and schools tended to be ad hoc. In the main, paediatric DSNs would make contact with a school once a child had been diagnosed, to provide basic information on awareness and day to day management of diabetes. However, paediatric DSNs cited the absence of school nurses in a great many schools across Wales as an impediment to the day to day management of children with diabetes.
- 119 Reviewers found a variable approach to provision of care for adolescents. Three out of twelve trusts had no specialist clinics for these patients. In the absence of adolescent diabetes clinics, young people with diabetes typically attend paediatric clinics until they are 18 and then transfer to the adult service. However, most trusts offer a degree of flexibility on the age of transfer depending on the patient's preference. Where clinics for adolescents are provided, their frequency varies from monthly to quarterly.
- 120 Trusts indicated that non-attendance rates at adolescent clinics was typically high and, at some sites, could approach 50 per cent. Four trusts had attempted to manage this by holding late afternoon/early evening clinics in attempt to improve attendance. In some areas this proved successful, whilst in others, problems persisted and further review of arrangements is needed. Involving young people in the way clinics are run is one way of potentially reducing problems with non-attendance rates (**Case study 6**).
- 121 Provision of adolescent clinics is a mechanism of managing the transfer between paediatric and adult care. Where they are absent, the difference in approach and clinical setting between paediatric and adult settings can be stark and potentially traumatic for patients. An absence of young adult/adolescent clinics tended to be associated with greater concerns that patients were being 'lost' to the service.
- 122 Most trusts appear to have developed a fairly robust approach to managing the transfer from paediatric to adult services. In the main, this involves some form of structured handover session in a clinic setting, with both paediatric and adult specialist nurses. This allows the patient to be introduced to the staff who will care for them in an adult setting and provides an opportunity to familiarise themselves with the new clinic setting and arrangements. An important consideration overlooked in most trusts is the need to provide an extended handover period for some patients.

## Services for pregnant women

- 123 Where guidelines on diabetes care have been produced they typically include the management of diabetes during pregnancy but, as previously stated, many of these guidelines require updating. In some areas, different hospital-based guidelines are in place within the same trusts and require consolidation and integration.
- 124 Eight of the twelve trusts reviewed run joint obstetric/diabetes clinics and have an obstetrician with a special interest in diabetes. However, only two trusts indicated that they have midwives with training in diabetes. Where 'joint clinics' exist, they do not always have a diabetologist present.

- 125 The frequency of measurement of HbA1c for pregnant women with diabetes varies across Wales from weekly to monthly. This is, in part, a reflection on the differences in clinical practice between consultants and also what has been prescribed through local guidelines.
- 126 Pre-pregnancy counselling and information is typically available at diabetic clinics for adults and adolescents (where these clinics are held). However, the type of interaction with patients varies from provision of leaflets to formal counselling. In general, there is scope for the service in Wales to be more proactive in the provision of pre-pregnancy advice and counselling.
- 127 Data from PEDW shows that the numbers of congenital malformations associated with diabetes has been fairly constant since 1995, at a total of around 50-60 a year across all of Wales. However, the baseline review did highlight wide variations in the percentage of babies born to diabetic mothers who are admitted to a special care baby unit (SCBU). This can vary from all babies to just 4 per cent and reflects differences in clinical policy and practice, both within and between trusts. Many trusts routinely admit all babies of diabetic mothers to SCBU for assessment, as a precaution following birth.
- 128 The monitoring of outcomes of pregnancy for women with diabetes in Wales is generally weak and is an area that needs attention. Trusts were typically unable to provide information on key outcomes, such as average birth weights, extent of foetal malformations and perinatal mortality.

## Care for people in hospital

- 129 The number of hospital admissions in Wales related directly and indirectly to diabetes has increased by 50 per cent since 1995. The baseline review highlighted a number of concerns around care of people with diabetes when they are admitted to hospital:
- ward based staff can often have limited knowledge of diabetes and its management (30 per cent of respondents to our patient survey indicated that they felt hospital staff did not have sufficient knowledge of diabetes);
  - patients on the ward do not receive sufficient information (75 per cent of patient survey respondents indicated that they had not received information or leaflets during their hospital stay);
  - inpatients do not always receive appropriate contact with DSNs during their hospital stay (over 50 per cent indicated that they had not had an opportunity to discuss their diabetes with a specialist nurse during their inpatient stay);
  - in some parts of Wales, patients reported difficulties in accessing the required medication to manage their diabetes, although this was not a trend replicated across all of Wales; and

- hospital catering systems are sometimes not flexible enough (just under 20 per cent of respondents to the patient survey indicated that they did not receive adequate food, at the right times, to help them manage their diabetes).
- 130 However, many trusts are working hard to overcome these problems. Typically, hospital based diabetic teams include specialist nurses with a dedicated ward liaison role. These nurses regularly visit the wards to oversee care of patients known to have diabetes. However, their ability to see every patient with diabetes is not realistic and, therefore, typically limited to referrals for patients with known problems.
- 131 As diabetes units and teams are sited in acute hospitals, their ability to provide routine support for patients in community hospitals is typically diminished. The review indicated that there is little, or no, DSN cover in some community hospitals in Wales and is an area that needs further attention.
- 132 Several hospitals have developed link nurses to assist in the management of diabetes at ward level. This works well in some trusts, but in others the system is not in place or has lost momentum and needs revisiting. Several trusts have developed hospital-wide protocols to help manage diabetes in different ward settings but, in many cases, these are old and need updating. This process is underway in some trusts, but needs fresh impetus in others to ensure that ward based diabetes guidelines are up to date and that ward nurses know they exist and make use of them.
- 133 Four trusts in Wales indicated that they had inpatient beds dedicated to the care of patients with diabetes. Creating this facility can help concentrate staff resources, develop ward based expertise and generally assist with managing and supporting the specialist needs of patients with diabetes.
- 134 Overall, however, the review identified the need to do more to raise awareness of diabetes and its complications amongst ward based staff. This will help reduce the risk of many patients going on to develop complications that require further hospital treatment.
- 135 Where training and awareness raising sessions on diabetes had been set up for ward based staff, attendance at these sessions was often a problem. Typically, this was due to nursing shortages on the wards. The relatively high turnover of staff and use of bank and agency staff within some trusts means that this sort of training needs to be repeated frequently for it to be effective. The effective use of link nurses and diabetic ward liaison nurses can partly overcome this problem, although link nurses themselves often struggle to attend training sessions if protected time is not made available.
- 136 There is evidence of good involvement of dieticians in menu planning in hospitals, but there are still concerns that hospital catering systems are too inflexible and that people with diabetes are not been provided with the right food at the right time.

Typically, this involves being able to provide patients with an evening snack to help maintain their blood sugar balance. Often this can be simply achieved by raising awareness of ward nurses and catering staff and providing extra food such as a pack of sandwiches with the evening meal.

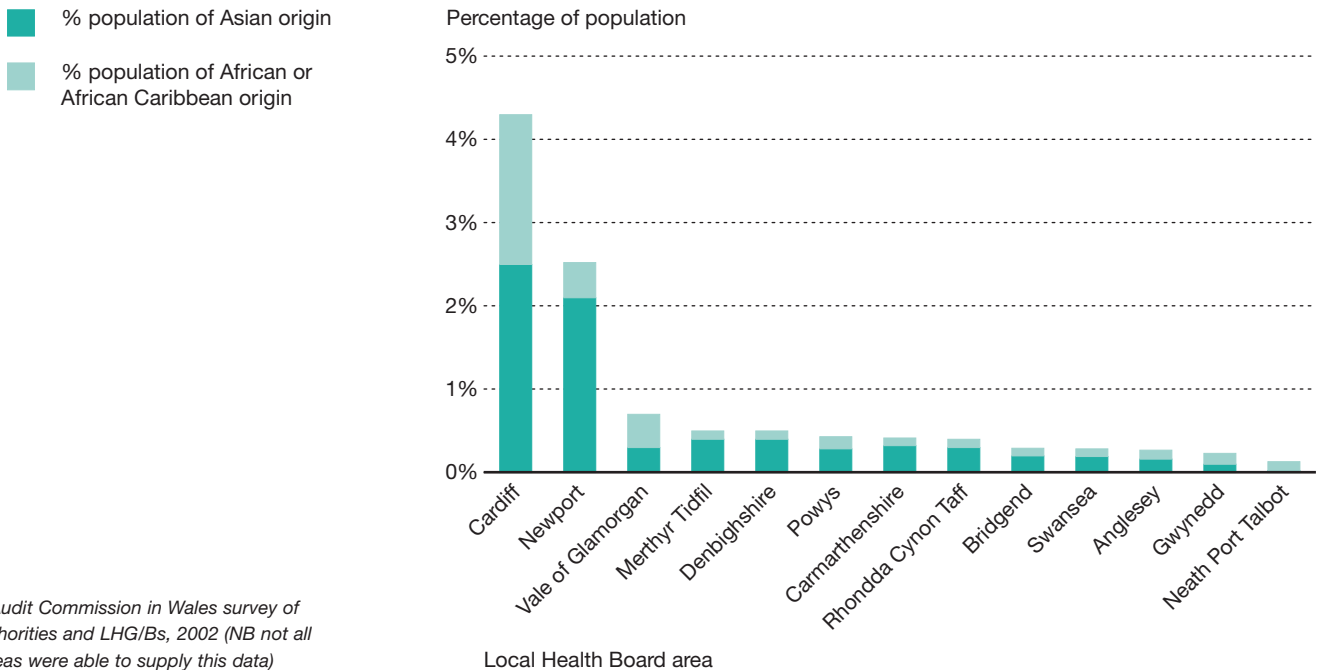
## Services for minority ethnic groups

137 The incidence of diabetes is higher for people with an Asian or African Caribbean background. Compared with the rest of Wales, Cardiff and Newport have a high percentage of the population from an Asian or African Caribbean origin (**Exhibit 10**). However, health information on minority ethnic groups and diabetes is very patchy, with a number of LHG/Bs unable to provide data on the proportion of their population of Asian or African Caribbean origin. Only one LHG/B could provide details of the percentage of people with diabetes in their area of Asian or African Caribbean origin, and only two trusts could provide the numbers of people with diabetes of these origins (neither of these trusts served Cardiff or Newport populations).

### Exhibit 10

#### Proportion of the population from minority ethnic background

The need to reflect the specific requirements of patients from minority ethnic areas is greater in some parts of Wales than others.



Source: Audit Commission in Wales survey of health authorities and LHG/Bs, 2002 (NB not all LHG/B areas were able to supply this data)

- 138 Interestingly, the data provided by health authorities and LHG/Bs is markedly different from that published by the National Assembly for Wales in a statistical bulletin on Ethnic Groups and Identity, based on 2001 census results (**Ref 10**). This data shows much higher proportions of non-white ethnic population across all local authority areas in Wales. For example, the figure in Cardiff is 8.4 per cent and in Newport 4.8 per cent. This indicates an underestimation of the numbers of black and minority ethnic population in NHS information systems, an issue which needs addressing as part of needs assessment and service planning work.
- 139 Not surprisingly, diabetes services in the Cardiff and Newport areas have needed to focus more attention on services for people with an Asian or African Caribbean background and some key initiatives have been developed (**Case study 7**). Other areas of Wales have not developed a similar focus, and it is argued that this reflects the low number of people with diabetes with these backgrounds. However, there is a potential concern that these services would be less well equipped to deal with such patients should they present.

### Case study 7

#### Coronary heart disease and diabetes project for at risk minority ethnic groups

The 'HeartLink' project in Cardiff aims to support healthcare professionals in the delivery of heart disease and diabetes health services. The project is working towards national standards set out within the Welsh NSF for both CHD and diabetes.

The project has a community focus, which is to raise awareness and undertake opportunistic screening sessions in areas with a high black and minority ethnic population. Screening sessions include taking measurements of an individual's risk of developing heart disease (including family history), blood pressure, blood glucose levels, height, weight, smoking status and levels of fitness.

By targeting people in those communities earlier and in places they are likely to visit, for example mosques, temples and community centres, a start can be made in addressing the health issues faced by these groups.

The project has received three years' funding from the Assembly's 'Inequalities in Health Fund' to offer effective treatment and advice to individuals who are at increased risk of heart disease and diabetes. Such advice might include how to modify existing lifestyle, looking at eating, exercise habits and smoking. A project team has been employed to carry out the above work, which consists of a project manager, nurse facilitator, dietician, podiatrist and linkworkers.

*Source: Audit Commission in Wales fieldwork visit*

## People who are housebound or in care homes

- 140 People with diabetes who are housebound, in care homes or residential settings are at particular risk of missing out on regular structured reviews and, therefore have a greater risk of developing complications.
- 141 Specialist diabetes staff typically reported concerns about the quality of general diabetic care received by patients in care homes, although in some areas DSNs had instigated a programme of training sessions to raise awareness amongst care home staff (**Case study 8**).
- 142 In general, a much more comprehensive and co-ordinated approach to the care of patients with diabetes in care homes is needed. This will involve investing time and resources to raise awareness amongst the healthcare professionals who care for patients in care homes about the general management of diabetes and recognising the signs of complications.

### Case study 8

#### Promoting awareness of diabetes amongst care home staff

The diabetes teams at both acute hospital sites of the **Bro Morgannwg NHS Trust** have developed training programmes for care home staff.

The diabetes team at the Princess of Wales Hospital in Bridgend have run a number of training sessions for care assistants in nursing and residential homes. The sessions are designed to help care home staff gain a better understanding of diabetes and its treatment, to help ensure that care home patients receive appropriate standards of care. The course consists of three one-and-a-half hour sessions, with a certificate of attendance being awarded at the end.

The DSNs at the Neath Port Talbot Hospital have developed a diabetes update day programme, which includes sessions on the importance of good diabetes control, footcare, dealing with hypo- and hyperglycaemia, exercise and diet and a demonstration of blood glucose monitoring equipment.

Staff at both sites are aiming to roll out the training sessions to all care homes in the area.

*Source: Audit Commission in Wales fieldwork visits*

- 143 Similar issues apply to people with diabetes who are housebound. In the main, they rely upon district nurses and GPs to support them with their diabetes and it is important that these healthcare professionals have appropriate levels of awareness about the management of diabetes. The review found evidence that healthcare professionals in some parts of Wales were taking action to improve the diabetes care of housebound patients (**Case study 9**).
- 144 LHBs will need to work with healthcare professionals in both primary and secondary care to ensure that robust arrangements are in place for the regular surveillance of people with diabetes in care homes or who are housebound.

### Case study 9

#### Annual review of housebound patients in Powys

A protocol has been agreed by the district nurse team in Llandrindod Wells to provide an annual review for people with diabetes who are housebound. The aim is to offer the same quality of service as that provided to patients able to attend the diabetes clinic at the GP surgery. The protocol outlines:

- the investigations that should be undertaken and their frequency;
- treatment goals; and
- the role of the GP, district nurse, podiatrist, optician and dietitian for different elements of the process.

The scheme has only recently been set up, but it is envisaged that three members of the district nursing team will take on this role in order to maintain competencies in this area of practice. A podiatrist has provided additional training on foot examinations and the use of monofilament; an update session on dietary advice is planned by a dietitian; and the patient information leaflets in use have been reviewed. Mobile clinic kits have been developed to allow all appropriate investigations to take place in the home.

The district nurses undertaking annual reviews liaise closely with other members of the primary care team involved in the provision of diabetic care. An annual review assessment tool is used by district nurses to record findings, and this is copied to the practice.

*Source: Audit Commission in Wales fieldwork visit*

## Recommendations

To improve support to vulnerable people with diabetes, specialist diabetes services need to work alongside LHBs to:

- develop more systematic liaison arrangements with nurseries and schools;
- ensure that systematic and robust transitional arrangements between paediatric and adult services are in place;
- review the provision of pre-pregnancy advice and counselling;
- improve the monitoring of outcomes related to pregnant women with diabetes;
- develop training programmes in diabetes for midwives, ward nurses and care home staff, with protected time being set aside in order for these staff to attend the appropriate courses and study days;
- improve the service to inpatients by providing better information, facilitating appropriate contact with specialist staff and providing more flexible catering arrangements;
- target prevention and early detection initiatives on people from Asian and African Caribbean backgrounds, informed by needs assessment of minority ethnic populations at LHB/unitary authority level; and
- develop a systematic approach with primary care to supporting people who are housebound, in care homes or residential settings, with the aim of providing a similar level of service as that available to other groups.

# 5



## Planning, co-ordinating and monitoring services

Implementation of the Diabetes NSF in Wales will be aided by the development of more effective mechanisms to plan, co-ordinate and monitor diabetes services. In the past, activity in this area has been limited and typically characterised by a lack of basic information to monitor the quality of care and outcomes for patients.

## Introduction

- 145** This chapter assesses the extent to which diabetes services in Wales are well planned and co-ordinated. Effective planning mechanisms that both involve users and gain the commitment of LHBs, NHS trusts and the different professional groups are needed if significant progress is to be made with developing services and implementing the NSF.
- 146** This chapter assesses the existing arrangements for:
- planning diabetes services;
  - monitoring service delivery; and
  - co-ordinating service provision across primary and secondary care.

## Planning services

- 147** Robust planning arrangements with local groups are needed that are effective in setting priorities and identifying how service improvements can be made. LHBs and Trusts need the capacity to deliver improvements, and users should be at the heart of the service improvement process. The extent to which priority has been given to diabetes services in recent years varies significantly and progress has been restricted by competing priorities such as implementing the CHD NSF.
- 148** The review found that specific plans for diabetes services covering all service settings have generally not yet been developed. There has been uneven coverage of diabetes across Wales in the pre-existing service plans of health authorities, LHGs and NHS Trusts. However, the launch of the NSF has stimulated the development of service planning in many parts of Wales, largely driven by LHGs and their successor, LHBs.
- 149** For planning to be successful and meaningful it must be done across health sectors and between health and social care. Service users and voluntary groups also have a key role to play. Over recent years, LDSAGs, or their equivalents, have been established as a forum to bring together a range of health professionals as well, as people with diabetes.
- 150** Historically, there has been a variation in the extent to which LDSAGs have strategically shaped diabetes services across Wales, with some groups perceived as being more effective than others. In addition, there have been concerns that membership of some LDSAGs was biased towards certain professional groups or geographical areas, and that some LDSAGs have had insufficient input from service users.

- 151 The advent of the NSF and structural change in NHS Wales has brought a fresh focus on LDSAGs. The review indicated a number of issues:
- new LDSAGs are being set up to replace groups that previously operated at health authority level, and which, in some areas, had been mothballed;
  - different approaches are being used across Wales, with some groups being set up at LHB level whilst others are based around NHS trusts; and
  - groups are at different stages of development and hence effectiveness, with progress in some parts of Wales being particularly slow.
- 152 LDSAGs, at whichever level they operate, will be vital in bringing together professionals from primary and secondary care along with health service commissioners, service users and voluntary groups. It will be important to get the membership of the group right and to have a clear idea of how the group will be used to shape local service delivery and monitoring.
- 153 Results from the baseline review surveys indicate that LDSAGs face a number of challenges in the way in which they engage with local service providers. The majority of general practices in Wales indicated that, to date, they had had minimal involvement with their LDSAG, or its equivalent, where one existed. There was a mixed response when practices were asked to rate LDSAGs' role in planning services and promoting joint working arrangements. In many parts of Wales, practices had little or no awareness of LDSAGs or their work.
- 154 There was also a variable response in relation to users' awareness of the existence and work of LDSAGs across Wales. Overall, just 25 per cent of respondents to the patient survey indicated they were aware of such groups.
- 155 The capacity of the service to plan and co-ordinate service improvements is often an issue. LHBs and trusts already have a varied and challenging agenda to respond to, and heavy reliance can be placed on the goodwill of LDSAG members. However, some trusts and LHBs have diabetes service managers or facilitators in post, and this can help with delivering more speedy and co-ordinated improvement **(Case study 10)**.
- 156 A minority of LDSAGs have encountered problems with appointing user representatives. The focus placed on gathering user views varies in different parts of Wales. Some areas have achieved little in this area, others have undertaken patient surveys, whilst a minority of areas have developed other initiatives, such as user focus events and patient involvement subgroups of the LDSAG.

- 157 The wider development of more innovative schemes is required if the views of people with diabetes are going to drive and shape service improvements. The review highlighted that examples of good practice in this area are starting to emerge (**Case study 11**), largely linked to the requirement in the Welsh Diabetes NSF to have user reference groups to support local service planning.

### Case study 10

#### Diabetes nurse facilitator

The **Newport Diabetes Nurse Facilitator Project** commenced in September 2000 as a result of Newport LHG identifying diabetes as a major service priority. The post was designed to support the development and delivery of diabetes services in primary care and to promote a seamless service with secondary care. Reducing the variations in the standards of care provided was a significant objective of the project. Key achievements to date include:

- establishing a baseline of current activity in primary care;
- establishing a multi-agency, multi-professional locality service planning group;
- developing guidelines for the management of diabetes in primary care;
- establishing links with specialist services and voluntary organisations to promote more effective communication;
- promoting public awareness on the level of services they should expect;
- running awareness days on diabetes for black and minority ethnic communities; and
- developing training programmes for primary care staff.

*Source: Audit Commission in Wales fieldwork visits*

### Case study 11

#### Promoting involvement in service planning

Diabetes UK currently organises and supports local reference groups, made up of people living with diabetes that meet approximately four times a year. The groups discuss local services, receive feedback from lay representatives on the LDSAG and consider views on topics for discussion by the LDSAG. The reference groups, therefore, provide a good mechanism for capturing and considering users' views when planning and monitoring services. The Diabetes NSF in Wales envisages that local NHS organisations will support the reference groups.

*Source: Diabetes UK Cymru, Audit Commission in Wales fieldwork*

## Monitoring service delivery

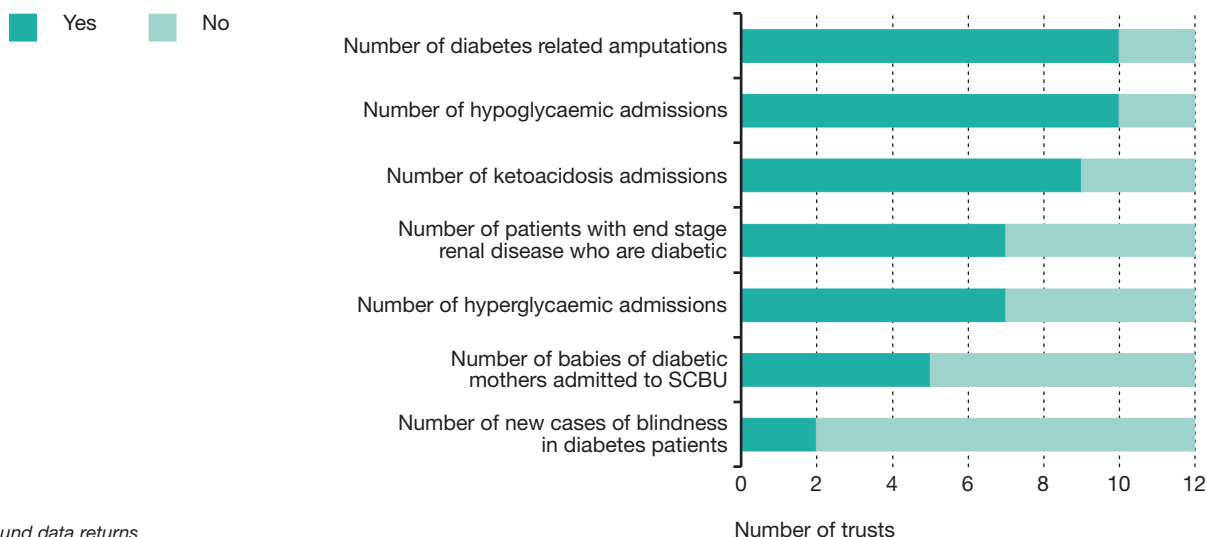
- 158 Historically, health authorities, LHGs and NHS trusts have had varying levels of involvement in monitoring diabetic services. The review indicated that commissioning bodies had typically not drawn up service specifications for diabetes or developed mechanisms to monitor service delivery. However, primary care contractual audits do go some way towards identifying levels of service delivery within general practice (**Case study 13, page 52**). Where effective LDSAGs have been in place, the responsibility for monitoring the extent and quality of services has rested with these groups. However, the ability to monitor service delivery is widely restricted by poor information and outcome measures together with variable audit activity.

- 159 The extent and quality of information is an issue at many trusts. For example, five trusts in Wales could not provide any data on the number of patients with diabetes by type under their care. The position in primary care is somewhat better. The majority of practices responding to the Audit Commission survey provided data on the number of patients with diabetes in their practice. However 48 out of 365 practices responding to our survey had to estimate the number of people with diabetes on their list and whether they had Type I or Type II diabetes.
  
- 160 There are isolated examples of the development of population based registers that hold a mixture of process and outcome data. However, in the main these are absent. Chronic disease management payments for diabetes have a requirement that general practices undertake an audit of diabetes care. As part of this process most practices maintain registers of patients of diabetes. Three hundred and fifty-one practices indicated that they maintained a practice based register however, in the main, these have not been developed into tools that can assist the planning and monitoring of diabetes services across a population. Effective population based registers will be the cornerstone of good quality diabetes care, and work to develop them in Wales is needed as a matter of urgency.
  
- 161 Registers will also help to provide information on the clinical outcomes of diabetes care. At present, information in this area is weak across Wales. As an example, Exhibit 11 shows that a number of trusts struggled to provide information on a range of key measures that were part of the requested dataset for the baseline review. There are, however, encouraging examples of good practice at individual NHS bodies, which can be used as a basis for improving clinical information (**Case study 12**).

### Exhibit 11

#### Availability of information clinical outcomes in trusts

Many trusts were not able to provide data on outcomes of diabetes care.



Source: Trust background data returns

## Case study 12

### Electronic patient record

At **Carmarthenshire NHS Trust** an electronic patient record, Diabeta 3, is in use. This package is designed for live use in clinical settings and provides a multidisciplinary record of the process of care and a patient education tool; facilitates communication with primary care; and provides quality and outcome measures.

The system is used by all diabetes team members, including podiatrists, requires little or no typing skills and is used during outpatient consultations. It is networked and linked to the hospital patient data system and to the digital retinopathy camera. Detailed and comprehensive GP letters are generated automatically.

The system also allows rapid audit of the process and quality of care, including:

- the quality of patient records in the outpatient diabetic clinics – covering the percentage of records with a recording of a variety of key investigations;
- diabetic complications – covering the percentage of patients seen at the diabetic outpatient clinics with a range of complications, including retinopathy and neuropathy; and
- the attainment of treatment targets – covering the proportion of patients achieving a range of treatment goals.

The system has been in operation for over two years, allowing comparisons to be made over time.

*Source: Audit Commission in Wales fieldwork visit*

- 162 There is a need to strengthen the arrangements for audit and review of diabetes services across Wales. In general, there has been an absence of multidisciplinary audits covering primary and secondary care. Where the review found evidence of audit activity, it had often only taken place along single professional or departmental, lines within either primary or secondary, care.
- 163 Most health commissioning bodies in Wales had an incomplete picture of how diabetes care was being delivered in their area. There were well-developed primary audit arrangements in some parts of Wales, which meant that LHGs (and subsequently LHBs) in those areas had a good knowledge of diabetes services in primary care (**Case study 13**).
- 164 However, LHG/Bs invariably had a poor awareness of the nature and quality of secondary care diabetes services. The NSF has put this problem into sharper focus and most new LHBs are using the local results of the Audit Commission's baseline review to help build a clearer picture of diabetes service provision in their area.

### Case study 13

#### Primary care audit of diabetes services

Annual audit processes have been developed in some parts of Wales. These include those developed by the **Dyfed Powys Primary Care Effectiveness Team** and the **Morgannwg Medical Audit Advisory Group**. These audits form part of the contractual audit linked to chronic disease management payments and, as a result, lead to a high proportion of general practices being covered by the audit.

The audits provide data on quality and outcome measures for diabetes care in general practices and provide comparisons over time and between GP practices and LHB areas. These audits provide details on:

- the profile of diabetes patients, prevalence rates and the number of patients offered and taking up an annual review at the practice;
- the recording of key test and investigation results in patient records; and
- the numbers of diabetic patients who are outside commonly agreed treatment goals.

*Source: Audit Commission in Wales fieldwork visits*

## Co-ordinating services

- 165** Many patients in Wales receive their diabetes care from both general practice and their local hospital. Effective links are needed between primary and secondary care to ensure care is appropriate and well co-ordinated. Moreover, the different professionals involved in providing care need to communicate well with each other. A number of approaches can be taken to promote care which is more co-ordinated and 'joined up'. These include:
- use of specialist staff as facilitators to co-ordinate care across sectors;
  - development and monitoring of service guidelines; and
  - shared patient record systems.
- 166** The review indicated that the use of diabetes facilitator posts is not well developed in Wales, despite the advantages that can be gained from such an initiative (see Case Study 10). Resource constraints are likely to be a key issue, since successful facilitator posts will need to carry a reduced clinical workload.
- 167** Overall, four out of ten general practices responding to the Audit Commission's primary care survey indicated that they did not have guidelines covering referral to hospital for specialist treatment. Marked geographical variations were observed, reflecting differences in the way diabetes services have been co-ordinated between primary and secondary care across Wales (**Exhibit 12**).

## Exhibit 12

### Availability of guidelines for referral to hospital services

There is scope to strengthen the use of guidelines to assist referral to specialist hospital teams.



Source: Audit Commission survey of general practices

- 168 In some areas, practices indicated that they did not have referral guidelines, even though they had been developed, indicating a need to promote awareness of their existence. As noted previously, in some parts of Wales existing guidelines need updating to reflect latest service developments.
- 169 Responses to the Audit Commission patient survey indicated that there is scope for duplication of activity across primary and secondary care, with the same tests being done at different settings. Moreover, a relatively low proportion of respondents indicated that they understood why they had to attend different venues for their diabetes care and many expressed the desire to be able to have all, or most, of their diabetic care provided at just one setting. There were also examples of patients highlighting the need for more consistent advice from different healthcare professionals.
- 170 The use of shared record systems can greatly assist in the co-ordination of diabetes care for patients. However, this remains an area for action, which will receive greater prominence if the Electronic Patient Record, envisaged in the Assembly's *Informing Healthcare (Ref. 11)* strategy is developed as intended. Reviewers found that many of the healthcare professionals involved in diabetes care keep patient notes separate. For a single patient, information on the management and outcomes of their diabetes is typically held in a number of different places, such as primary care notes, district nursing notes, their main hospital casenote and separate patient files held by diabetes specialist nurses, podiatrists and dieticians.

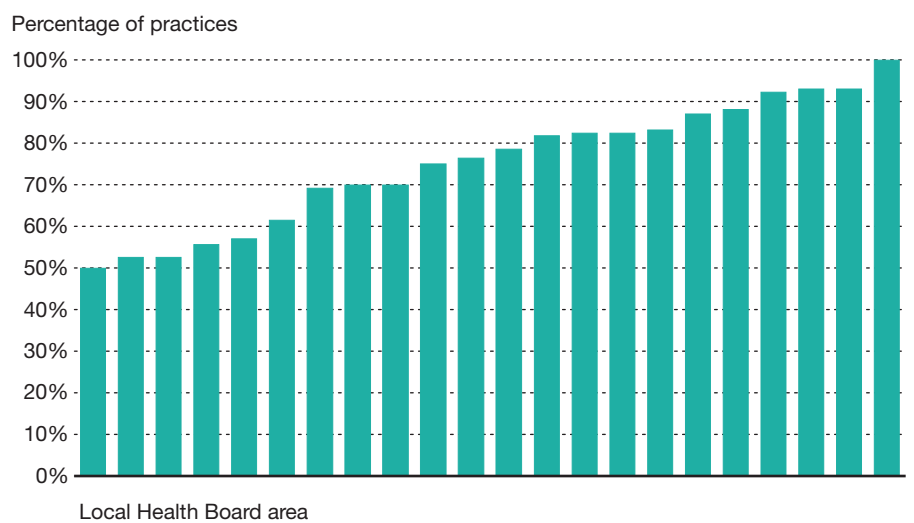
## Developing and supporting primary care

- 171 Primary care is playing an increasing role in the management of diabetes in Wales, particularly for people with Type II diabetes. However, the extent of both this role and the development of diabetic services in general practices, vary between and LHB areas.
- 172 Increasing demand on diabetes services is likely to result in primary care teams providing more routine care for people with diabetes, with specialist services playing an increasing role in supporting staff in primary and community settings. However, across Wales, only 59 practices indicated that they operated a formal shared care protocol with hospital based services, indicating a need for greater communication and co-ordination of care across primary and secondary care.
- 173 Encouragingly a significant proportion (77 per cent) of general practices indicated they had a 'lead' GP with a special interest in diabetes, although this varied by LHB area (**Exhibit 13**). Similarly, the majority of practices (89 per cent) indicated they had a lead nurse for diabetes, although, again, this picture varied geographically.

### Exhibit 13

#### Proportion of general practices with a 'lead' GP for diabetes

Several LHB areas reported high levels of 'specialism' within general



Source: Audit Commission in Wales survey of general practices, 2002

practice.

- 174** If primary care is to undertake an increased role in the management of routine diabetes care, issues around training for GPs and practice nurses in diabetes will need to be addressed since:
- forty-eight practices in Wales indicated that none of their GPs had attended a postgraduate training course in diabetes during the previous three years;
  - a further 111 practices indicated that less than half their GPs had attended such a course in that time period; and
  - only 24 per cent of lead nurses for diabetes had completed accredited training programmes such as the Warwick or Bradford courses.
- 175** The majority (90 per cent) of practices indicated that they had routine access to support from specialist hospital based diabetes services, although within some LHB areas practices felt less well supported. Typically, specialist support involved referral to hospital to be seen by a consultant physician, DSNs or other specialist staff such as podiatrists and wound care specialists. However, there were other examples of types of support provided by hospital based services such as:
- education and training for GPs and practice nurses;
  - general advice on setting up practice based care programmes; and
  - open access clinics.
- 176** The nature of specialist support beyond routine hospital clinics varies considerably across Wales. For instance, all practices responding to the survey in one LHB area indicated that they had received specialist advice on setting up practice based care programmes, whilst in another LHB area no practices had received such assistance.
- 177** When asked to rate the effectiveness of the support they received from hospital based teams, practices were generally happy with specialist care provided at consultant or specialist nurse led clinics, but were less happy with the provision of education and training, general advice and access to specialist services, such as podiatry and wound care.

## Communication between professionals

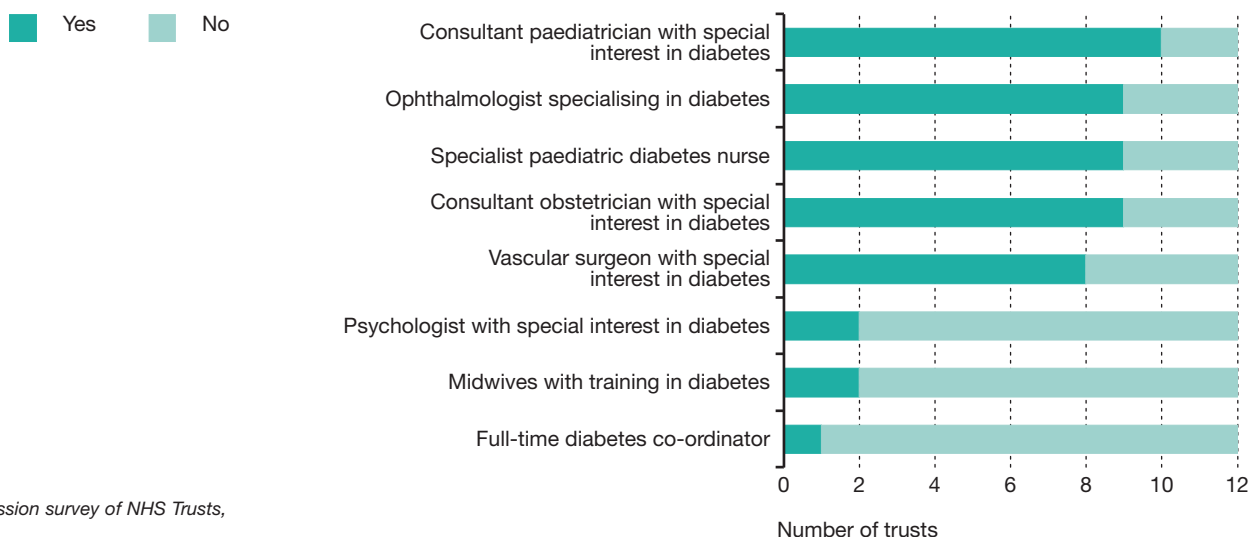
- 178** Effective communication between healthcare professionals is essential if diabetes care is to be delivered to a high standard. Communication from the specialist hospital teams to general practices is typically based on a traditional letter to the GP outlining the results from the patient's outpatient appointment. Generally this communication is sound, although practices in some parts of Wales raised concerns about the timeliness and completeness of information received from their local hospital.
- 179** Communication from general practices to specialist staff for people receiving care from both settings is weaker. Similarly, the quality of referral information received from primary care was reported by specialist staff to be very variable within, and between,

LHB areas. This is likely to reflect a number of factors, including the extent to which local guidelines and protocols have been developed, levels of GP training in diabetes and individual doctor behaviour.

- 180 Where specialist staff keep separate patient records, systems need to be in place to ensure information is shared appropriately. The podiatry survey found that most, but not all, podiatry services (nine of thirteen trusts surveyed) routinely send results of diabetic foot assessments to other health care professionals, and in seven trusts, podiatrists make manual entries into GP/hospital notes.
- 181 Some dietetic and podiatry services have identified a lead for diabetes. These roles provide leadership and guidance to fellow professionals and liaison with other health professionals. However, the extent and development of such roles varies across Wales. For example, ten out of thirteen Trusts have an identified lead podiatrist for diabetes, with between 0.3 WTE to 4.0 WTE devoted to this role.
- 182 Good links are also required with other hospital specialties including ophthalmology, vascular surgery, renal medicine, obstetrics and paediatrics. Clinics run jointly by the diabetes team and associated specialties can help co-ordinate patient care. However, the extent of joint clinics varies across hospital sites (see Exhibit 4). Similarly, some trusts do not have staff with a specialist interest in diabetes in all associated specialties (**Exhibit 14**).

### Exhibit 14 Specialist staff with interest in diabetes

Some trusts do not have specialist posts with an interest in diabetes in all the key specialties.



Source: Audit Commission survey of NHS Trusts, 2002

## Recommendations

To ensure diabetes services are appropriately planned, co-ordinated and monitored...

LHBs need to:

- ensure that effective multi-agency LDSAGs are established with appropriate membership, terms of reference and lines of accountability;
- ensure mechanisms are in place to reflect the views of service users and their carers in planning processes;
- develop, in conjunction with LDSAGs, prioritised implementation plans for the diabetes NSF with projected targets and clear responsibilities for delivery; and
- ensure that NSF implementation plans include:
  - a strategy for the development of services in primary care; and
  - a workforce review that includes both staff numbers and skill sets.

Specialist services and LHBs need to work together to:

- begin work on the development of population diabetes registers, building on existing good practice;
- develop multidisciplinary audits of diabetes care across all service settings;
- agree referral guidelines to specialist services and shared care protocols;
- develop patient-held records, or at least ensure that, in their absence, there are agreed mechanisms governing how all professionals are to keep their colleagues informed of the care and advice provided to patients; and
- review whether all specialties have suitable leads for diabetes or staff with a special interest in diabetes.

The Assembly should:

- provide planning guidance to LHBs that includes priorities for action and a timetable for both the production of the plan and its implementation;
- develop an information strategy that sets a framework for the identification and collection of all key aspects of information associated with the successful delivery of diabetes care; and
- ensure that information systems permit the collection and sharing of data on service provision and clinical outcomes.

# 6



## Meeting the challenge

Variations in service delivery and organisation, gaps in staff resources, and the need for better co-ordination of care across service boundaries are among the key challenges that will need to be tackled if the Diabetes NSF is to be successfully implemented in Wales. These are significant challenges but there is a good platform to build upon with many examples of emerging good practice and national initiatives to support local action.

## Introduction

- 183** The final chapter of the report considers what will be required of the different agencies if NSF standards are to be delivered over the coming years, with resulting improvements to services for people with diabetes in Wales.
- 184** The first part of this chapter summarises the findings of the baseline review to provide a current 'gap analysis' against the NSF standards. It also highlights the different barriers that healthcare professionals have identified as impediments to service improvements. The chapter then goes on to highlight some of the key actions that are needed to build capacity in the service and to ensure that the right systems, networks and frameworks are put in place to plan, deliver and monitor services.

## The current baseline position against the NSF standards

- 185** Table 3 uses findings from the baseline review to provide an overall 'gap analysis' of current services against the NSF standards. The extent to which the issues identified are applicable in each LHB area will vary and are addressed in locality level feedback reports.

**Table 3**  
**Current position against NSF standards**

NSF standard	Summary baseline position for Wales
<p><b>Standard 1</b> The NHS will develop, implement and monitor strategies to reduce the risk of developing Type II diabetes in the population as a whole and to reduce the inequalities in the risk of developing Type II diabetes.</p>	<p>There remains much to do in this area, although work underway as part of the CHD NSF will be able to provide a platform from which specific action can be taken. The development of health, social care and well-being strategies will provide further impetus and an overarching framework for action in this area.</p> <p>Key areas for attention:</p> <ul style="list-style-type: none"> <li>• Development of primary prevention strategies (making appropriate links to work already underway for CHD and other health promotion activities).</li> <li>• Focus on lifestyle factors, diet and nutrition, increasing physical activity, smoking and alcohol consumption.</li> <li>• Strategies targeted at the whole population, but also at specific subgroups who have a higher risk of developing diabetes.</li> <li>• Training for staff to support behaviour change amongst patients with diabetes and their relatives/carers.</li> </ul>

*Continued overleaf*

Table 3 (continued)

NSF standard	Summary baseline position for Wales
<p><b>Standard 2</b> The NHS will develop, implement and monitor strategies to identify people who do not know they have diabetes.</p>	<p>To date, concerted effort in this area has been limited. In the absence of a national evidence based screening programme, there has been ad hoc local action which would benefit from standardisation.</p> <p>Key areas for attention:</p> <ul style="list-style-type: none"> <li>• Development of a more systematic, standardised and evidence based approach to screening that is targeted at 'at risk' elements of the population.</li> <li>• Setting up a structured programme of raising awareness about risk factors and symptoms of diabetes amongst the population and health care professionals.</li> </ul>
<p><b>Standard 3</b> All children, young people and adults with diabetes will receive a service which encourages partnership in decision making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan and carers should be fully engaged in the process.</p>	<p>There are numerous examples of well-structured approaches to patient education across Wales, with DSNs taking a key role. However, time, facilities and lack of expert support from professionals such as psychologists can be barriers. Action is also needed to support and encourage patients to take more ownership of their diabetes.</p> <p>Key areas for attention:</p> <ul style="list-style-type: none"> <li>• Identification of a 'core curriculum' for patient education across primary and secondary care, informed by a review of what constitutes effective educations and recent NICE guidelines.</li> <li>• A more explicit approach to the development of personal care plans is needed, as part of a move towards patient-held records.</li> <li>• Ensuring that lessons learnt from the Chronic Disease Self Management pilot programme in Wales are used to support good practice approaches to self management of diabetes across the whole of Wales.</li> </ul>
<p><b>Standard 4</b> All adults with diabetes will receive high quality care throughout their lifetime, including support to optimise the control of their blood glucose, blood pressure and other risk factors for developing complications of diabetes.</p>	<p>Healthcare professionals in Wales are working hard to cope with increasing demand and deliver high quality services to people in their care. However, a number of fundamental issues need to be addressed to secure further improvements.</p> <p>Key areas for attention:</p> <ul style="list-style-type: none"> <li>• Development of multidisciplinary and multi-agency planning forums with clear lines of accountability.</li> <li>• Development of population based registers for all known people with diabetes.</li> <li>• Prioritised plans for service delivery in each locality that address the current gaps in the service and long-term implementation of NSF standards.</li> <li>• Detailed assessments of the extent to which services need to be redesigned to meet the needs of patients and the associated implications of supporting frontline staff, including: <ul style="list-style-type: none"> <li>– appropriate balance of service provision between primary and secondary care;</li> </ul> </li> </ul>

NSF standard	Summary baseline position for Wales
	<ul style="list-style-type: none"> <li>– education and training needs for all healthcare professionals who treat people with diabetes;</li> <li>– workforce numbers and skill sets, including plans to address current shortfalls in specialist staff posts; and</li> <li>– arrangements to monitor and review service delivery.</li> </ul> <ul style="list-style-type: none"> <li>• Action aimed at promoting better co-ordination of services across primary and secondary care.</li> <li>• Concerted efforts to improve the quality and availability of information that exists to help plan, deliver and monitor diabetes services.</li> </ul>
<p><b>Standard 5</b> All children and young people with diabetes will receive high quality care and they, with their families and others involved in their day to day care, will be supported to optimise the control of their blood glucose and their physical, psychological, intellectual, educational and social development.</p> <p><b>Standard 6</b> All young people with diabetes will experience a smooth transition of care from paediatric to adult services, whether hospital or community based, either directly, or via a young people's clinic. The transition will be organised in partnership with each individual and at an appropriate age and agreed with them.</p>	<p>Services for children and young people with diabetes are well developed in many parts of Wales with a strong emphasis on patient support and empowerment. However, gaps in access to specialist staff can cause problems, whilst the transfer from children to adult services is not always robustly managed.</p> <p>Key areas for attention:</p> <ul style="list-style-type: none"> <li>• Workforce planning to ensure that children have access to a paediatrician with a special interest in diabetes and a paediatric DSN.</li> <li>• Ensure service guidelines include the provision of care to children and young people with diabetes.</li> <li>• Provision of psychological support to at-risk groups, particularly adolescents.</li> <li>• Improve effectiveness of arrangements for transition to adult services via provision of appropriately timed adolescent clinics and well structured handover arrangements between the paediatric and adult specialist teams.</li> </ul>
<p><b>Standard 7</b> The NHS will develop, implement and monitor agreed protocols for rapid and effective treatment of diabetic emergencies by appropriately trained health care professionals. Protocols will include the management of acute complications and procedures to minimise the risk of recurrence.</p>	<p>The review did not indicate any major problems with patients getting access to emergency treatment when it was needed. However, waiting times for access to specialists can vary significantly and out of hours specialist advice and support is not always available.</p> <p>Key areas for attention:</p> <ul style="list-style-type: none"> <li>• Ongoing review of arrangements for access to specialist treatment in the case of emergencies, with appropriate targets for rapid access and treatment.</li> <li>• Ensure people with diabetes have access to appropriate advice and support outside of work hours, and are aware of who to contact in the case of emergencies.</li> <li>• Programmes of raising awareness for healthcare professionals on recognising and treating diabetic emergencies.</li> </ul>

Continued overleaf

Table 3 (continued)

NSF standard	Summary baseline position for Wales
<p><b>Standard 8</b> All children, young people and adults with diabetes admitted to hospital, for whatever reason, will receive effective care of their diabetes. Wherever possible, they will continue to be involved in decisions concerning the management of their diabetes.</p>	<p>A number of key issues need addressing in order to ensure effective management of diabetes during a stay in hospital. These relate to both awareness of diabetes and its complication amongst ward staff, and the ability of patients to manage their own diabetes whilst in hospital.</p> <p>Key areas for attention:</p> <ul style="list-style-type: none"> <li>• Ongoing programmes of awareness raising of symptoms and management of diabetes and its complications are needed for ward staff.</li> <li>• Identifying protected training time for ward nurses to attend educational events on diabetes.</li> <li>• Ensuring people with diabetes in hospital receive appropriate contact with specialist staff as necessary, including specialist nurses, dieticians and podiatrists.</li> <li>• Identify mechanisms to support patients to manage their own diabetes whilst in hospital, including reviews of catering arrangements, use of their own medication and access to information.</li> <li>• Well organised and co-ordinated discharge planning.</li> </ul>
<p><b>Standard 9</b> The NHS will develop, implement and monitor policies that seek to empower and support women with pre-existing diabetes and those who develop diabetes during pregnancy to optimise the outcomes of their pregnancy.</p>	<p>Arrangements for the management of diabetes during pregnancy are generally robust across Wales. However, there are variations in practice that need addressing.</p> <p>Key areas for attention:</p> <ul style="list-style-type: none"> <li>• Ensuring diabetologist and diabetes team involvement in joint diabetes/obstetric clinics.</li> <li>• Consistent and appropriate policies on admitting babies born to mothers with diabetes to SCBU.</li> <li>• Review provision of training in diabetes to midwives.</li> <li>• More explicit monitoring of outcomes for babies born to women with diabetes.</li> </ul>
<p><b>Standard 10</b> All young people and adults with diabetes will receive regular surveillance for the long-term complications of diabetes.</p> <p><b>Standard 11</b> The NHS will develop, implement and monitor agreed protocols and systems of care to ensure that all people who develop long-term complications of diabetes receive timely, appropriate and effective investigation and treatment to reduce their risk of disability and premature death.</p>	<p>Review findings suggest that the majority of people with diabetes in Wales are receiving appropriate surveillance to help manage their diabetes and detect complications. However, the surveillance to detect eye, foot and kidney problems is not as robust as it could be in all parts of Wales. Moreover, patients in certain settings are at risk of receiving less regular and robust surveillance.</p> <p>Key areas for attention:</p> <ul style="list-style-type: none"> <li>• Action to improve the routine surveillance of people with diabetes who are housebound, in care homes and residential settings.</li> <li>• Completeness of structured review process to ensure at least annual monitoring of eyes, feet and kidney function.</li> <li>• Ensure systems are in place to link management of diabetic complications into other existing and planned NSF programmes (for example CHD, children's and renal services).</li> </ul>

NSF standard	Summary baseline position for Wales
<p><b>Standard 12</b> All people with diabetes requiring multi-agency support will receive integrated health and social care.</p>	<ul style="list-style-type: none"> <li>• Provision of better information to monitor clinical outcomes for patients with complications.</li> <li>• Ensure that service planning for diabetes is multi-agency and has appropriate involvement with all agencies that provide care and support for people with diabetes.</li> </ul>

## Barriers to effective care

- 186 Healthcare professionals were asked to identify the barriers that prevented them from delivering better care to people with diabetes. Each locality has its own specific issues and these have been highlighted in local LHB level reports. However, there was a strong commonality in most of the responses received, both within and across healthcare settings. The review has allowed a comparison to be made between views of general practice, hospital teams and patients (**Exhibit 15**).
- 187 The fact that a lack of time came through so clearly as a major barrier is indicative of the pressure services are under. There is a real danger that increasing prevalence of diabetes, coupled with tight staff resources and the improvement agenda driven by a range of related NSFs, will put services under even greater strain.

### Exhibit 15

#### Barriers to effective care

Common barriers were identified.

Staff in general practice	Hospital based teams	Patients
<ul style="list-style-type: none"> <li>• Lack of time</li> <li>• Getting patients to alter their lifestyles</li> <li>• Funding arrangements for diabetes care</li> <li>• Joint working with social service agencies</li> <li>• Access to chiropody/podiatry services</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of time</li> <li>• Getting patients to alter their lifestyle</li> <li>• Less well developed diabetes care in some general practices</li> <li>• Patient's non-attendance at clinics</li> <li>• Access to specialist support, particularly psychologists with a special interest in diabetes</li> </ul>	<ul style="list-style-type: none"> <li>• Access to chiropody/foot care</li> <li>• Waiting times for appointments at hospital clinics</li> <li>• Not being able to go to just one place to have checks ups done</li> <li>• Waiting times while at hospital clinics</li> <li>• Getting in consistent advice</li> </ul>

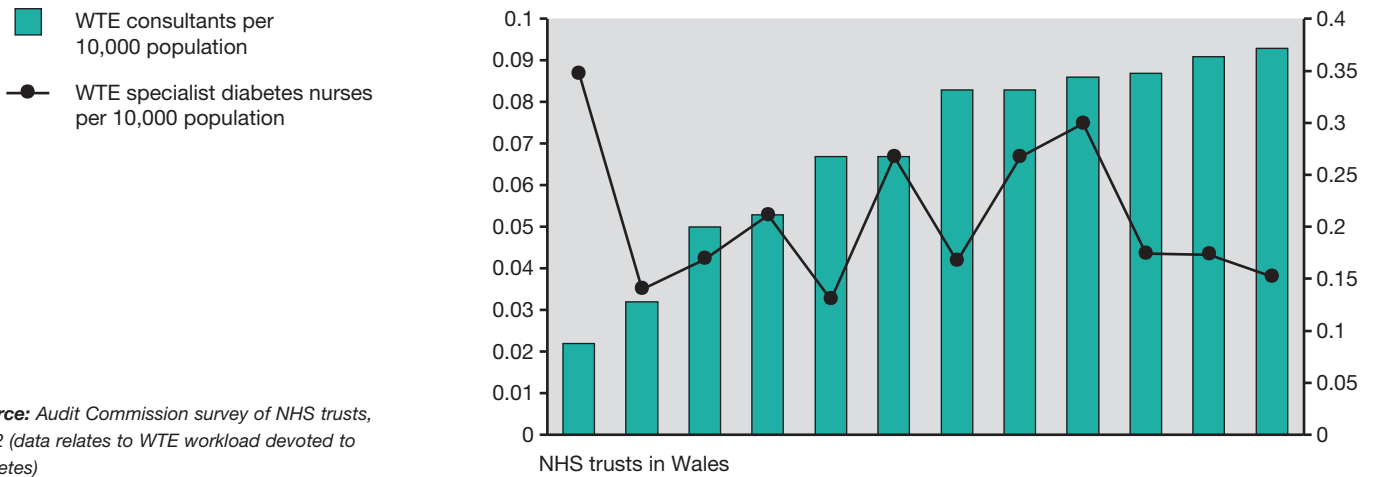
**Source:** Audit Commission in Wales surveys of general practices, NHS Trusts and people with diabetes, 2002

- 188 It is clear that if the NSF for diabetes is to be successfully delivered, there will need to be an increase in resources to support the frontline staff who deliver the services. A much more explicit approach to funding diabetes is needed to underpin this workforce planning. During the baseline review, it was not possible to identify the current spend on diabetes in Wales since it is 'hidden' within the general medical purse. Moreover, as few members of staff are solely dedicated to diabetes, it was not possible to quantify, with accuracy, the resources and costs allocated to diabetes services. The fact that the presence of diabetes can complicate medical and surgical procedures, increasing the length of hospital stay and, therefore, cost, must also be considered.
- 189 Cost is, therefore, likely to be a key barrier in implementing the NSF. Diabetes accounts for a significant and growing proportion of NHS spend. Regular and intensive treatment has been shown to be the most effective way to minimise the effect of complications (**Ref. 6**). However, this has resource implications in terms of specialist staff resources and treatment regimes, such as the use of anti-hypertensive treatments to control blood pressure. There is no 'ringfenced' funding for implementation of the Diabetes NSF in Wales and, as such, funding for developing diabetes services will need to be identified through the annual Service and Financial Framework (SaFF) process. This means that diabetes services will be in competition with other service priorities for funding.
- 190 As for most clinical areas, staffing at various levels will be one of the major drivers of costs. The service in Wales will start from a baseline that shows significant variations in specialist staffing levels across Wales (**Exhibit 16**). Interestingly, some trusts with low consultant numbers in relation to population have relatively high specialist nurse resources, which may provide a degree of compensation. Equally, there are other trusts where both consultant and specialist nurse staffing levels appear relatively low, indicating a gap in specialist staff resources. A similar variation is seen when specialist nurse staffing levels are examined in relation to the numbers of patients seen in hospital diabetes clinics. **Exhibit 17** shows that there can be a three-to four-fold variation in specialist nurse staffing in relation to clinic appointments.
- 191 Drawing firm conclusions from the data presented in Exhibits 16 and 17 is difficult, since there are no evidence based guidelines on optimum staffing levels in relation to population or at diabetes clinics. Moreover, specialist staff are used in different ways at different sites. However, it does indicate a very uneven picture and one which will require urgent attention in some areas if the appropriate level of patient contact is to be achieved.
- 192 The picture in respect of other professions involved in diabetes care is similarly variable in terms of staffing provision. Levels of dietetic and podiatry support vary significantly across Wales. Our survey of general practices indicated that 88 per cent of responding practices had routine access to dietitian advice and 66 per cent to

podiatry services. However, the averages mask significant variations across LHB areas, with resultant variations in waiting times for treatment and advice following referral to these important support specialties.

### Exhibit 16 Specialist staffing levels

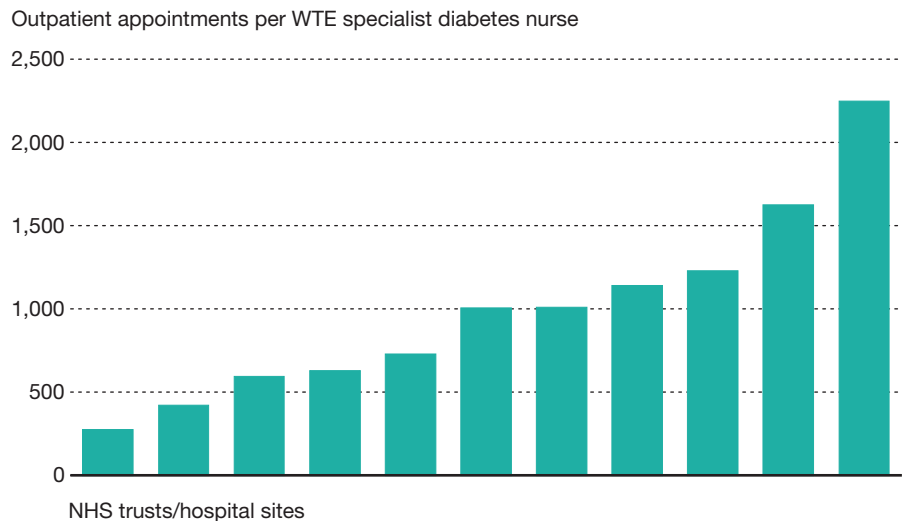
There are great variations in consultant staffing numbers.



Source: Audit Commission survey of NHS trusts, 2002 (data relates to WTE workload devoted to diabetes)

### Exhibit 17 Specialist nurse staffing levels

There is a similar degree of variation in specialist nurse staffing resources across trusts.



Source: Audit Commission survey of NHS trusts, 2002

- 193 The survey of general practices also indicated that there is pressure on staff resources in primary care, where the burden of managing chronic disease can be substantial and is increasing. Many respondents to the survey indicated that their practices needed more resources, particularly in the form of practice nurse time, to be able to cope with the increasing demand for diabetes care. This problem can be particularly acute where there are a high number of single-handed GPs, although there is evidence that, in some areas, local solutions are being put in place to provide appropriate support arrangements (**Case study 15**).
- 194 Tackling these staffing issues will not be easy. Recruitment problems in primary care are well documented. Some parts of Wales are also experiencing recruitment problems for specialists including diabetologists, dieticians and podiatrists. The problems with recruitment of psychologists with a special interest in diabetes have been documented elsewhere in this report.
- 195 It follows that a key step to the successful implementation of the NSF will be to undertake workforce reviews, both locally and nationally, in terms of staff numbers and skill sets. This will need to be considered by the All-Wales Workforce Development Group as a matter of urgency.

### Case study 15

#### Supporting primary care

A Primary Care Support Unit (PCSU) was established in 2000 by **Rhondda Cynon Taff** LHG from primary care development funds. The PCSU is a peripatetic unit for the Cynon Valley with high numbers of single-handed GPs and a high proportion of GPs approaching retirement age.

The aim of the unit is to support primary care professionals delivering high quality care and education to people with diabetes within primary care settings. The core team includes four WTE salaried GPs, a clinical director, three nurse facilitators and one diabetes nurse facilitator.

A wide range of support initiatives are provided, for example:

- GPs standing in for practice GPs so that they can attend training courses;
- the nurses provide extensive support to practice staff, and hands-on support during regular diabetes clinics; and
- education and training for practice nurses and GPs.

The PCSU team helps to ensure a consistent and high quality approach to diabetes care throughout the Cynon Valley.

**Source:** *Audit Commission in Wales fieldwork visit*

## Building capacity

196 Each local health community in Wales will need to build up its capacity to implement the NSF and its standards over the next ten years. There are key actions that require immediate attention and others which need to be part of a longer term strategy. These are considered below.

### Immediate actions at a local level

- LHBs must ensure that there is an operational and effective **LDSAG** or similar in operation. These groups will be crucial to help shape and monitor service delivery. They need appropriate membership, including healthcare professionals and people with diabetes. They must also have clear terms of reference and lines of accountability.
- Each LDSAG should be informed by a reference group of people with diabetes, as envisaged by the Diabetes NSF in Wales.
- Results of this baseline review at LHB level and associated local work need to be assessed and used as a 'gap analysis' of current local provision. This can then inform the creation of **local implementation plans**, which highlight service priorities and projected targets for implementing NSF standards.
- A **workforce review** must be part of the gap analysis and implementation plans, and should address staff numbers, roles and skill sets in different clinical settings.
- The planning priorities identified locally must be costed and reflected in the SaFF process. Identification of **appropriate funding** to take forward service development will be crucial.
- Identification of additional resources needs to be considered alongside **reviews of current working practices** to ensure that services are organised as efficiently, effectively and economically as possible.
- A systematic process needs to be put in place to **monitor progress** in implementing the standards. This will need clear accountabilities for service delivery to be identified and agreed. Processes to audit the local delivery of diabetes services across primary and secondary care also need to be established.

### Longer-term actions

197 There are other equally important actions that need to be taken but which, practically, are likely to need a longer development time. Work needs to begin on the following actions now, with a view to having arrangements in place over the next three years:

- Development of **population based diabetes registers** will be an essential tool in helping patients to manage their own diabetes and to target treatment to those individuals with poor control and higher risk of developing complications. They

will also be invaluable in facilitating clinical audit and monitoring of outcomes. The potential for amalgamating diabetes registers with those required by other NSFs (for example CHD, older people and children's services) should be fully evaluated.

- Development of local population based registers will assist in the roll out of the **All Wales Diabetes Retinopathy Screening Programme**. Contact details, taken from local registers, should be able to assist in identifying patients for initial referral to the retinal screening service. The retinopathy screening programme creates the potential ultimately to develop an all-Wales register of patients with diabetes.
- **Patient-held records and personal care plans** need to be developed as a means of helping with co-ordinating care across different health settings and giving patients more ownership of the management of their diabetes.
- There will be a need to ensure that **systematic and standardised approaches** to treatments are adopted within and across localities. This relates to key elements of patient care such as regular surveillance, structured education for patients, access to specialist care and transfer from one part of the system to another (for example from paediatric to adult services).
- Delivery of the NSF will need to be underpinned by appropriate programmes of **continuing professional education and training** for healthcare professionals involved in diabetes care. Training will need to encompass a broad spectrum that ranges from awareness of signs and symptoms, through to clinical management. Time for education and training will need to be protected and courses will need to be validated and accredited.

## National support for local action

- 198 Local implementation of the NSF will need to be supported by an appropriate programme of all-Wales action by the Assembly. This will require the Assembly to create its own capacity to provide both leadership and support to the health service and its partners.
- 199 The Department of Health's Delivery Strategy for the Diabetes NSF (**Ref. 12**) identifies a number of key national actions to support local delivery. These include the appointment of a National Clinical Director for Diabetes, support to local health systems from the NHS Modernisation Agency and the development of a Diabetes Information Strategy.
- 200 The Assembly will need to ensure that the service in Wales receives an equivalent and appropriate level of support. This will involve working in partnership with the Department of Health and also developing unique solutions and initiatives that meet the needs of Wales.

- 201 Urgent attention needs to be given to the development of an information strategy that will support the delivery of the NSF in Wales. This will need to be an intrinsic part of the agenda set by the Assembly's strategy, *Informing Healthcare* (Ref. 11). Particular attention needs to be paid to the:
- quality and availability of clinical data;
  - development of core datasets for diabetes; and
  - identification and implementation of outcome measures and performance indicators that will allow the progress with service development to be measured.
- 202 The Assembly can also help to ensure high and systematic standards of care by providing advice and guidance on the content of core elements of diabetes care such as annual reviews, patient education programmes and development of patient-held records and personal care plans. Developing a central capacity to identify, validate and share best practice will also be extremely important.

## Looking ahead

- 203 There is much good work to build on to develop diabetes services in Wales. Many patients who responded to our survey indicated that they were extremely satisfied with the standard of care they receive. However, this study has also shown that more needs to be done to ensure that all people with diabetes in Wales are receiving the support that they need.
- 204 The key problems highlighted in *Testing Times* (Ref. 1) are still present, namely, variations in the way services are organised and delivered, gaps in elements of patient surveillance and co-ordination of care across healthcare boundaries.
- 205 It is clear that diabetes services are under pressure, with mismatches between staff resources and the increasing demands being placed on them. The NSF will bring an increased focus on service delivery and meeting standards. Many health professionals are concerned that it will not be possible to deliver the NSF and achieve optimum management of diabetes without substantial injections of resources.
- 206 The NSF should be not be seen as an additional burden, but as an opportunity to review fundamentally the provision of diabetes services. Devising implementation strategies for the NSF will allow LHBs and trusts to identify where the key gaps in resources and service provision exist. The findings from this study will help inform that debate.
- 207 Providing additional resources is only part of the challenge. There is a need to look at the way that current services are organised and delivered. *Testing Times* (Ref. 1) argued that increasing demand for services would mean that more routine care will need to be done in primary care. In some parts of Wales there has been an obvious effort to promote the capacity of primary care to deliver good quality diabetes care.

However, there is still a need to develop primary care capacity in many parts of Wales. Where primary care diabetes services are less well developed, hospital teams feel less confident about discharging patients back to general practice, with the result that workload in secondary care continually expands.

- 208** This is not sustainable and requires a re-focusing of services. Primary care has the potential to provide most of the routine care for people with diabetes, but it will need to be supported by specialist staff to ensure that appropriate training for practice staff and programmes of care for patients are in place. In some parts of Wales, specialist diabetes facilitator posts have been used to good effect to help support the development of primary care diabetes services and promote better links with hospital teams. There is scope for this sort of model to be used more widely and a general need for closer working between specialist diabetes teams and staff in the primary and community sectors.
- 209** An additional focus on prevention and early detection is also needed and is a strong feature of the NSF. The baseline review has indicated that progress in these areas has been minimal. Investing resources in activities aimed at prevention and early diagnosis are likely to secure longer-term cost savings if they result in fewer patients going on to develop complications that require intensive and expensive treatment. More importantly, early intervention and good routine management offer the potential to minimise the impact diabetes can have on individuals' quality of life.
- 210** The results of this study should help inform the debate on what is needed to implement the NSF. At a local level, LHBs, trusts and LDSAGs will be able to use the findings to help develop a broader understanding of what diabetes services currently look like and to draw up local implementation plans with targets for improving services. The study will also give the Assembly an all-Wales picture of diabetes services to inform its work on supporting local implementation of the NSF. The review has shown that Wales has good foundations from which to build high quality diabetes services, however, significant challenges lie ahead.

# Appendix

## Surveys used to inform the baseline review

### Survey of people with diabetes

As part of the baseline review of diabetes services in Wales, the Audit Commission conducted a survey of people with diabetes in Wales. The survey was developed following consultation with the Assembly's Implementation Group and Diabetes UK Cymru.

Responses were received from a total of 1,467 people with diabetes in Wales. Approximately 22 per cent of the returns were from people with Type I diabetes and 76 per cent from people with Type II diabetes.

The returns from individual LHB areas (as ascertained by postcode) are shown in the table below.

#### Response rate from survey

LHG	Number of returns
Anglesey	18
Blaenau Gwent	46
Bridgend	66
Caerphilly	66
Carmarthenshire	13
Ceredigion	30
Cardiff	63
Conwy	105
Denbighshire	61
Flintshire	29
Gwynedd	43
Monmouth	63
Merthyr Tydfil	36
Neath Port Talbot	18
Newport	86
Pembrokeshire	39
Powys	124
Rhondda, Cynon, Taff	177
Swansea	55
Torfaen	96
Vale of Glamorgan	146
Wrexham	87
<b>Total</b>	<b>1,467</b>

## Survey of general practices in Wales

As part of the baseline review of diabetes services in Wales, the Audit Commission conducted a survey of all general practices in Wales. The survey was developed following consultation with the Assembly's Implementation Group and the LHG General Manager's Group.

Responses were received from a total of 365 practices in Wales. The response rate per LHG/B area is shown in the table below.

### Response rate from survey of general practices in Wales

LHB	Total number of practices	No. of practices responding to survey	Response rate
Anglesey	11	11	100%
Blaenau Gwent	22	8	36%
Bridgend	19	19	100%
Caerphilly	33	13	39%
Carmarthenshire	27	19	70%
Ceredigion	16	8	50%
Cardiff	56	43	77%
Conwy	19	13	68%
Denbighshire	16	11	69%
Flintshire	26	21	81%
Gwynedd	27	18	67%
Monmouth	14	3	21%
Merthyr Tydfil	13	13	100%
Neath Port Talbot	23	17	74%
Newport	23	23	100%
Pembrokeshire	18	12	67%
Powys	17	17	100%
Rhondda, Cynon, Taff	44	18	41%
Swansea	37	30	81%
Torfaen	14	14	100%
Vale of Glamorgan	19	12	63%
Wrexham	22	22	100%
<b>Total</b>	<b>516</b>	<b>365</b>	<b>70%</b>

## Survey of podiatry services in Wales

The All Wales Podiatry Diabetes subgroup undertook a survey across Welsh NHS trusts. All podiatry services in Wales responded to the survey.

The results of the survey were made available to the Audit Commission in Wales and have been used to inform the baseline review.

## Glossary of terms

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<b>Annual (structured) review</b>	A series of tests and examinations carried out regularly by health professionals, normally once a year. The examination includes checks of blood glucose control, blood pressure, weight, eyes, feet, renal function and cardiovascular risks. The aim is to monitor control of patients' diabetes and screen for the development and management of complications.
<b>Body mass index (BMI)</b>	Calculated by dividing weight in kilos by height in metres, and considered to be a superior measure of weight control.
<b>Chronic disease management programme</b>	Scheme in which GPs receive remuneration for providing a chronic disease service for the management of conditions such as diabetes and asthma.
<b>Chronic disease self management programme</b>	A pilot initiative run at two LHB areas during 2003, aimed at promoting the development of 'expert patients'. The programmes provide education and training to develop confidence and motivation in people to use their own skills and knowledge to manage chronic illness effectively.
<b>Coronary heart disease (CHD)</b>	General descriptive term associated for clinical problems associated with narrowing or blocking of the coronary arteries which supply blood to the heart. An NSF for CHD has been developed.
<b>CHD risk assessment</b>	The CHD NSF in Wales contains a requirement that all patients on primary care CHD management systems will have a comprehensive risk assessment and appropriate treatment plan. The risk assessment includes measurement of parameters relevant to diabetes care, such as fasting blood glucose, blood pressure, nutritional assessment and BMI.
<b>Diabetes facilitators</b>	Specialist staff, typically DSNs, employed specifically to help develop diabetes services run by other health professionals such as GPs, practice nurses and district nurses. Can also be referred to as diabetes liaison nurses.
<b>Diabetes mellitus</b>	A complex disorder of the pancreas affecting the body's ability to maintain normal blood glucose levels.
<b>Diabetes UK</b>	An organisation that campaigns to raise awareness of diabetes, funds research and supports patients and professionals. Previously known as the British Diabetic Association.

<b>Diabetic ketoacidosis</b>	A serious condition caused by a lack of insulin with resultant high blood glucose levels and excretion of ketones in the urine. Patients may have vomiting and drowsiness which can progress to coma, and a smell of acetone on the breath.
<b>Diabetic renal disease/failure</b>	Also called nephropathy. Kidney damage caused by high blood glucose and blood pressure. Initially characterised by 'leakage' of protein into the urine (see microalbumin), progressing, if untreated, to impaired kidney function and in the most severe cases to kidney failure.
<b>Diabetic retinopathy</b>	Problems affecting the retina, the light sensitive part at the back of eye, which transmits visual images to the brain.
<b>Diabetic specialist nurse (DSN)</b>	Specialist nurses providing expert care to people with diabetes.
<b>Diabetologist</b>	Consultant physicians (in general medicine), who specialise in diabetes and endocrine disorders.
<b>HbA1c</b>	A blood test which measures the stability and level of blood glucose over a two to three month period. As such, it gives a better overall picture of diabetic control, than a single snapshot measurement of blood glucose level.
<b>Health social care and well-being strategies</b>	LHBs and their coterminous unitary local authority have a statutory responsibility to formulate and implement a health, social care and well-being strategy for their local area. The Strategy should span the whole spectrum of preventative action to improve health and reduce the risk of ill health. The first strategy should be operative for a three year period from 1 April 2005.
<b>Hyperglycaemia</b>	High blood glucose level, generally 10mmol/litre and above (also see diabetic ketoacidosis). Usually occurs as a result of poor diabetic control, missed insulin injections or infection.
<b>Hypoglycaemia</b>	Low blood glucose level, generally 4mmol/litre and below. Patients can develop a crisis when blood glucose levels drop too low, resulting in loss of consciousness and convulsions. Can be caused by excessive dose of insulin, inadequate food or sudden exercise.
<b>Photocoagulation</b>	Process by which laser therapy is used to treat retinal damage in the eye.

<b>Link nurses</b>	Ward nurses who have been trained in the management of diabetes and provide a point of reference to raise awareness about diabetes and its management amongst colleagues on the ward in which they work. They act as a link between the ward and the hospital diabetes team.
<b>Local Diabetes Service Advisory Group (LDSAG)</b>	A group covering a defined geographical area with multi-agency and multiprofessional members and user representatives. Groups typically report to, and inform, health service commissioners.
<b>Local Health Boards (LHBs)</b>	Created on 1 April 2003, following abolition of health authorities in Wales. There are 22 LHBs in Wales, coterminous with unitary local authorities. LHBs are responsible for promoting the health and well being of their local population, commissioning hospital and community based services and developing primary healthcare.
<b>National Institute of Clinical Excellence (NICE)</b>	NICE was set up as special health authority for England and Wales on 1 April 1999 to provide patients, health professionals and the public with authoritative, robust and reliable guidance on current best clinical practice.
<b>National Service Framework (NSF)</b>	An initiative aimed at ensuring consistency of healthcare services by setting national standards and defining models of care. Implementation is staged over a defined timescale, in the case of diabetes, ten years.
<b>Neuropathy</b>	Damage to the nerves and nerve endings.
<b>Patient-held records</b>	A casenote or similar document which is kept by patients and contains details of tests and consultations performed by all healthcare professionals involved in the management of the condition.
<b>Personal care plans</b>	A plan that sets out an agreed programme of care for an individual, including action that the patient themselves can take.
<b>Podiatrist/chiroprapist</b>	Speciality concerned with diagnosis and/or medical, surgical, mechanical, physical and adjunctive treatment of diseases, injuries and defects of the human foot. Synonymous with chiroprapist, the term podiatrist is now preferred by the profession.
<b>Registers</b>	A register, usually electronic, of all patients with diabetes in a geographical area. Registers should include information about the type of diabetes, date of diagnosis, and results of annual reviews including retinal screening and foot checks.

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<b>Service and financial framework (SaFF)</b>	SaFFs provide a planning framework that identify how Assembly priorities and requirements will be met alongside local priorities, within the resources available.
<b>Type I diabetes</b>	Also known as insulin dependent diabetes, refers to a type of diabetes that must be treated with insulin.
<b>Type II diabetes</b>	Also known as non-insulin dependent diabetes. This type of diabetes usually has a later age of onset and can be managed with diet or with a combination of diet and medication. However, some people with Type II diabetes may become dependent on insulin to manage their diabetes as the condition develops.
<b>United Kingdom Prospective Diabetes Study (UKPDS)</b>	A longitudinal study which has demonstrated the benefits associated with tight control of blood glucose and blood pressure in preventing complications of Type II diabetes.
<b>Urinary albumin/creatinine</b>	The ratio of albumin and creatinine in the urine, used as an indicator of kidney function.
<b>Urinary microalbuminuria</b>	Excretion of very small amounts of protein in the urine, which are often undetectable by dipstick test. Seen, therefore, as an important early indicator of kidney impairment.
<b>Visual acuity</b>	A test of vision, usually by means of reading a traditional optician's (Sneller) chart of characters of diminishing size.

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