Diabetes: State of the Nations 2006
Progress made in delivering the national diabetes frameworks

A report from Diabetes UK
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Diabetes UK

Diabetes UK is the charity for people with diabetes. We stand for the interests of people with diabetes by campaigning for better standards of care. We fund research to improve the treatment of diabetes and to find a cure and we provide practical information and support services to help people manage their own diabetes.

Diabetes UK has over 170,000 members and a network of offices across the UK. We are one of the largest patient organisations in Europe.

The mission of Diabetes UK is to improve the lives of people with diabetes and to work towards a future without diabetes.

This report addresses key strategic issues for the development of diabetes services, each of which is a priority for Diabetes UK. Drawing on recent research, particularly the Diabetes UK members’ survey for 2006, this report identifies issues for all those involved in improving the lives of people living with diabetes in the UK.

Early identification

Thousands of people are living in the UK today with undiagnosed diabetes. The longer they remain unaware of their condition, the more likely it is that they will have to cope with serious complications.

Early identification of diabetes requires targeted testing of people at risk. Information and services should be in place to enable people at high risk, but who do not have diabetes, to be informed about what they can do to reduce their risk. Systematic efforts to do this are still far from commonplace.

Health professionals who see people at risk every day are not making the most of the opportunities they have to identify people with undiagnosed diabetes and inform them about reducing risk.

The new National Screening Committee guidelines must be seen as the starting point for a comprehensive, targeted screening and risk reduction programme for diabetes.

Emotional and psychological support

Living with diabetes is a long-term challenge that puts considerable pressure on individuals and families. Emotional and psychological needs must be addressed if this challenge is to be met.

Gaps remain in the provision of specialist psychological services for those who find coping with diabetes very difficult.

Most emotional support is provided by clinical professionals whose time and skills may not always be sufficient to meet the complexity of emotional needs.

Clinical professionals’ role in signposting and referring their patients to the full range of support services is not fully exploited.

Greater efforts should be made to promote peer support as an effective source of emotional support.
Education for self-care

Day-to-day responsibility for diabetes management rests with the individual living with diabetes and his/her family. This challenge is enabled and supported by information and education.

Only half of adults (and a quarter children and young people) living with diabetes are aware of any structured education courses to help them manage their condition.

The provision of structured education is still limited, especially for young people. Information about the courses that are available is also lacking.

A majority of people newly diagnosed with diabetes do not receive structured education in their first year living with the condition. Provision for this group needs to be universal.

Structured education courses should be offered as part of a range of information and education interventions for people with diabetes. People require very different levels of support at different times and services must be sensitive to these differences and able to respond appropriately to them.

Children and young people

The majority of diabetes among children and young people is Type 1 but incidence of Type 2 is growing as more young people become overweight and obese.

The care and support that children and young people receive from specialist hospital teams is highly regarded.

Almost all children and young people get support from specialist teams between clinic visits, predominantly from diabetes specialist nurses. Many paediatric diabetes specialist nurses are overstretched with huge caseloads. Further investment is needed in this professional role and in provision of emotional and psychological support for children and their parents.

Stronger links are needed between specialist diabetes teams and schools to ensure that children and young people do not feel isolated or unsupported.

Many young people still experience problems when their care is transferred to adult diabetes services. Greater efforts are needed to ensure that young people are full partners in this process.

Retinal screening

Diabetes is the leading cause of blindness in the working-age population. Prevention of blindness is possible through regular retinal screening.

All the nations of the UK have ambitious targets for comprehensive retinal screening of people living with diabetes. Retinal screening coverage has improved in all nations.

Nine out of 10 adult Diabetes UK members received a retinopathy eye test in 2005/06. National figures identify that up to forty per cent of people with diabetes in England have still not had their eyes screened and are at increased risk of visual impairment.

Four out of five screening services now use digital cameras.

Fifty three per cent of Primary Care Trusts (PCTs) report not meeting the national target of 70 per cent of people with diabetes offered screening having received it by June 2006.

Quality assurance of retinal screening programmes is crucial.

Treatment and care

Results from the national quality outcomes framework (QOF), part of the General Medical Services (GMS) contract for general practitioners, indicate a year-on-year improvement in outcomes for people with diabetes in all nations.

Problems remain with exception reporting within QOF but these national indicators provide a strong basis for tackling inequalities in diabetes care both locally and nationally.

Two in five adults and more than four in five children and young people have poor blood glucose management that puts them at risk of complications. Yet access to blood glucose testing strips is still restricted in some areas.

Satisfaction with local diabetes services is high among members of Diabetes UK.

Recommendations

Publication of all national diabetes frameworks has resulted in improvements in England, Northern Ireland, Scotland and Wales. However, local service failures remain. We would like to see government action to ensure that these are addressed and information made available about
whether or not the recommendations listed have been achieved.

Prevention and early diagnosis

• Promote responsible food labelling and restrict advertising of junk food to help reduce population obesity levels and prevalence of Type 2 diabetes.
• Publish guidance on targeted diabetes screening as part of a cardiovascular disease risk reduction programme.

Information, education and support

• Increase provision of talking therapies to improve psychological support.
• Promotion of peer support services to enable people with diabetes to talk with and learn from others.
• Fund delivery of diabetes structured education programmes in all localities to meet individual needs.
• Ensure provision of high quality information about diabetes, treatments, staffing and service quality to inform and empower people with diabetes. Participation in audit and publication of results will support this goal.

Treatment and care

• Continue progress to guarantee that all people with diabetes are digitally screened for retinopathy. National reporting of targets must meet the standards for delivering a systematic retinal screening programme. Centrally funded and independent quality assurance is required.
• Protect the rights of people with diabetes by assuring the recruitment and local deployment of appropriate levels of specialist diabetes expertise to support community services and deal with complex management issues and special groups.
• Guarantee that all staff working with people with diabetes can access appropriate education and training and that competences are assured.
• Investment in paediatric specialist diabetes teams to reduce variations in care, reduce caseloads and improve links with schools for children with diabetes and families.
• Eradicate the postcode lottery to accessing drugs, devices and care guidelines that have been approved by the government watchdog the National Institute for Health and Clinical Excellence (NICE).

Prioritising diabetes

• Local services to commission and deliver diabetes services meeting national standards ensuring that people with diabetes are involved.
• Strategies to be in place in all localities to reduce inequalities within communities.
Introduction

Action today, health tomorrow

Diabetes is one of the greatest health challenges facing the UK today. Over two million people in the UK are currently living with diabetes (Table 2.1). Up to half a million more have not had their condition diagnosed. Prevalence of diabetes has increased over the last nine years\(^1\). As the population gets older and obesity levels rise prevalence will increase further\(^1\).

Diabetes has a profound impact on health, quality and length of life. Up to 5 per cent of NHS expenditure is spent on diabetes, accounting for over £1 billion\(^2\). People who live with diabetes have a high risk of heart disease, stroke, blindness, kidney disease and amputations. They are five times more likely than the general population to suffer heart failure. Diabetes is the leading cause of blindness in the working age population. Across the UK one thousand people with diabetes start kidney dialysis every year.

### 2.1 Prevalence of diabetes in the UK, 2005/6

<table>
<thead>
<tr>
<th>Nation</th>
<th>Prevalence</th>
<th>No. of people</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK</td>
<td>3.5%</td>
<td>2,238,000</td>
</tr>
<tr>
<td>England</td>
<td>3.6%</td>
<td>1,891,000</td>
</tr>
<tr>
<td>N. Ireland</td>
<td>3.1%</td>
<td>55,000</td>
</tr>
<tr>
<td>Scotland</td>
<td>3.4%</td>
<td>170,000</td>
</tr>
<tr>
<td>Wales</td>
<td>4.1%</td>
<td>127,000</td>
</tr>
</tbody>
</table>

*Source: Quality Management & Analysis System (QMAS)*\(^14\)

There is huge scope for improving the treatment and care of people with diabetes and reducing the costs to the health service and to society as a whole. Prevention of long-term complications through better management and support for self care will improve the lives of people living with diabetes and reduce costly emergency hospital admissions.

In all nations of the UK there are service frameworks in place to promote the health of people with diabetes\(^3,4,5,6,7\). They provide a clear direction for improvement and promote the integration of diabetes services with prevention and self-management.

This report describes the state of diabetes services in the four UK nations in 2006. It offers information and insight for all those working to achieve better outcomes for people with diabetes and those at risk.

The principal source of data for this report is Diabetes UK’s survey of its members\(^8\). With over 29,000 respondents, this provides a clear view of the contemporary reality of living with diabetes and the experience of diabetes services. Gaps highlighted may underestimate national needs as Diabetes UK members are more likely to be aware of what care to expect and able to demand that care. The report also draws on surveys of English primary care trusts (Diabetes UK 2006\(^9\) and Northern Ireland health and social service boards, (Diabetes UK 2006\(^10\)), qualitative research into the experience of people newly diagnosed (The Listening Project 2006\(^11\)), the National Diabetes Audit for the period 2004/05\(^12\), the Scottish Diabetes Survey (2005\(^13\)) and results from the primary care Quality Outcomes Framework (2005/6)\(^14\).

The report focuses on the five key priority areas of Diabetes UK: early identification of diabetes, psychological and emotional support, education for self-care, retinal screening and services for children and young people. It provides a clear agenda for action that all those who care about the needs of people living with diabetes can take forward with confidence.
Early identification

Key points

➢ Thousands of people are living in the UK today with undiagnosed diabetes. The longer they remain unaware of their condition, the more likely it is that they will have to cope with serious complications.

➢ Early identification of diabetes requires targeted testing of people at risk. Systematic efforts to do this are still far from commonplace.

➢ Health professionals who see people at risk every day are not making the most of the opportunities they have to identify undiagnosed diabetes.

➢ The imminent National Screening Committee guidelines must be seen as the starting point for comprehensive targeted screening for diabetes.

A Diabetes UK priority

All people with diabetes should be identified and diagnosed early.

Up to half a million people in the UK have undiagnosed diabetes. As half of those who are diagnosed with Type 2 diabetes present with advanced complications, particularly retinopathy, a systematic approach to identifying diabetes in high-risk communities is needed.\(^{15}\)

Many people with diabetes feel that if they had been diagnosed earlier, they would have been able to take action to prevent the onset of complications.\(^{16}\)

Increasing rates of obesity are contributing to the increasing incidence and prevalence of Type 2 diabetes. Tackling this requires actions to support people at high risk of diabetes, who do not yet have it, to reduce their risk.

National policy

UK

The UK National Screening Committee announced in May 2006 that diabetes screening would be included in the Vascular Disease Assessment and Management Programme. The aim of this programme will be to minimise the risk of vascular disease and to test for diabetes using random blood glucose testing. Work is in progress to identify the programme’s criteria and costs.

England

Standard 2 of the National Service Framework requires the NHS to develop, implement and monitor strategies to identify people who do not know they have diabetes.

The Wanless report for England noted that there is scope for significant cost-savings through prevention of diabetes, earlier diagnosis and better management.\(^{17}\)

The White Paper Our Health, Our Care, Our Say announced the introduction of a new NHS ‘life check’ throughout 2006-08 for people to assess their lifestyle risks and access health advice where appropriate.\(^{18}\)

Northern Ireland

Prevention, early detection and the screening of high-risk groups were identified as an area for early action by the 2003 Blueprint for Diabetes Care in Northern Ireland.
Scotland
In Delivering for Health\textsuperscript{19}, the Scottish Executive commits to tackling health inequalities through ‘anticipatory care’. From October 2006, those aged 45-64 at risk of cardiovascular disease in some of the most deprived communities in Scotland are being invited to attend for a ‘keep well’ health check. The aim of this programme is to identify and target those at particular risk of preventable serious ill-health, offering appropriate interventions and services to them and providing monitoring and follow-up.

The Scottish Executive has also recently stated that work on diabetes screening is to be taken forward in the context of addressing general cardiovascular risk factors and is awaiting the advice of the National Screening Committee.

Wales
Standard 2 of the National Service Framework requires the NHS to develop, implement and monitor strategies to identify people who do not know they have diabetes.

In 2003 the Audit Commission in Wales called for a more systematic approach to screening for diabetes and the National Assembly has since voted for active case finding of Type 2 diabetes, involving regular targeted screening. The Assembly Government’s 10 year plan for the NHS, Designed for Life, promotes early assessment and accurate, timely diagnosis of a range of conditions including diabetes.

Research findings

Prevalence of undiagnosed diabetes
An estimated 19 per cent of people with diabetes are undiagnosed or not recorded on general practice registers. This estimate is based on a comparison of the practice registrations reported to the National Diabetes Audit and the overall prevalence of diabetes as calculated within the model developed by the Yorkshire and Humber Public Health Observatory, Brent Primary Care Trust and University of Sheffield School of Health and Related Research\textsuperscript{12}.

This model also predicts a higher prevalence of diabetes among women than men, yet the audit data reveals more registrations by men. This suggests that there may be relative under-diagnosis of women with diabetes.

Circumstances of diagnosis
Members of Diabetes UK who had been diagnosed in the previous 12 months reported the circumstances of their diagnosis:

- 41 per cent of diagnoses were due to having a test for another condition or problem.
- 23 per cent were due to a routine test offered by the GP or practice nurse.
- 23 per cent were due to going to the doctor with symptoms or asking the doctor for a test.
- 6 per cent were due to an emergency hospital admission.
- 3 per cent were due to having a test at a pharmacy.
- 2 per cent were due to an optician recommending a test.
- 2 per cent were due to a medical for insurance or work.

Source: Diabetes UK 2006 Members survey

The majority of these diagnoses were not a response to the specific symptoms of diabetes. This demonstrates the importance of opportunistic testing for diabetes, especially within high-risk groups.

More members were diagnosed through routine testing in 2006 (23 per cent) compared to 2005 (15 per cent). Conversely fewer diagnoses were in response to specific symptoms: 23 per cent in 2006 compared to 37 per cent in 2005. This shift is encouraging as it suggests that more people are being diagnosed through opportunistic screening before they become symptomatic.

Within a small sample of South Asian people with diabetes the pattern is similar:

- 39 per cent of diagnoses were due to seeking help with symptoms
- 31 per cent were due to a routine test
- 23 per cent were due to a test for another condition\textsuperscript{20}.

Early identification programmes
In England 53 per cent of PCTs have a programme in place to promote early identification of diabetes\textsuperscript{5}. Two of the health and social services boards in Northern Ireland have early identification programmes in place\textsuperscript{10}. In Scotland, the ‘keep well’ programme, targeting cardiovascular risk, is being piloted in five areas.
Systematic programmes ought to complement widespread opportunistic testing within primary and secondary care but plenty of opportunities are still being missed.

*I was feeling ill and I kept going backwards and forwards to the GP. He kept on taking my blood pressure and saying it was OK. Then I was lucky and saw a different GP and he did a blood test. The nurse rang me to tell me I had diabetes.*

*Source: Diabetes UK Listening Project 2006*

### Issues to address

Although an increasing number of new diagnoses are due to routine testing, the potential of targeted case finding and opportunistic testing remains seriously under-exploited.

The level of investment in local programmes to actively identify people with undiagnosed diabetes is far too low. Furthermore, tackling this issue appropriately requires access to information and services to support people at high risk to reduce their risk.

Responsible advertising and food labelling will help to inform the public's food purchasing behaviours, but local prevention and health promotion services are also a prerequisite.

All healthcare professionals ought to be able to identify individuals who are at high risk of diabetes and be encouraged to test people before they become symptomatic. Professional education and training that addresses this issue is much needed. The cost of early identification is small when compared to the cost of complications arising from unmanaged, undiagnosed diabetes yet there is still reluctance to develop programmes which systematically integrate screening of high-risk patients, opportunistic testing and public education.

The new guidelines from the National Screening Committee ought to provide a foundation for the development of early identification programmes throughout the UK. These are eagerly awaited.
Emotional and psychological support

Key points

- Living with diabetes is a long-term challenge that puts considerable pressure on individuals and families. Emotional and psychological needs must be addressed if this challenge is to be met.
- Gaps remain in the provision of specialist psychological services for those who find coping with diabetes very difficult.
- Most emotional support is provided by clinical professionals whose time and skills may not always be sufficient to meet the complexity of emotional needs.
- Clinical professionals’ role in signposting and referring their patients to the full range of support services is not being fully exploited.
- Greater efforts should be made to promote peer support as an effective source of emotional support.

A Diabetes UK priority

*All people with diabetes should have access to the emotional and psychological support required to come to terms with living with the condition.*

The nature of the emotional and psychological support sought by people with diabetes ranges from talking to others about living with the condition to gaining specialist support in dealing with intractable coping difficulties. The emotional issues associated with the condition include anxiety, difficulties accepting restrictions in diet, isolation and the effects of stress and illness on relationships.

National policy

**England**

Standard 3 of the National Service Framework requires that all people with diabetes 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.

The White Paper *Our Health, Our Care, Our Say* prioritises health, independence and wellbeing and the provision of better mental health and emotional support. ‘Talking’ therapies, such as cognitive behavioural therapy, are to be expanded.

**Northern Ireland**

Emotional and psychological support was identified as an area for early action by the 2003 *Blueprint for Diabetes Care* in Northern Ireland.

**Scotland**

Standard 3 of the Clinical Standards for Diabetes in Scotland identifies that people with diabetes should have appropriate access to identified key health professionals including psychology services. The Scottish Diabetes Framework Action Plan 2006-2009 further commits to ‘improve access to psychological and emotional support for people with diabetes’.

**Wales**

Standard 3 of the National Service Framework requires that all people with
diabetes 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.

In December 2003 the Audit Commission in Wales found that access to specialist psychological support is a significant problem across the whole of Wales.

Research findings

Psychological support

In 2005/06 one in every 25 members of Diabetes UK (4 per cent) felt that they needed to see a specialist for psychological support to help cope with their diabetes (Chart 4.1). Of these, only half actually saw a specialist (Chart 4.2). This level of unmet need for psychological support is fairly consistent across nations.

Among children and young people, the need for psychological support is significantly higher: 8 per cent said they needed to see a specialist for psychological support to help cope with their diabetes. A higher proportion of those in need in this group did actually get to see a specialist (71 per cent).

In England, 86 per cent of PCTs claim to provide psychological support for adults with diabetes and 70 per cent provide for children and young people aged 16 or under. All health and social services boards in Northern Ireland provide psychological support for adults and children with diabetes. In Scotland, access to clinical psychology services is limited and very few areas have dedicated psychology services for people with diabetes. Referral to general psychology services involves extensive waiting times.

4.1 Adults who needed psychological support in last 12 months

<table>
<thead>
<tr>
<th></th>
<th>0%</th>
<th>50%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK</td>
<td>4%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>England</td>
<td>4%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N Ireland</td>
<td>5%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scotland</td>
<td>4%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wales</td>
<td>4%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Diabetes UK 2006 Members survey

Emotional support

Half of all adult Diabetes UK members (48 per cent) received some form of emotional support to help cope with their diabetes in 2005/06 (Chart 4.3). Professionals in primary care were most commonly cited as sources of this support, followed by hospital-based professionals and family and friends (Chart 4.4).

Two thirds of children and young people (66 per cent) received some form of emotional support. This result was consistent across all nations. In contrast with the adults, children and young people are much more likely to turn to family and friends first for emotional support, or to their specialist hospital teams (Chart 4.5).

4.2 Adults in need of psychological support who saw a specialist

<table>
<thead>
<tr>
<th></th>
<th>0%</th>
<th>50%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK</td>
<td>49%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>England</td>
<td>50%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N Ireland</td>
<td>53%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scotland</td>
<td>43%</td>
<td></td>
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</tr>
<tr>
<td>Wales</td>
<td>53%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Diabetes UK 2006 Members survey

4.3 Adults who received emotional support in last 12 months

<table>
<thead>
<tr>
<th></th>
<th>0%</th>
<th>50%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK</td>
<td>48%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>England</td>
<td>49%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N Ireland</td>
<td>48%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scotland</td>
<td>43%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wales</td>
<td>49%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Diabetes UK 2006 Members survey
4.4 Provider of support, for adults who sought it

<table>
<thead>
<tr>
<th>Provider</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes specialist nurse at surgery</td>
<td>45%</td>
</tr>
<tr>
<td>GP</td>
<td>36%</td>
</tr>
<tr>
<td>Nurse at GP surgery</td>
<td>23%</td>
</tr>
<tr>
<td>Diabetes specialist nurse at hospital</td>
<td>20%</td>
</tr>
<tr>
<td>Consultant at hospital</td>
<td>19%</td>
</tr>
<tr>
<td>People with diabetes (not support group)</td>
<td>14%</td>
</tr>
<tr>
<td>Telephone helpline</td>
<td>8%</td>
</tr>
<tr>
<td>Patient support group</td>
<td>2%</td>
</tr>
<tr>
<td>Counsellor</td>
<td>1%</td>
</tr>
<tr>
<td>Social worker</td>
<td>&lt;1%</td>
</tr>
</tbody>
</table>

Source: Diabetes UK 2006 Members survey

We went on a Diabetes UK Family Weekend 10 months after he was diagnosed and it was the best thing we did. Talking to other mums was a great help to me. I wish we had done it sooner, but I couldn’t talk about it without crying. It didn’t matter if you cried there. Everybody understood and they cried with you.

Source: Diabetes UK Listening Project 2006

4.5 Provider of support, for children and young people who sought it

<table>
<thead>
<tr>
<th>Provider</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family/friends</td>
<td>57%</td>
</tr>
<tr>
<td>Paediatric diabetes nurse at hospital</td>
<td>50%</td>
</tr>
<tr>
<td>Paediatric diabetes consultant at hospital</td>
<td>29%</td>
</tr>
<tr>
<td>People with diabetes (not support group)</td>
<td>12%</td>
</tr>
<tr>
<td>GP</td>
<td>7%</td>
</tr>
<tr>
<td>Counsellor</td>
<td>4%</td>
</tr>
<tr>
<td>Family weekend</td>
<td>4%</td>
</tr>
<tr>
<td>Diabetes specialist nurse at surgery</td>
<td>4%</td>
</tr>
<tr>
<td>Nurse at GP surgery</td>
<td>4%</td>
</tr>
<tr>
<td>Patient support group</td>
<td>3%</td>
</tr>
<tr>
<td>Telephone helpline</td>
<td>2%</td>
</tr>
<tr>
<td>Email chatroom</td>
<td>1%</td>
</tr>
</tbody>
</table>

Source: Diabetes UK 2006 Members survey

Issues to address

A relatively small proportion of adults and children living with diabetes feel the need for professional psychological help. Nonetheless, only half the adults who report this need are actually getting a service, indicating a serious gap in provision.

Many people with diabetes gain emotional support from the health professionals who help them manage their diabetes. Although this may often be appropriate, the high level of dependence on these professionals raises the question of whether they are always the best placed, and best-skilled, to provide for this need.

The time limitations on encounters between clinical professionals and their patients is a major constraint on the power of these relationships to meet significant emotional needs.

Diagnosis is a time of acute need for emotional support yet this need is all too easily obscured by competing clinical priorities.

Clinical professionals should enable their patients to access a wide range of psychological and emotional support. Information about specialist clinical services should be complemented by referrals to peer support and the resources of patient organisations.
Key points

- Day-to-day responsibility for diabetes management rests with the individual living with diabetes and his/her family. This challenge is enabled and supported by information and education.

- Only half of adults (and a quarter of children and young people) living with diabetes are aware of any structured education courses to help them manage their condition.

- The provision of structured education is still limited, especially for young people. Information about the courses that are available is also lacking.

- A majority of people newly diagnosed with diabetes do not receive structured education in their first year living with the condition. Provision of structured education for this group needs to be universal.

- Structured education courses should be offered as part of a range of information and education interventions for people with diabetes. People require very different levels of support at different times and services must be sensitive to these differences and able to respond appropriately to them.

A Diabetes UK priority

All people with diabetes will be provided with the structured education they need to be able to effectively manage their condition on a day-to-day basis.

Self-care is the cornerstone of diabetes care as 95 per cent of managing the condition is self-care. The extent to which people can manage their diabetes to reduce the risk of complications is determined by their understanding and confidence in making daily decisions. Many people do not understand the key elements of diabetes management and this negatively affects their quality of life, access to services and satisfaction.

Education programmes improve quality of life, satisfaction and clinical outcomes. They help people to feel in more control of their diabetes, leading to reduced complications. High quality structured education is a key intervention to support self-care that should be tailored to the individual to account for age, social circumstances, disability and culture.

In collaboration with the National Diabetes Support Team, Diabetes UK has published guidance on how structured education should be delivered to meet NICE guidelines.

Many education courses are currently running across the UK. These include the DESMOND and XPERT for Type 2 diabetes and over 20 courses for those with Type 1 diabetes including DAFNE, BERTIE, DAFYDD (Wales), Jigsaw, Insight and PDAC amongst others. Those running locally developed courses in England and Wales are being supported by the Type 1 Education Network to meet national criteria and standards. Most health providers offer generic chronic disease self-management training which some people with diabetes have found to be of benefit. However this does not replace...
the need for specific education about diabetes self-management.

National policy

England
Standard 3 of the National Service Framework requires that all people 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.

Following an appraisal of diabetes patient education models, NICE recommended from January 2006, structured patient education to be available to all people with diabetes.

The National Diabetes Support Team and Diabetes UK produced criteria for implementing NICE recommendations in 2005 and a self-assessment tool to enable PCTs and local programmes to assess if they are meeting criteria (2006).

The White Paper Our Health, Our Care, Our Say announced the trebling of investment in the Expert Patient Programme and the development of an ‘information prescription’ for people with long-term conditions.

Northern Ireland
Education for people with diabetes was identified as an area for early action by the 2003 Blueprint for Diabetes Care in Northern Ireland.

The strategy Priorities for Action – Planning Framework for the HPSS 2006-2008 includes the target ‘by 31 December 2006, Boards and Trusts should develop proposals to introduce a structured educational programme, including psychological support, for people with diabetes to help them to manage their own condition more effectively.’

Scotland
Standard 3 of the Clinical Standards for diabetes in Scotland requires that all those newly diagnosed with diabetes are offered at least one tailored formal education sessions and are provided with written information. Educational programmes should continue after diagnosis and include diet, foot care and eye care as well as day-to-day management of diabetes.

The Scottish Diabetes Framework Action Plan 2006-2009 commits to additional investment in structured education for people with Type 1 diabetes and to ensuring that all people with Type 2 diabetes are offered at least one structured education session within three months of diagnosis.

Wales
Standard 3 of the National Service Framework requires that all people 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.

In December 2005 the Welsh Assembly Government instructed all local health boards to implement NICE guidelines on structured education.

Research findings

Awareness of, and participation in, education courses
In 2006 less than half of Diabetes UK members (48 per cent) were aware of any education courses to help them manage their diabetes (Chart 5.1). Slightly over a quarter of the young members (28 per cent) were aware of such courses (Chart 5.2).

A small minority of members (6 per cent of adults and 5 per cent of children and young people) had participated in an education or training course in the previous 12 months. However, among those who had been diagnosed in this period, 27 per cent had participated in a course.

The education courses attended by Diabetes UK members ranged from those lasting less than a day to some that lasted for five days or more in total (Chart 5.3).

Among those who had been offered a course but could not participate, the most common reasons for inability to attend were that the time or day was inconvenient or that the location was inconvenient (Chart 5.4).
5.1 Adults who were aware of education courses

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<td>Wales</td>
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Source: Diabetes UK 2006 Members survey

5.2 Children and young people who were aware of education courses

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<td>England</td>
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<td>Wales</td>
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</table>

Source: Diabetes UK 2006 Members survey

5.3 Course length

- < 1 day: 32%
- 1 day: 21%
- 2-4 days: 24%
- 5+ days: 23%

Source: Diabetes UK 2006 Members survey

5.4 Reasons for not being able to participate (among adults offered training opportunities)

- The time or day was inconvenient: 23%
- The location was inconvenient: 13%
- I don't like group training: 9%
- The course didn't cater for my disability: 3%
- The course wasn't suited to my cultural needs: 1%
- There were no male-only or female-only courses: 1%

Source: Diabetes UK 2006 Members survey

Provision of education courses

The provision of structured education by PCTs in England is not universal. In 2006, structured education was provided by 72 per cent of trusts for people with Type 1 diabetes and 90 per cent of trusts for people with Type 2 diabetes. Only 47 per cent of PCTs provided structured education for children and young people.

The difference in the education provision for adults and for children is consistent with the difference in awareness of education courses between these age groups – adults are approximately twice as likely to be provided with education and twice as likely to be aware of any courses.

Structured education opportunities in Northern Ireland are currently very limited with only one course for Type 1 and one course for Type 2 available in one area.

In Scotland, there are currently only three sites providing DAFNE and the pilot of DESMOND (two sites) will report in April 2007. The X-PERT programme operates in one health board area and the other health boards provide varying levels of access to education.

Most local health boards in Wales are running courses of some type and central funding has been made available to support staff training in the X-PERT programme (though not their delivery). Diabetes UK Cymru is currently running a number of DESMOND courses in areas of particular need.

A majority of PCTs (87 per cent) in England and health and social services boards in Northern Ireland are aware of the Structured Diabetes Assessment Tool developed by Diabetes UK and the National Diabetes Support Team.

Other interventions

The provision of basic information and advice is much more common. Nine out of 10 of the young members of Diabetes UK said they received information and advice from the hospital to help achieve good control (Chart 5.5). Around three quarters of children and young people in all four nations feel confident in managing their diabetes (Chart 5.6).
5.5 Children and young people who received information and advice about control

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<td>Wales</td>
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</table>

Source: Diabetes UK 2006 Members survey

5.6 Children and young people who are confident in managing their diabetes

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<td>Wales</td>
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<td>74%</td>
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</table>

Source: Diabetes UK 2006 Members survey

In England, 92 per cent of PCTs provide information, including Diabetes UK information, at the time of diagnosis and most (89 per cent) claim that this information takes account of cultural sensitivities. However 24-hour telephone helpline support is only provided by 20 per cent of PCTs.

Personal care plans are agreed with people newly diagnosed with diabetes in two thirds (65 per cent) of English PCTs and patient-held records are provided by 39 per cent.

The Southern Health and Social Services Board is the only board in Northern Ireland that reports providing 24-hour telephone helpline support, personal care plans and patient-held records.

Meeting individual needs

Education is a very high priority for people who are newly diagnosed with diabetes yet many people are still left confused and frustrated by inadequate interventions that fail to address their personal needs and concerns.

I was sent to a class but there were 20 people in the group and there was a lot of information and we couldn’t ask questions.

Source: Diabetes UK Listening Project 2006

Issues to address

Structured education courses for adults with Type 2 diabetes are now more widely available but there are significant gaps in provision for Type 1 diabetes and in particular for children and young people. Questions remain about availability of most courses, which are not universally promoted locally, or if they all meet national standards.

Many adults and a majority of children and young people are unaware of opportunities for structured education. This is only partly accounted for by the gaps in provision. More information about these courses is also needed.

The needs of people who are recently diagnosed are particularly acute, yet only a minority are currently benefiting from structured education in their first year living with the diabetes.

Structured education should provide participants with a framework within which to raise and address personal questions and concerns. This cannot be taken for granted: the quality and responsiveness of structured education should always be evaluated.

The individuality of need should be respected by health professionals in their everyday interactions with people with diabetes. Structured education is one of many interventions available to address information and education needs and the value of other resources, from simple leaflets to hand-held records, should be maximised.

People with diabetes need to be provided with the knowledge and ability to take control of their own diabetes, rather than it controlling them. Everyone should have access to the knowledge and tools to manage their diabetes effectively. Once diagnosed, diabetes is a lifelong condition and removing the barriers that disempower will help people to cope and enable them to live full lives.
Retinal screening

Key points

- Diabetes is the leading cause of blindness in the working age population. Prevention of blindness is possible through regular retinal screening.
- All the nations of the UK have ambitious targets for comprehensive retinal screening of people living with diabetes.
- Nine out of 10 adult Diabetes UK members received a retinopathy eye test in 2005/06. Retinal screening coverage has improved in all nations.
- Four out of five screening services now use digital cameras.
- National figures identify that up to forty percent of people with diabetes in England have still not had their eyes screened and are at increased risk of visual impairment.
- Over 50 per cent of PCTs report not meeting the national target for people with diabetes receiving screening by June 2006.
- Quality assurance of retinal screening programmes is crucial.

A Diabetes UK priority

All people with diabetes will have their eyes checked at least once a year.

People with diabetes are at risk of developing retinopathy, the leading cause of blindness in the working population. Early detection and treatment of sight-threatening diabetic retinopathy has been shown to prevent visual impairment, thereby reducing the health, social care and personal costs of diabetes.

The lifetime costs of dealing with retinopathy can be up to £237,000 per person. If 1,000 cases of diabetic retinopathy could be avoided, the potential savings to the government could be as high as £237 million.

National policy

UK

Guidance on how to set up and run a local retinal screening programme is contained within the Diabetic Retinopathy Screening Workbookv3 (www.nscretinopathy.org.uk).

England

The National Service Framework requires:

- by March 2006: 80 per cent of people with diabetes to be offered retinal screening within previous 12 months.
- by December 2007: 100 per cent of people with diabetes to be offered retinal screening using digital photography within previous 12 months.

Retinopathy screening is co-ordinated and funded by PCTs, supported by the guidance and standards produced by the National Screening Committee and NICE.

Northern Ireland

All four Health and Social Services Boards are participating in a regional diabetic retinopathy screening programme with centralised quality assurance, currently
being implemented across Northern Ireland.

The Northern Ireland Diabetic Retinopathy Screening Programme aims:

• by March 2007: full coverage of Northern Ireland

• by 1 April 2008: everyone eligible for diabetes retinopathy will be screened on an annual basis.

Implementation is supported by the guidance and standards of the Clinical Resource Efficiency Support Team 34.

Scotland
The Scottish Diabetes Framework Action Plan states that:

• All NHS Boards will fully implement the national diabetic retinopathy screening programme during 2006/07.

Retinopathy screening is co-ordinated by health boards with the national Diabetes Retinopathy Collaborative providing central guidance and support 35.

Wales
Retinopathy screening is delivered by a national service, the Diabetic Retinopathy Screening Service for Wales (DRSSW), operating through local venues. Digital imaging is the method of delivery, with images then centrally stored for grading and comparison. The service has been commissioned by all 22 Local Health Boards and aims:

• by September 2007: to offer annual retinal screening to all people with diabetes in Wales.

Research findings

Screening rates
In 2006, 92 per cent of Diabetes UK members reported having had an eye test for retinopathy in the previous 12 months. There was very little variation across the four nations (Chart 6.1).

The rate of screening was lower among young people aged 12 years and over, with three quarters (74 per cent) reporting a test in the previous 12 months (Chart 6.2). This difference was more pronounced in Northern Ireland and Wales.

These results are encouraging and demonstrate an improvement on 2005 when 90 per cent of adult members had been offered an eye test. Improvements were recorded in all nations.

Screening rates among Diabetes UK members are likely to be higher than in the general population of people living with diabetes. According to the National Diabetes Audit for 2004/05, only 61 per cent of adults with diabetes had an eye examination during this period 11.

The Department of Health’s own returns from PCTs in England show that in the first quarter of 2006, 76 per cent of registered patients with diabetes had been offered retinal screening in the previous 12 months and 62 per cent had actually been screened 36. Fifty three per cent of PCTs report not meeting the national target of 70 per cent of people with diabetes offered screening having received it by June 2006 37.

These differences in rates of screening uptake point to difficulties with some of the data. For example the Department of Health’s reports do not exclude missing data, leading to under-reporting of uptake. Problems with data collection and publication are similar in Scotland.

Seventeen per cent of PCTs in England report that they do not yet have a centralised co-ordinating centre to support call and recall 9. This will impact on the quality of centrally reported data.

Access to retinal screening has also been a common concern this year in the feedback posted on the Diabetes UK website. Fifty-four people reported problems or frustrations relating to retinal screening.

6.1 Adults tested for retinopathy in last 12 months

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Source: Diabetes UK 2006 Members survey
6.2 Young people (12+) tested for retinopathy in last 12 months

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Source: Diabetes UK 2006 Members survey

Digital photography

The adoption of digital cameras for retinopathy eye tests is now widespread. In England 86 per cent of PCTs report that retinal screening is delivered through a systematic programme using digital cameras.

This result is consistent with the experience of the members of Diabetes UK: 79 per cent of adults who had received retinal screening and were able to identify the method said that a digital camera had been used (Chart 6.3). Adoption is high in all nations.

Exactly the same result was obtained for young people across the UK – 79 per cent reported the use of a digital camera. Data for the individual nations is too small to report confidently for young people but is also likely to reflect the adult results.

The use of digital cameras has improved since 2005 when 73 per cent of adult Diabetes UK members who were able to identify the method said that a digital camera had been used.

6.3 Adults whose retinopathy eye test was conducted with a digital camera

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<td>Wales</td>
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Source: Diabetes UK 2006 Members survey

Issues to address

Good progress has been made in extending the coverage of retinal screening with most national targets met, at least for members of Diabetes UK.

Problems remain in comparing retinal screening data from different national sources. However it is clear that there is still work to be done to achieve comprehensive coverage.

The quality of screening programmes is steadily improving in most areas. Some areas still need to establish the centralised call and recall systems as part of a systematic programme. The implementation of digital technology for retinal screening has also progressed well, with only a fifth of screening services still to make this change. Some areas have been experiencing difficulties with the implementation of centralised call and recall systems.

Localities should ensure that the data reported against national targets is accurate and, in England, consistent with line descriptors defining the characteristics of a local systematic screening service. If an area does not have a centralised programme using digital cameras with the software to support call and recall, it is not meeting national standards.

The full implementation of retinal screening must meet national standards and guidelines. Strong links with ophthalmology services need to be developed locally to ensure that retinopathy can be treated when identified, to prevent visual impairment. Diabetes UK has received reports that some people with diabetes have been referred for laser treatment for sight threatening retinopathy and had follow-up appointments cancelled or delayed. Further investigation is needed of this issue. Internal and external quality assurance of National Screening Committee (NSC) standards through monitoring and audit remain crucial to identifying such problems.
Key points

- The majority of diabetes among children and young people is Type 1 but incidence of Type 2 is growing as more young people become overweight and obese.
- The care and support that children and young people receive from specialist hospital teams is highly regarded.
- Almost all children and young people get support from these specialist teams between their clinic visits, predominantly from diabetes specialist nurses. Further investment is needed in this professional role.
- Stronger links are needed between specialist diabetes teams and schools to ensure that children and young people do not feel isolated or unsupported in this central locus of their daily lives.
- Many young people still experience problems when their care is transferred to adult diabetes services. Greater efforts are needed to ensure that young people are full partners in this process.

A Diabetes UK priority

*All children with diabetes will be provided with access to local, high quality, specialist care.*

Two in every 1,000 young people aged under 18 have diabetes. The incidence of Type 1 diabetes in the under fives is increasing, as is the incidence of Type 2 diabetes among school children. The latter increase is typically a result of weight gain due to poor diet and lack of exercise. However Type 1 is still 50 to 60 times more common in under-18s than Type 2. Around 900 people under 18 in Northern Ireland currently have Type 1 diabetes. The present increase in newly diagnosed people with diabetes under 15 years of age is 3.2 per cent per year. In addition, Type 2 diabetes is predicted to emerge in the adolescent age group for the first time in our populations.

The health, emotional and social needs of children and young people differ from those of adults. It is vital that from diagnosis through to transfer to adult services children and young people receive support that is sensitive to their individual needs and circumstances, including family needs, to reduce the risk of complications in later life.

National policy

**UK**

Diabetes UK has recently begun a campaign based on the Royal College of Nursing recommendation that no paediatric diabetes specialist nurse should have to care for more than 70 children.

**England**

Standard 5 of the National Service Framework requires that all children and young people with diabetes will receive consistently 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.
Northern Ireland
The joint CREST / Diabetes UK Report on Diabetes (2003) identified children and young people within the key theme of targeting vulnerable groups. Children and young people are identified as an area for early action. The Priorities for Action – Planning Framework for Health and Personal Social Services 2006 – 2008 states that all four Boards will be required to develop and implement a managed clinical network for children with diabetes.

Scotland
The Scottish Diabetes Action Plan commits to a programme of work focussing on children and adolescents, including: improved access to out of hours services; an audit of diabetic ketoacidosis (DKA); new national DKA management guidelines for adolescents and adults with Type 1 diabetes; and a national best practice initiative in collaboration with the Scottish Study Group for the Care of the Young with Diabetes.

Wales
Standard 5 of the National Service Framework requires that all children and young people with diabetes will receive consistently 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.

Research findings

Summary of findings from preceding chapters
The following results are all from the Diabetes UK survey of young members 2006:

- 8 per cent of young members wanted specialist psychological support, of whom 71 per cent saw a psychologist.
- Children and young people tend to turn to family and friends first for emotional support, followed by their specialist hospital teams.
- 28 per cent of young members were aware of structured education courses and 5 per cent had participated in a course in the previous 12 months.
- 92 per cent of young members had received information and advice from the hospital to help achieve good control.
- 77 per cent of young members felt confident in managing their diabetes.
- 74 per cent of young members had received a retinal eye screen in the previous 12 months, of whom 79 per cent had a test with a digital camera.

Satisfaction with services
Among young members of Diabetes UK, satisfaction with local services is high: four out of five are pleased with the service they get and only 4 per cent are actively displeased (Chart 7.1). There is little variation across the nations (Chart 7.2).

7.1 Satisfaction of children and young people with their local diabetes services


7.2 Children and young people pleased or very pleased with their local diabetes services

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<td>80%</td>
<td>83%</td>
<td>75%</td>
<td>78%</td>
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</table>

Source: Diabetes UK 2006 Members survey

Nonetheless, there is plenty of scope for improvement. The following is a ranked list (most popular first) of the top ten improvements that children and young people would like to see to their diabetes services:

- improve communication between specialist service and school to help manage diabetes in school
- reduce waiting times in clinic
- improve access to insulin pumps
- more emotional support
• see the same doctor every each time
• improve knowledge of hospital staff
• more focussed education
• get correct prescription from GP
• better information
• access to dietary advice/appointments.

Source: Diabetes UK 2006 Members survey

In England 83 per cent of primary care trusts have a policy in place for the provision of insulin pumps. Two of the health and social services boards in Northern Ireland have such policies. In Scotland, each Managed Clinical Network will produce an ‘insulin strategy’, including an examination of the use of insulin pumps.

Professional support
Almost all children and young people receive care from specialist paediatric teams. Doctors, nurses and dietitians all make major contributions to the provision of care to children and young people attending diabetes specialist clinics (Chart 7.3).

In 2006 95 per cent of the young members of Diabetes UK said they had access to specialist help in-between clinics (a 10 per cent increase on 2005). Nurses play the biggest part in delivering this care in all nations (Chart 7.4 to 7.7)

7.3 Professionals seen by children and young people at specialist clinics.

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<thead>
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<td>Doctor</td>
<td>32%</td>
<td>34%</td>
<td>38%</td>
<td>23%</td>
</tr>
<tr>
<td>Nurse at hospital</td>
<td>79%</td>
<td>69%</td>
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<tr>
<td>Dietitian</td>
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<td>34%</td>
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<tr>
<td>Psychologist</td>
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<td>5%</td>
<td>8%</td>
<td>3%</td>
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<td>GP</td>
<td>27%</td>
<td>30%</td>
<td>32%</td>
<td>23%</td>
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</table>

Source: Diabetes UK 2006 Members survey
In England the ratio of paediatric diabetes specialist nurses (PDSNs) to patients ranges from 1:50 to 1:300. A quarter (23 per cent) of PCTs report that this ratio has improved in the last year, compared to 9 per cent where it has got worse. This is significantly higher than the national recommendation of 1:70. Two health boards in Northern Ireland did not identify a ratio of PDSN to patients, stating that DSNs within the board area work with both children and adults and this has remained the same in the last year. One board has a ratio of 1:100 and states that this has increased in the last year.

Transfer to adult services

The experience of young people when being transferred from children’s to adult services is mixed. Many young people feel that the transfer is arranged at an inappropriate time and all too often the transfer is neither planned nor explained (Chart 7.8). The 2006 results do not show any improvement on 2005.

7.8 Young people’s experience of transfer to adult services

Although most primary care trusts in England (88 per cent) have protocols for the initial care and assessment of children with diabetes, only three in every five (60 per cent) have a protocol for transferring young people with diabetes to adult care. This is however an increase from protocols reported to be in place in 2005.

All health and social services boards in Northern Ireland have protocols for the initial care and assessment of children with diabetes. Two boards have protocols for transfer in place, one is developing transition clinics.

Issues to address

Very few children and young people surveyed are unhappy with their diabetes services and a majority feel confident in managing their condition. However, more support is needed from the public institution that they have the most contact with: school. Better links between schools and specialist diabetes services are needed.

Beyond the walls of the specialist clinic, the everyday challenge of managing diabetes takes over. The professional support offered to children and young people to meet this challenge is crucial. As it is principally nurses who provide this support, further investment is needed in this professional role to ensure all children and young people get the advice and support they need. Parents in particular identify concerns about the lack of access to specialist support and advice when required, between clinic visits.

Transfer to adult services is a critical point in the experience of young people with diabetes. When this does not go well, some young people lose contact with services altogether. There is still much to do to improve practice here as far too many young people feel that the process of transfer is poorly planned, explained and executed. All organisations should have clear protocols for transfer yet these are still far from universal.

Many children and young people with diabetes are interested in insulin pumps and would like to see better access to them.
Diabetes: State of the Nations 2006  Chapter 8

Treatment and care

Key points

➢ Results from the national quality outcomes framework (QOF) indicate a year-on-year improvement in outcomes for people with diabetes in all nations.

➢ Problems remain with exception reporting within QOF but these national indicators provide a strong basis for tackling inequalities in diabetes care both locally and nationally.

➢ Two in five adults and more than four in five children and young people have poor blood glucose management that put them at risk of complications. Yet access to blood glucose testing strips is still restricted in some areas.

➢ Satisfaction with local diabetes services is high among members of Diabetes UK.

Research findings

Clinical indicators

The national quality outcomes framework for primary care includes a set of indicators for the treatment of people with diabetes. The four QOF indicators reported here are HbA1c of 7.4 or less (Chart 8.1), HbA1c of 10 or less (Chart 8.2), blood pressure of 145/85 or less (Chart 8.3) and cholesterol of 5 or less (Chart 8.4). All 2005/06 results in all nations show an improvement over 2004/05.

There are problems with the reporting of QOF data which these results disguise. In particular, patients can be excluded from the analysis for a variety of reasons. Levels of ‘exception reporting’ are very variable, potentially leading to distortions in the data.

In England, however, the National Diabetes Audit for 2004/05 reported that 58 per cent of adults with diabetes achieved the HbA1c target of 7.4 or less, consistent with the QOF results. Only 16 per cent of children under 16 years achieved this target. Children and young people are also more likely to experience ketoacidosis: 7 per cent of children under 16 had at least one episode in 2004/05.

In Scotland, however, the figure in 2004 for adults with an HbA1c of 7.5 and under was 43.1 per cent. And less than 10 per cent of children in Scotland achieved an HbA1c of 7.5 or less.

8.1 Patients with HbA1c of 7.4 or less

<table>
<thead>
<tr>
<th>Nation</th>
<th>2005/6</th>
<th>2004/5</th>
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<tbody>
<tr>
<td>England</td>
<td>62%</td>
<td>59%</td>
</tr>
<tr>
<td>N Ireland</td>
<td>60%</td>
<td>57%</td>
</tr>
<tr>
<td>Scotland</td>
<td>59%</td>
<td>56%</td>
</tr>
<tr>
<td>Wales</td>
<td>61%</td>
<td>57%</td>
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Source: Quality Management and Analysis System (QMAS)
Blood glucose control is central to the self-management of diabetes yet across all the feedback posted on the Diabetes UK website this year, much the most common concern was restrictions in access to blood glucose testing strips (77 people). Short term cost savings from restrictions of this kind have significant long-term costs in the increased risk of complications of poor blood glucose management.

Improving services
There is a high level of satisfaction with local diabetes services in all nations. More than three quarters of adults (78 per cent) are either satisfied or highly satisfied with

Only 5 per cent actively dissatisfied (Chart 8.5).

The following is a ranked list (most popular first) of the top ten improvements that adults would like to see to their diabetes services:

- see same doctor each time
- more podiatry care
- improve information
- improve access to dietary advice
- regular appointments for care
- reduce time between appointments
- reduce waiting time at clinic
- better communication between primary and specialist services
- improve knowledge of hospital staff (not the diabetes team) when in hospital
- improve emotional support.

The effect of funding cuts and job losses on the quality of services is a concern among people with diabetes: 57 people posted feedback on the Diabetes UK website this year expressing significant worries about such changes and the lack of consultation about, and agreement with, service provider changes.

In England almost all primary care trusts (98 per cent) still provide free podiatry services for people with diabetes, as do all health and social services boards in Northern Ireland. In Scotland, footcare services for people with diabetes are included in the priorities contained in the Action Plan.

Issues to address
The available evidence suggests that outcomes for people with diabetes in all nations are improving. However, two in every five people with diabetes still have
relatively poor blood glucose control (HbA1c more than 7.4 per cent).

Indicators for children and young people, most of whom have Type 1 diabetes, are much worse than those for adults. Greater efforts are needed to improve outcomes for children and young people to reduce the risk of complications. Involving children, young people and parents in the way that local services are delivered has shown to improve clinic attendance and engagement in some areas. Prioritising the provision of emotional support and opportunities to meet others also needs to be facilitated.

Increasing reports of cuts in specialist diabetes services is of growing concern to people with diabetes and Diabetes UK. We already know that people with diabetes have problems with reduced access to services. Service cuts will only make this worse. This is causing anxiety amongst people with diabetes who are worried about the impact this will have on their own care and on the ability of local diabetes services to access specialist support. Managed diabetes networks need to ensure that local models of diabetes care provision involve users in development and service delivery.

Further work is needed to improve the reliability of QOF data, given variations in exception reporting, but congruence with National Audit data is encouraging. Inequalities in access to glucose testing strips, podiatry and dietetic services need to be removed. The basics of good care – continuity, information and communication – also require on-going improvement.
Conclusion

Long-term thinking

The implementation of the national frameworks for diabetes in the UK has brought real benefits to the health and quality of life of people living with diabetes. Satisfaction with services by Diabetes UK members is high and progress has been made in many key areas: retinal screening will soon be universal and clinical indicators have improved year-on-year. Overall, the NHS can reasonably claim to be delivering a professional and valued service.

There is, however, still much to do. Diabetes is a long-term condition for which early identification and good self-management pay great long-term dividends. Prevalence of the condition is increasing year on year and action is needed to enable those at high risk to reduce their risk. Yet it is difficult for the NHS, an institution that is always drawn to the demands of those in immediate need, to take this view on board, even where it is Government and Executive policy. As Diabetes UK enjoys greater freedom of action, it can plan and act for the long term – and keep the pressure on statutory services to do the same. This is why the organisation's priorities lie with early identification and secondary prevention through empowerment and self-care.

The identification of people with undiagnosed diabetes is a core concern. Diabetes UK will continue to promote testing and raise public awareness of the risks of living with undiagnosed diabetes. Health professionals, especially those in primary care, must give greater priority to the identification of undiagnosed diabetes. If this was actively considered in every day-to-day patient encounter, the diagnosis rate would rise rapidly. Diabetes UK will work with the NHS both to promote active case-finding and targeted screening of those at high risk.

Individuals newly diagnosed with diabetes have complex information and education needs. Although basic information is widely available, resources that address the individuality of need – including structured education – are harder to come by. Education, information, tools such as blood glucose testing and support give people the power to make choices about service and treatment options and management of their diabetes. Choices have to be informed and based on a sound understanding of the condition and the impact of choices made. Diabetes UK will continue to promote a diverse, responsive approach to education that enables people at different stages of their own self-management journey to find information and support to meet their needs. Diabetes UK will work with the NHS to ensure that new opportunities for structured education form part of a wider portfolio of education and information resources.

Emotional support can be just as important to successful self-care and risk reduction as educational interventions. People with diabetes who feel unable to cope with their condition or unhappy about their health and lifestyle will find it harder than others to manage their blood glucose, diet and exercise on a daily basis. Although a very wide range of people currently provide emotional and
psychological support, much of this support is highly constrained. Diabetes UK will continue to provide its own range of support services for individuals and families living with diabetes such as Diabetes UK Roadshows, care support events, family weekends, children’s holidays, and Careline service. We will also work with the NHS to improve the specialist support available through diabetes services.

Too many people with diabetes, especially children and young people, face a heightened risk of long-term complications due to poor self-care. As clinical monitoring and care continue to improve, every effort is needed to maximise the opportunities for people with diabetes to take control of their condition and live full and rewarding lives.

Diabetes is a complex condition that touches every part of a person’s life once diagnosed. The key requirement for good diabetes care is that it is integrated and enables people with diabetes to care for themselves. This cannot be achieved without the continuous support and advice of skilled healthcare professionals. The provision of integrated care relies on the co-ordination of services and deployment of the skills of both primary, community and specialist care – together with the person with diabetes – to achieve national diabetes framework standards. This requires that people with diabetes have timely access to the right care, in the right place at the right time.

Meeting national policy goals, reducing long-term health costs, delivering the commitments contained within diabetes frameworks and improving the lives of people living with diabetes demands that diabetes is prioritised.

Members of local communities need to get involved, to press for action and work with health and social care services to ensure that the action taken is in the best interests of people with diabetes.

Demands placed on health services are high, localities are in deficit and service reconfiguration is happening across the board. The stakes are high for people with diabetes. There is much to do and we all – people with diabetes, friends, family, health and social care professionals, healthcare managers and Diabetes UK – have a role in working together to ensure that people with diabetes receive the standards of care that they should expect.
References


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43 Greene S, Waugh N. *DIABAUD 3 Glycaemic Control in Children and Adolescents under 15 years of age with Type 1 diabetes in Scotland* (November 2004). On behalf of the Scottish Study Group for the Care of Diabetes in the Young

44 Diabetes UK. *Involvement of children and young persons in paediatric diabetes care services* (2006). Pre publication
## Diabetes UK

### National and regional offices

<table>
<thead>
<tr>
<th>Office</th>
<th>Telephone</th>
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<tbody>
<tr>
<td>Central Office</td>
<td>020 7424 1000</td>
</tr>
<tr>
<td>Diabetes UK Cymru</td>
<td>029 2066 8276</td>
</tr>
<tr>
<td>Diabetes UK Northern Ireland</td>
<td>028 9066 6646</td>
</tr>
<tr>
<td>Diabetes UK Scotland</td>
<td>0141 332 2700</td>
</tr>
<tr>
<td>Diabetes UK Eastern</td>
<td>01376 501390</td>
</tr>
<tr>
<td>Diabetes UK East Midlands</td>
<td>0115 950 7147</td>
</tr>
<tr>
<td>Diabetes UK London</td>
<td>020 7424 1116</td>
</tr>
<tr>
<td>Diabetes UK Northern &amp; Yorkshire</td>
<td>01325 488606</td>
</tr>
<tr>
<td>Diabetes UK North West</td>
<td>01925 653281</td>
</tr>
<tr>
<td>Diabetes UK South East</td>
<td>01372 720148</td>
</tr>
<tr>
<td>Diabetes UK South West</td>
<td>01823 324007</td>
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<tr>
<td>Diabetes UK West Midlands</td>
<td>01922 614500</td>
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Visit [www.diabetes.org.uk/in_your_area/](http://www.diabetes.org.uk/in_your_area/) for email addresses

## Useful contacts

<table>
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<tr>
<th>Service</th>
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<tbody>
<tr>
<td>Become a member</td>
<td>0800 138 5605</td>
</tr>
<tr>
<td>Customer Services</td>
<td>0845 123 2399</td>
</tr>
<tr>
<td>Diabetes UK Careline (or if hearing impaired)</td>
<td>0845 120 2960*</td>
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<tr>
<td></td>
<td>Textphone 20 7424 1031</td>
</tr>
<tr>
<td>Publications orderline</td>
<td>0800 585 088</td>
</tr>
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Visit [www.diabetes.org.uk](http://www.diabetes.org.uk) for further information

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*Diabetes UK Careline* is here to help. Call **0845 120 2960** for support and information (although unable to provide individual medical advice).

Calls cost no more than 4p per minute. Calls from mobiles usually cost more.