Diabetes guide for London
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Healthcare for London has already identified that much needs to be done to improve the care of people with diabetes in London and to bring care up to the national standards to deliver the *Diabetes National Services Framework*. The fact that less than 15% of Londoners with diabetes have undertaken structured patient education and a similar proportion are unaware of which type of diabetes they have is indicative of the fact that London has not adequately invested in diabetes care.

Diabetes UK therefore welcomes the Healthcare for London programme which we believe will improve prioritisation, investment and organisation of integrated diabetes care. People with diabetes need access to the right skills, in the right place, at the right time through generalist, specialist and social care working together. We are particularly pleased that the Healthcare for London model recognises these needs and holds people with diabetes at its heart, in terms of care planning and user involvement to deliver supported self-management.

The aspirations of the plan are challenging but we believe they can be achieved and look forward to contributing to measurable improvements over the next three years.

**Douglas Smallwood**  
**Chief Executive**  
**Diabetes UK**
In July 2007, Professor Lord Darzi set out ambitious plans for improving the health and healthcare of Londoners in the report *Healthcare for London: A Framework for Action*. It identified priority areas of work, including the transformation of care for people with long-term conditions.

The Healthcare for London programme was established by the capital’s 31 primary care trusts (PCTs) to transform healthcare services. Diabetes was selected as the focus of the first long-term conditions project because of the major impact this illness has on individuals and on our local communities.

The case for changing the way we deliver diabetes care in the capital is compelling. There are more than two million people with diabetes in the UK and prevalence is predicted to increase in the future. There are, moreover, significant inequalities in the way diabetes is prevented, diagnosed and treated across London. People with long-term conditions are the biggest users of healthcare in London and account for 80% of GP consultations nationally. Spending on diabetes now accounts for an estimated 10% of the NHS budget.

Healthcare for London aims to dramatically improve access to high-quality diabetes care for all Londoners and to reduce health inequalities in the capital. A new model of care and care pathways have been developed with healthcare professionals, people with diabetes and commissioners. It will put patients at the centre of care provision. People with diabetes will be supported to self-manage their condition through education programmes, jointly agreed personal care plans, and more support and advice from trained professionals.

A major goal is to improve prevention and early detection of diabetes. We are also seeking to prevent complications and offer appropriate acute management for people with diabetes. To achieve this we need to provide better education for people with diabetes and training for the workforce, with a greater emphasis on self-management. We also need to better manage diabetes in pregnancy, in children and adolescents with diabetes, and for people receiving care in inpatient settings.

This guide aims to advise clinicians and commissioners how to implement the new model of care, either developing their own care pathways or adapting existing pathways for their local areas. The next key step will be local engagement between clinicians and commissioners, and with service users to drive forward diabetes care at the local level.

The outcomes of our work in this area will inform the development of models of care and care pathways for other long-term conditions.

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What is diabetes?

Diabetes mellitus is a condition where the amount of glucose in the blood is too high because the body cannot use it properly. Diabetes was originally described more than 2,000 years ago as “a dreadful affliction leading rapidly to death”. Today, diabetes still carries the risk of life-threatening acute illness and debilitating long-term complications.

There are two main types of diabetes:

- **Type 1 diabetes** develops because the body cannot produce any insulin. It is the least common of the two main types, accounting for around 10% of people with diabetes.

- **Type 2 diabetes** develops when the body cannot produce enough insulin and is resistant to what is produced. It is the most common type, affecting around 90% of people with diabetes. Type 2 diabetes is often associated with being overweight and usually appears in people over 40, or over 25 in south Asian and African-Caribbean people. More recently, a greater number of children are being diagnosed with type 2 diabetes.

Diabetes can cause short-term acute illness and lead to long-term complications affecting the kidneys, eyes and feet. Diabetes also increases cardiovascular risk, including the risk of heart disease, stroke and dementia. A person with diabetes is as likely to have a heart attack as someone without diabetes who has already had a heart attack.

Long-term complications arising from diabetes have significant implications:

- Diabetic kidney disease is the most common single cause of the need for dialysis/transplantation.
- Diabetic eye disease is the most common preventable cause of blindness.
- Diabetic foot disease increases the risk of ulcer and amputation, as well as other problems.

About this guide

When using this commissioning guide, readers are asked to note the following:

- **It has been kept as short as possible, with readers directed to appendices available on the Healthcare for London website [www.healthcareforlondon.nhs.uk](http://www.healthcareforlondon.nhs.uk)**
- This guide has intentionally been written in simple, accessible style to make it easy to use.
- Where reference is made to ‘people with diabetes’ please read this as ‘people with diabetes and their carers’, especially where education, care planning and user involvement are concerned.
- Where reference is made to ‘commissioners’, this term refers to all levels of commissioning including PCTs and practice-based commissioning (PBC) commissioners.
The case for change

This section sets out why we need to develop world-class diabetes services in the capital.
The case for changing services in London is compelling:

- Diabetes in London and the UK is increasing at an alarming rate because of rising obesity and unhealthy lifestyles.
- The standards of service offered in the capital are poor compared with the rest of the country.
- There is unacceptable variation across London with regard to access to services for people with diabetes.

In this section we discuss

- Diabetes in London
- London’s performance in diabetes care
- Impact of poor diabetes management
- What we want to achieve
1 Diabetes in London

1.1 Prevalence of diabetes

There are more than 350,000 people with diabetes in London. Diabetes is more common in people of black and south Asian origin. For instance, the prevalence of diabetes is up to five times higher in Pakistani and Bangladeshi people than in white people. Diabetes tends to present at a younger age in people of black and south Asian descent, and these groups have a higher risk of developing diabetes-related long-term complications.

Generally, London has a higher proportion of black and Asian ethnic groups compared with the rest of the country. For this reason, London has a higher prevalence of diabetes and diabetes complications.

1.2 Level of undiagnosed diabetes

It is estimated that around one in four people with diabetes in London, about 80,000 people\(^2\), do not know they have it. These people are at significant risk of developing long-term complications.
There is variation in the level of undiagnosed diabetes across London PCTs (figure 1).

Around half of people with diabetes have complications at diagnosis, suggesting that they have already had the condition for up to 10 years. Undiagnosed diabetes, presenting as an acute emergency, contributes to the need for unscheduled emergency care and acute admission. Diabetes-related accident and emergency (A&E) attendances and hospital admissions significantly impact on secondary care workload.

1.3 Increasing prevalence of diabetes

Diabetes is the long-term condition that will increase most in terms of prevalence. The number of people with diabetes in London is expected to increase by up to 200,000 between 2005 and 2025 (figure 2), unless successful obesity prevention strategies are introduced.

The rising prevalence of diabetes is due to an ageing population and unhealthy lifestyles leading to obesity. This is a risk factor particularly significant for those of Asian or African Caribbean descent.

The incidence and prevalence of diabetes is rising dramatically, with recent data suggesting a 75% increase in the past seven years. For the first time in London, more young women with diabetes who become pregnant now have type 2 rather than type 1 diabetes.

2 London Health Observatory (LHO), March 2007. In estimating prevalence, the LHO used Greater London Authority demographic data on population counts and overlaid the impact of ethnicity, age and gender distributions to estimate the proportion of a PCT-based population that is likely to be diabetic. The estimate does not account for the impact an increase in obesity may have. The estimated prevalence was then compared to the number of diabetics recorded on QOF registers by PCT to demonstrate the variation in unmet demand.

Figure 2: Diabetes projections for London
1.4 Mortality from diabetes

One in 10 people aged between 20 and 79 in England will die of diabetes-related conditions.

The impact of diabetes on mortality rates in London is significant:

- London has the highest percentage of deaths in England attributable to diabetes for people aged 20-79 years.
- London has higher than average deprivation which is a major risk factor for mortality from diabetes (figure 3).
- Two-thirds of these deaths are premature (aged under 75 years) and therefore represent a significant economic loss to society.
- Almost 12% of all premature deaths in London are attributable to diabetes.

- Life expectancy is reduced by 25% (five years for males and seven years for females) if diabetes develops at age 55 years, and more if it develops at a younger age\(^3\).

\(^1\) Yorkshire and Humberside Public Health Observatory 2006/07
\(^4\) UK QRESEARCH database

Figure 3: Age standardised death rate per 1,000 persons with diabetes by deprivation\(^4\)
1.5 Diabetes and psychological health

People with poor diabetes management, despite intensive medical input, have a higher risk of diabetes-specific psychological problems, such as fear of hypoglycaemia, self-testing and injecting. In particular, some people with type 2 diabetes – who have family experience of diabetes – can have concerns relating to taking medication and the use of insulin.

Depressive symptoms are common among people who have diabetes, affecting around one in four people. This group may need significant psychological support.

People with diabetes are twice as likely to have depression than the general population and clinical depression is associated with multiple adverse outcomes. People with depression are more likely to neglect their diabetes self-care, have worse physical symptoms, worse glycaemic control, increased risk of complications and have two to five times increased mortality.

Mental health treatments such as psychological treatments and antidepressants can improve depression outcomes.

Depression among people with diabetes is associated with poorer outcomes. People suffering from both depression and diabetes have lower levels of self-care and are more likely to have days off work.

People with diabetes and depression also have significantly higher medical costs than those who are not depressed.

The Department of Health and Care Services Improvement Partnership have developed guidelines for commissioning services for people suffering long-term conditions and depression.
2 London’s performance in diabetes care

2.1 An assessment of performance

London performs significantly worse in most diabetes indicators than the rest of the UK. Performance is weak in:

- diagnosis
- supporting self-management
- screening for complications
- preventing and treating complications.

Most London PCTs performed below the national average on a number of the quality and outcome framework (QOF) indicators (figure 4). Most London PCTs also received a ‘red rating’ for all four QOF indicators on screening for complications (figure 5). For instance, only 84% of people with diabetes across London were offered retinal screening, which is crucial to reducing the risk of blindness. This is significantly worse than the national average. Also, many people with diabetes do not get blood pressure checks, monitored for blood glucose control or screened for complications even once a year. Where blood pressure was checked, many patients still did not get a HbA1c check or complications screening – an indication that the care is not well-organised for optimal diabetes management. This lack of basic essential care and co-ordination is associated with increased morbidity and mortality.

A recent analysis by the London Health Observatory indicated the QOF figures may not represent the true scale of this problem (see appendix 1). An analysis of diabetes registers showed that only 91% of people with diabetes had their HbA1c levels (a measure of medium-term glucose control) checked annually and that the level of those who were not monitored varied according to the area in which they lived. These results vary significantly both between PCTs and within a single PCT.

5 Yorkshire & Humber Public Health Observatory
6 Renders et al. Interventions to improve the management of diabetes mellitus in primary care, outpatient and community settings, 2007
Quality and outcome framework 2006/07

<table>
<thead>
<tr>
<th></th>
<th>% patients who have a record of HbA1c</th>
<th>% patients who have a HbA1c of less than 7.5</th>
<th>% patients who have a HbA1c of 10.0 or less</th>
<th>% patients with last measured total cholesterol of 5 or less</th>
<th>% patients with record of blood pressure of 145/85 or less</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>97.06%</td>
<td>67.65%</td>
<td>92.66%</td>
<td>83.11%</td>
<td>78.74%</td>
</tr>
<tr>
<td>London</td>
<td>95.20%</td>
<td>64.56%</td>
<td>90.02%</td>
<td>79.83%</td>
<td>78.76%</td>
</tr>
</tbody>
</table>

Figure 4: Ongoing care – measures of long-term glucose control (HbA1c, blood pressure and cholesterol)—key risk factors for the development of late complications of diabetes—are lower in London than in England.

Quality and outcome framework 2006/07

<table>
<thead>
<tr>
<th></th>
<th>% patients with record of microalbuminuria testing</th>
<th>% patients with proteinuria or microalbuminuria treated with ACE inhibitors or A2 antagonists</th>
<th>% patients with record of presence/absence of peripheral pulse</th>
<th>% patients with record of neuropathy testing</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>85.63%</td>
<td>89.00%</td>
<td>90.68%</td>
<td>90.20%</td>
</tr>
<tr>
<td>London</td>
<td>83.03%</td>
<td>88.29%</td>
<td>89.91%</td>
<td>89.53%</td>
</tr>
</tbody>
</table>
A 2007 Healthcare Commission audit of PCTs on diabetes care found that 26% of all the ‘weak’ performers in the country were in London. In the same audit, no London PCT was rated ‘excellent’.

London’s diverse and mobile population makes delivering diabetes care challenging. There is a higher proportion of at-risk communities in London than nationally and these communities are unevenly distributed within London itself.

However, there is a substantial variation in the performance of PCTs in London that cannot be explained solely by the demographics of the population. Figure 6 illustrates the span of performance across London PCTs on delivery of key diabetes performance indicators for 2006/07. The chart shows wide variation in performance, particularly on some key indicators. Each circle on the chart represents the average performance of a PCT on a specific diabetes indicator.

**Figure 6: Range of performance on QOF diabetes mellitus indicators, 2006/07 data**

Source: Information Centre for Health and Social Care

A national review, *Our Health, Our Care, Our Say*, highlighted specific issues and common shortcomings in the delivery of care for people with long-term conditions:

- There is often a lack of co-ordination – both between community and hospital health staff, and between health and social services.
- There is not enough support to help people manage their own condition through self-care, taking the correct medication or accessing therapies.
- There are still too many people in need of emergency care because their day-to-day care has broken down.
- Overall diabetes care is poorly structured in London with organisational boundaries significantly affecting diabetes care provision and access to services for patients – be it between provider organisations or PCTs. This particularly disadvantages those with more complex needs and/or lower health literacy.

### Challenges for London

- over 350,000 people have diabetes and many are yet to be diagnosed;
- young populations at high-risk of diabetes and its complications;
- mobile population;
- ethnic and cultural diversity at high-risk of diabetes and its complications at a young age;
- deprivation;
- large inequalities in outcomes;
- organisational barriers leading to unstructured care affecting those at highest risk of diabetes.

These issues contribute to the significant inequalities in outcomes for people with diabetes.

Around 48% of all admissions for lower limb amputations in London are due to diabetes.
2.2 Organisation of diabetes care in London

There is a significant inequality in the uptake of diabetes services, diabetes education and access to specialist services – contributing to differences in morbidity and mortality between areas of London. The organisation of diabetes care varies across London and few PCTs have effective networks as recommended in the Diabetes National Service Framework and by National Diabetes (formerly known as the National Diabetes Support Team).

In many cases, care across London is unstructured and it is difficult for people with diabetes to access. One PCT may have developed services for a particular hard-to-reach community which an individual living on the border of that PCT cannot access. This fragmented care is a real concern in providing diabetes care and could be avoided by developing effective clinical networks based on user input.

2.3 Lack of education and self-management support

Effective self-management is essential for achieving good outcomes in diabetes care. However, less than 15% of Londoners with diabetes have undertaken structured patient education (figure 7).

The Our Health, Our Care, Our Say national review found that half of those with long-term conditions generally were not aware of the treatment options available and did not have a clear plan setting out what they could do to better manage their condition. In the 2006 Healthcare Commission audit of people with diabetes, 14% of respondents in London were not sure whether they had type 1 or type 2 diabetes.

The diabetes user group which informed the project highlighted that lack of access to structured and culturally appropriate education and self-management skills are a key concern. We must promote and support patients to manage their condition and develop educational courses that are more accessible and appropriate for different populations in London.

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Figure 7: Percentage of people with diabetes who have participated in an education or training course

<table>
<thead>
<tr>
<th>Borough</th>
<th>%</th>
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<tbody>
<tr>
<td>Bexley</td>
<td></td>
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<tr>
<td>Greenwich</td>
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<td>Redbridge</td>
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<tr>
<td>Sutton &amp; Merton</td>
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<td>Lewisham</td>
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<tr>
<td>City &amp; Hackney</td>
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<td>Lambeth</td>
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<td>Newham</td>
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<td>Westminster</td>
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<td>Bromley</td>
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<td>Islington</td>
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<td>Harrow</td>
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<td>Hounslow</td>
<td></td>
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<tr>
<td>Tower Hamlets</td>
<td></td>
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<tr>
<td>Southwark</td>
<td></td>
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<tr>
<td>Bromley &amp; Dagenham</td>
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<tr>
<td>Croydon</td>
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<td>Haringey</td>
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<tr>
<td>Richmond &amp; Twickenham</td>
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<tr>
<td>Kensington &amp; Chelsea</td>
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<tr>
<td>Kingston</td>
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<tr>
<td>Hammersmith &amp; Fulham</td>
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<td>Havering</td>
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<td>Ealing</td>
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<td>Barnet</td>
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<td>Waltham Forest</td>
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<td>Enfield</td>
<td></td>
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<td>Hillingdon</td>
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Source: Healthcare Commission, National Survey of people with diabetes, 2007
3 Impact of poor diabetes management

In an average PCT in London there are about 10-12,000 people with diabetes. Of these, around:

- 1,000 people will have kidney disease;
- 1,000 people will have HbA1c levels above a clinically desirable level;
- 1,000 people will not have had a recent HbA1c test, despite half having had their blood pressure (BP) checked.

The impact of poor diabetes management is significant:

- Twenty per cent of people with diabetes are admitted to hospital each year either for care directly associated with diabetes or its complications.

People with diabetes occupy about 10% of hospital beds and have an increased length of stay that can be improved with a more systematic approach to care.

Furthermore, it is estimated that patients with a long-term condition account for 80% of all GP consultations nationally.\(^\text{10}\)

Department of Health. Chronic disease management: a compendium of information, May 2004

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Figure 8: Estimated number of patients requiring diabetes support in an average London PCT

- 1,000 people with HbA1c >10%
- 1,000 people have no record of HbA1c
- 1,500 people have not been screened for early diabetic kidney disease (microalbuminuria/proteinuria)
- But 500 of these people have had their BP checked

10 Department of Health. Chronic disease management: a compendium of information, May 2004
3.1 Impact on Londoners with diabetes

Poor diabetes management increases the risk of preventable complications, including short-term illness, blindness, amputation, cardiac and renal disease, and stroke.

For the patient, this can lead to:

- reduced quality of life, ability to earn a living and independence;
- adverse impacts on carer’s and family’s life;
- reduced life expectancy;
- increased use of emergency and inpatient services.

3.2 Impact on the NHS

Poor diabetes management adversely impacts both diabetes services and other health services because:

- there is an increased use of emergency services;
- long-term, recurring interventions (such as renal dialysis) are very expensive;
- commissioners’ ability to invest in developing new services for diabetes, or other health services, is diminished if funding is diverted to deal with the consequences of poorly managed long-term conditions;
- there will be insufficient resources to set up services to deal with the predicted increase in demand and current undiagnosed need.
3.3 Spending on diabetes

Spending on diabetes now accounts for an estimated 10% of the NHS budget\(^\text{11}\), or £30 million per year for the average PCT. People with long-term conditions are the highest users of healthcare, nationally and in London.

Diabetes-related complications not only impact on quality of life, but also increase healthcare costs five-fold, social services costs four-fold, triple personal expenditure and double the need for carers\(^\text{12}\).

As much as 40% of diabetes-related spending is in the inpatient setting\(^\text{13}\) – with about 6,000 emergency admissions for type 2 diabetes and its complications. Where type 2 diabetes is the primary diagnosis, 10% of admissions are due to coma and ketoacidosis.

Around three-quarters of diabetes-related spend is for treating advanced complications such as dialysis and amputations, rather than prevention. In London, a quarter of those accepted on dialysis programmes have diabetic kidney disease, costing each PCT more than £500,000 per year.

Given the high prevalence of diabetes, the strain on NHS services and the level of spending is significant. Improving diabetes care through earlier detection and better management will ultimately reduce the costs of treating complications. It is estimated that improving diabetes care could save each PCT £3 million per year, by preventing kidney and vascular complications, and by reducing emergency admissions and the need for unscheduled care. Investing in earlier, better diabetes care is vital to reduce these costs.

\(^{11}\) Department of Health. *Turning the corner, improving diabetes care*, 2006

\(^{12}\) King’s Fund et al. TARDIS: Type 2 diabetes. *Accounting for a major resource demand in society in the UK*, 2000

\(^{13}\) Ibid
4 What we want to achieve

In recent years improvements have been made in care for people with diabetes, particularly with the introduction of national service frameworks and the QOF. However there is still much to be done. The poor comparative performance of care delivery, significant unmet need and rising prevalence of diabetes in London make compelling arguments for change.

The case for change has informed discussions and agreement on a diabetes model of care for London, which is the basis of the commissioning guidelines for all London PCTs. The practical outcome of our proposals should be effective care pathways across London—adapted for local use by clinical networks—based on the jointly agreed model of care.

The result must be a measurable improvement in diabetes care across London in the near future. The ultimate success of the project will not be demonstrated in ‘quick wins’ but in a sustained improvement in clinical outcomes. As an indication that diabetes care in London is on the right track, we aim to raise the standard of care on key indicators for diabetes to the upper quartile of all England performance by the end of 2010/11.

4.1 Aspirations of users for diabetes care in London

This guide was informed by a representative group of users who identified issues and priorities they wished to be addressed (see appendix 2). The group highlighted a number of issues as priorities for action.

People with diabetes and their carers need education and support from healthcare professionals to self-manage their diabetes. PCTs need to develop services that support people with diabetes, their carers and healthcare professionals. There needs to be greater recognition of a mobile, culturally diverse population. This will require a fully integrated model of care and changes in approach for healthcare professionals, people with diabetes, provider organisations and commissioners.

Most diabetes care in London is provided in primary care and in the community, and more support for these services will be required. Additionally, better partnerships between NHS services, social care and voluntary sector support services will benefit people with diabetes, particularly in hard-to-reach communities.
To improve health inequalities and provide a structured, consistent service for all Londoners, there needs to be more collaboration between healthcare professionals across primary and secondary care, and across PCT and provider structures. In developing services for hard-to-reach communities, healthcare providers and commissioners should consider:

- deprivation;
- ethnicity;
- physical or mental co-morbidities;
- mobility of population;
- language;
- health literacy.

People with diabetes need to be more involved in decisions relating to their own care. Collaborative care planning will be a requirement for managing all long-term conditions by 2010. Currently, only a small proportion of people with diabetes feel as involved in their care as they would like to be.

**What users want**

- Culturally sensitive education and support for those with diabetes, their carers and families, on a timely basis.
- Competency in diabetes care wherever they are seen.
- Awareness of diabetes issues across the healthcare system.
- Good communication for and among everyone involved.
- Access to all services and to specialists when required.
- Full integration and communication between specialists and other healthcare professionals.
- Care which is jointly agreed between patients and healthcare professionals.
This section sets out the model of care for all London PCTs and providers to use to help define locally-agreed care pathways. The model has been informed by extensive stakeholder engagement and reflects guidance from the Department of Health.

**In this section we discuss**

- The principles underlying the model of care:
  1. Early detection and identification
  2. Individual with diabetes at the centre of their care
  3. Care planning and self-management
  4. Integration of care
  5. Quality assurance, evaluation and monitoring
  6. Targeting high-risk populations

- Tiers of care
- Prevention, diagnosis and patient groups with particularly complex needs
- Key enablers for successful delivery
- Assessing effectiveness
5 Principles underlying the model of care

5.1 Early detection and identification

Intervention at an early stage of the disease is essential for good long-term outcomes. In addition to the vascular risk assessment programme, identifying people with undiagnosed diabetes requires two fundamental approaches:

- case-finding of those at high risk particularly when using NHS services;
- innovative approaches for hard-to-reach communities, including social marketing initiatives.

Local networks will be vital to designing approaches tailored to the local population.

5.2 Individual with diabetes at the centre of their care

Once diagnosed, a person with diabetes should develop and agree their care plan, with short-term and long-term goals, in collaboration with their healthcare team. They should be supported to make lifestyle changes and understand the importance of these changes to their health.

People with diabetes need support to develop self-management skills. Involving patients in planning their own care and choosing how to manage their own condition is a critical step towards improving clinical outcomes.

An important aspect of this will be a shift towards a more collaborative relationship between clinicians and patients. This will require clinicians and patients to develop new skills and approaches, as well as changes to healthcare systems and cultural change.

Adequate psychological support needs to be provided on an ongoing basis for people with diabetes. In the longer term, some of these skills should increasingly be incorporated in the training of healthcare professionals who provide care for people with long-term conditions.

Continuity in the relationship between healthcare professionals and the person with diabetes is key to better outcomes for patients and must be a priority.

Across London, people with diabetes need better access to a broad range of services as outlined in figure 9.

“It is important that knowledge is kept up-to-date by all involved in diabetes care, that access to appropriate care is available at any time, and that care is thought about on a more personal level.”

Person with diabetes
Figure 9: Range of services required for people with diabetes

- Structured education
- Care planning
- Identification/diagnosis
- Institutional care/housebound
- Routine care screening
- Insulin start
- Kidney/eye/foot/erectile dysfunction
- Heart/stroke/peripheral vascular disease
- Type 1 diabetes
- Pre-natal/ante-natal
- Children's/young people
- Inpatient care
- Heart/stroke/peripheral vascular disease
- Diabetes
5.3 Care planning and self-management

Care planning should be a collaborative exercise. The person with diabetes, their carer and the healthcare professional must agree together how the person’s condition will be managed. Care planning requires patients and carers, who have sufficient information and understanding of the condition, to jointly agree priorities and actions with skilled, trained healthcare professionals.

The diabetes model of care should:

• support people with diabetes to self-manage their condition by providing education and information resources;
• involve patients in the system and designing their care pathway;
• provide healthcare professionals with training and information resources.

It is vital that people with lower rates of health literacy (the ability to read, understand and act on medical advice) also benefit from these approaches, which may need specific additional resources to be commissioned. Lower health literacy is independently associated with worse glycaemic control and higher rates of retinopathy15.

“Rules for creating a higher-quality health system – continuous relationships with the care team, individualisation of care according to patients’ needs and values, care that anticipates patients’ needs, services based on evidence, and co-operation among clinicians.”

Improving chronic illness care16

“The involvement of people with long-term conditions in planning their own care and choosing how to manage their own condition is a critical step towards improving patient-related outcomes. Both users of the service and healthcare professionals should be able to influence the service.”

Bolton’s Diabetes Journey14

14 Schillinger et al. Association of Health Literacy with Diabetes Outcome, JAMA July 2002
15 Bolton PCT. Bolton’s Diabetes Journey
Improving education

Measurements of the effectiveness of education will need to be developed, and must include:

- uptake of eligible patients, such as the proportion of newly-diagnosed patients who attend education workshops;
- feedback from patients and healthcare professionals;
- evaluation of how education has impacted on the care planning process;
- quality of life and biomedical outcome data.

What users have said:

Users wanted more and better education and easy access to specialist care when needed.

5.4 Integration of care

All patient care should be integrated to avoid duplication and reduce the likelihood of conflicting advice and messages, which might undermine self-management efforts.

The principles of integrated care are:

- some essential aspects of care are required for everyone with diabetes;
- some care is most appropriately delivered by primary care;
- some care is most appropriately delivered by specialist care;
- the setting of care must be the likeliest to achieve the objectives for the person with diabetes;
- all care is part of an integrated diabetes service;
- integrated diabetes care requires integrated service management.

Collaboration between healthcare professionals in all healthcare settings is vital to achieve integration. Specialist services should be as unified as possible with full integration with primary care and community services.

5.5 Quality assurance, evaluation and monitoring

Services should be monitored and evaluated at all levels across the care pathway to ensure patients receive high-quality diabetes care (see section 9, assessing effectiveness). Rigorous evaluation and monitoring should underpin the commissioning process to ensure that hard-to-reach communities benefit and health inequalities are reduced.
5.6 Targeting high-risk populations

Diabetes care pathways must deliver effective care for those at highest risk where substantial health inequalities currently exist. Programmes should include targeting of hard-to-reach and high-risk populations. Rigorous evaluation of care pathways and education programmes should be put in place to ensure these populations benefit. There are examples of innovative programmes such as targeted community clinics in areas with high-risk populations\textsuperscript{17}, the Diabetes Intervention and Prevention Programme (see case study opposite) and international models such as the Migrant Health Service Inc diabetes program\textsuperscript{18}. Such programmes should be evaluated and learning disseminated across London.

\textsuperscript{17} Mayer et al. Effect of Nurse-Directed Diabetes Care in a Minority Population, 2003

\textsuperscript{18} Heuer et al. Meeting the Health Care Needs of a Rural Hispanic Migrant Population with Diabetes, The Journal of Rural Health, USA, 2004

“Miscommunication, inconsistent and inaccurate advice, and contradictory information are major issues.”

Person with diabetes
The diabetes intervention and prevention programme helps people from ethnic communities access appropriate services. The programme works to:

- publicise and raise awareness of the causes, symptoms and prevention of type 2 diabetes through seminars and other education programmes;
- promote early detection of obesity and diabetes through increasing health checks and primary intervention in the community;
- encourage healthy eating and increase physical activity by delivering health activities in the community;
- encourage partnerships between the diverse Asian communities, GPs, pharmacists, retailers, the local PCT and local authority;
- reduce avoidable hospital admissions, retinopathies, diabetes-related neuropathies and lower limb amputations, to improve patients’ quality of life.

The programme is funded by the Department of Health and is based with the Sikh Community Care Project.

**Case study: Diabetes intervention and prevention programme**

<table>
<thead>
<tr>
<th>Progress</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Out of 431 people registered with the programme, 86 people, who had never previously had readings taken, have had comprehensive health checks.</td>
<td>Of these 86 people:</td>
</tr>
<tr>
<td>nine had high blood sugar levels;</td>
<td></td>
</tr>
<tr>
<td>six had high blood pressure and high blood sugar levels;</td>
<td></td>
</tr>
<tr>
<td>four had slightly above normal glucose levels.</td>
<td></td>
</tr>
</tbody>
</table>

Those newly diagnosed were referred to their GP for further intervention (see appendix 3 for details).
6 Tiers of care

The diabetes model of care is based on four tiers of care provided in three settings: primary care, the community and in hospital. According to their individual needs, a person with diabetes may receive care in all of these settings. When receiving care, people with diabetes should have a seamless experience, regardless of where care is provided or who is providing it. The transfer of care between settings should only occur where training and support systems are in place, and where there is adequate staff with appropriate skills.

The majority of diabetes care is currently provided in primary care and community settings; and around 80% of care will be provided in these settings in future. However, people with diabetes spend a relatively small amount of time in NHS care settings. Therefore, people with diabetes must be supported to manage their health at home.

To achieve this, patients need effective, ongoing education tailored to their needs (segmented by population where required) and joint care planning, which recognises the needs and priorities of the individual. Users and carers need to have access to advice and support by phone and email.
Tier one: Essential care
GPs and other practice staff will provide a consistent level of quality care and advice.

Tier two: Enhanced essential care
Some GP practices will provide enhanced care services, such as the management of foot disease, as well as tier one care.

Tier three: Specialist care
A consultant-led team will provide care for patients with more complex needs, provided in the community, such as a community-based diabetes clinic, health centre or polyclinic.

Tier four: Hospital-based care
A consultant-led team will provide specialist care and advice for patients with complex needs in hospital.

Figure 10: Settings of care
Tier one: Essential care

Tier one care will include essential care provided by GPs and other practice staff in a primary care setting. It will also include other enhanced services such as email, telephone support and care planning, which should become increasingly part of essential care.

Commissioners must ensure that everyone with diabetes, irrespective of type or complexity, receives essential care including diagnosis, education, access to specialist advice and support (see figure 11 for a full list of services).

Practices will need to meet a series of requirements to achieve tier one provider status, measured against performance indicators, including:

- a complete diabetes register showing that good systems are in place for detecting and diagnosing people with diabetes. This would be assessed by reviewing the size of the register against the estimated expected prevalence;
- an up-to-date (cleaned and validated) diabetes register;
- a fully-trained disease register co-ordinator for each practice or cluster of practices;
- competence in delivering essential diabetes care, including care planning;
- competence in ongoing insulin management to at least a basic level.

Tier two: Enhanced essential care

Tier two care should be defined locally, but will include essential and enhanced diabetes care including:

- treatment escalation – for example, insulin initiation in people with type 2 diabetes, following accredited training;
- structured education programmes for patients and carers.

GP practices will define and agree the level of service they wish to offer. This will be confirmed through ongoing review and audit by commissioners, for example, through the National Diabetes audit tool for diabetes care\(^1\). Local commissioning, advised by the local clinical network, will determine what services are appropriate to be offered as part of enhanced tier two care.

The viability and cost-effectiveness of running services at tier two should be considered. Some of these services may be better delivered in clusters. Generally tier two care will be delivered by practices although, where appropriate, it can be delivered by intermediate diabetes teams.

\(^1\) Department of Health. *Turning the corner, improving diabetes care*, June 2006

“More important to us than the physical location of the setting is the level of expertise available there.”

*Person with diabetes*
Tier three: Specialist care

Tier three will include specialist care and advice (consultant-led) in a community-based setting for patients with complex needs. Care could be provided in a polyclinic, community-based diabetes centre or health centre. Community-based diabetes clinics risk being less efficient than traditional secondary care services. Therefore, community settings should be chosen where there is definite added value in terms of quality of the care that can be provided and improved access to services.

Tier four: Hospital-based care

Tier four will include specialist care and advice provided in a hospital-based setting for patients with complex needs. It will be consultant-led (medical consultant and diabetes specialist nurse/nurse consultant) with a multidisciplinary team approach. Collaboration across provider/PCT boundaries is needed to enable seamless access to more specialised services, such as children’s care, care of complex complications of diabetes, continuous subcutaneous insulin infusion (CSII), and care of complex pregnancies. There should be protocols for sharing best practice, as well as mentorship and protected time for continuing professional development. Collaboration between different secondary care providers will also be necessary. Governance of these complex specialist interventions should apply across the whole care pathway even where they cross provider boundaries, such as between secondary and tertiary care.

What users have said:

Users wanted better access to specialist care and services. They expressed concern about the lack of consistency in specialist services, lack of expertise in some areas and lack of access to potentially beneficial therapies and services.

Additional care for people with type 1 diabetes

People with type 1 diabetes should have access to specialist review at least once a year at tiers three or four. Essential care should include agreeing individualised targets for glycaemic control and proactive recognition of problematic hypoglycaemia. Patients should have access to structured education and more specialist services such as continuous subcutaneous insulin infusions, where necessary.
## Intermediate diabetes team: Support and develop services

All care settings should enable collaborative care planning, and this should be measured.

**Tier 1**  
*Primary/community*

- Support and develop essential care, including:
  - detection, diagnosis, register maintenance;
  - personal care planning;
  - medicines review (potentially with community pharmacy services);
  - complications screening;
  - patient and carer advice – telephone and email;
  - family planning and initial pregnancy planning advice.

Intermediate diabetes team to provide or co-ordinate access to:
- specialist diabetes dietetics and podiatry;
- psychological support;
- patient education programmes;
- training;
- joint clinics;
- telephone and email support;
- access to insulin initiation and new therapies if appropriate;
- access to specialist opinion when needed.

### Quality control governance

- Evaluation and governance across the whole care pathway is essential to ensure adequate resourcing and expertise.
- Records (paper or electronic) should be shared among healthcare professionals to avoid duplication.

**Tier 2**  
*Primary/community*

- Support and develop essential care with extra provision including insulin initiation and patient education.

Intermediate diabetes team to provide or co-ordinate access to:
- other services e.g. psychological support, specialist dietetic support, insulin start groups;
- training;
- joint clinics;
- telephone and email support.

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**Figure 11: Services to be provided in different settings**
### Tier 3

**Community specialist care**

Intermediate diabetes team: Provide care

All care settings should enable collaborative care planning, and this should be measured.

<table>
<thead>
<tr>
<th>Deliver and co-ordinate:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• multidisciplinary clinics;</td>
</tr>
<tr>
<td>• consultant-level support;</td>
</tr>
<tr>
<td>• access to specialist diabetes dieticians, podiatrists or other specialists;</td>
</tr>
<tr>
<td>• research and development, and training;</td>
</tr>
<tr>
<td>• patient education;</td>
</tr>
<tr>
<td>• insulin initiation;</td>
</tr>
<tr>
<td>• healthcare professional education;</td>
</tr>
<tr>
<td>• family planning and pregnancy planning advice.</td>
</tr>
</tbody>
</table>

### Tier 4

**Hospital care**

Deliver and co-ordinate:

| • joint clinics; |
| • foot/kidney services; |
| • pregnancy planning advice; |
| • children and adolescent services; |
| • care and education for people with type 1 diabetes; |
| • insulin initiation; |
| • insulin pump; |
| • CSII management; |
| • patient and carer advice – telephone and email; |
| • patient education; |
| • research and development, and training; |
| • in-patient management. |

### Quality control governance

- Evaluation and governance across the whole care pathway is essential to ensure adequate resourcing and expertise.
- Records (paper or electronic) should be shared among healthcare professionals to avoid duplication.
7 Prevention, diagnosis and patient groups with particularly complex needs

Within this section we set out some key issues regarding prevention and early diagnosis, which should be seen alongside the generic tiers of care described in the previous section. We also outline some requirements for patients with particularly complex needs.

Care pathways have been developed to manage people with newly-diagnosed diabetes. These can be adapted for local use by the clinical network.

Work has focused on the difficult areas of care that have not been covered in detail in other published guidance, rather than revisiting established guidance on common pathways.

Four specially-commissioned care pathways were developed (see appendix 4) for the areas clinicians identified as the most difficult to address in current working practice:

• care of people with diabetes who also have severe mental illness;
• pre-pregnancy care of women of child-bearing age who have diabetes;
• care of people with diabetes who live in a residential care home;
• care of adolescents with diabetes (including the transition to adult services).

The care pathways are compatible with the model of care and national guidance produced by the Department of Health.

It is recommended that these care pathways be used to inform local service provision and adapted for local use. Two working guides accompany them: one sets out the practical and clinical aspects of each step in the pathway in detail; the second provides guidance on adapting the pathways for local use.

Commissioners may wish to use the Map of Medicine20, a web-based tool for communicating locally adapted care pathways to professionals at all levels of care. This tool provides care pathways for a wide range of specialties. Local PCT networks can define their own care pathways using the Map of Medicine.

20 Map of Medicine, www.mapofmedicine.com
7.1 Prevention

The largest single preventable risk factor for diabetes is obesity. One in six adults in London is obese; and childhood obesity rates are particularly alarming.

Reducing obesity will lead to a reduction in the longer-term incidence of diabetes, particularly type 2. It is estimated that around 90% of people with diabetes in the UK have type 2\(^{21}\); therefore the potential for reducing future demands on service provision is enormous.

The 2008 Healthy Weight, Healthy Lives\(^{22}\) strategy outlines the Department of Health’s plans to promote healthier weight. Guidance is available to support PCTs and their partners to develop a healthy weight action plan for local areas\(^{23}\).

Diabetes prevention and vascular health strategies overlap considerably, especially in younger individuals. In developing this guide, Healthcare for London worked with the Vascular Prevention Group, a multidisciplinary group crossing health and social care organisations. The Vascular Prevention Group is developing the Healthy London strategy which will focus on two main areas of strategic prevention:

- maintaining healthy weight through diet and exercise;
- reducing smoking.

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\(^{22}\) Department of Health. Healthy Weight, Healthy Lives, 2008

7.2 Early diagnosis

*Healthy London* incorporates recommendations from the new national programme of vascular risk assessment and management for those aged 40-74. In its *Putting Prevention First* report, the Department of Health outlined the significant benefits of vascular risk assessment and management.

An estimated 25% of people with diabetes are currently undiagnosed. Implementing the vascular risk assessment programme, including vascular screening for those over 40 years of age, is expected to reduce this. Therefore, commissioned diabetes services will need to have extra capacity to accommodate people newly diagnosed by screening programmes. It is essential that people diagnosed with diabetes receive a high level of care at diagnosis. Earlier diagnosis and high-quality diabetes care will lead to reduced demands on unscheduled care and fewer complications in the longer term.

People diagnosed with diabetes should also receive an individually-tailored assessment that sets out their level of risk and ways to manage their condition. This may include general advice, weight-management programmes, interventions to increase physical activity, or stop smoking services. Those at highest risk, for example those with impaired glucose tolerance or impaired fasting glucose, may require statin medication, blood pressure treatment or intensive lifestyle management programmes.

NHS London is developing the vascular prevention delivery model. However, it is vital that PCT networks start to:

- develop a ‘process map’ for how vascular risk assessment will work in local populations;
- develop robust project plans for implementation;
- put plans in place to improve the development of local disease registers and the management of hypertension and high cholesterol levels in primary care;
- develop plans for earlier diagnosis and management of diabetes.

Care pathways presented in the model of care for diabetes reflect the vascular risk assessment programme, and will need to be revisited by PCTs as they develop local diabetes care pathways and vascular risk assessment programme initiatives.

7.3 Caring for children and adolescents with diabetes

Children and young people with diabetes should have support that enables them to live healthily, stay safe and lead full and active lives. This includes supporting children and young people to meet their educational potential by minimising the need to miss school for routine appointments. Best practice care pathways should be developed for children with diabetes.

Service integration must be improved:

- between GP practices and hospital specialists, and between health and social care, including social services and mental health services (as required);
- at London-wide and sector-wide levels through effective clinical networks.

Building on the National Institute for Health and Clinical Excellence guidelines for diagnosing and managing type 1 diabetes in children, young people and adults,25 every child or young person with diabetes in London should have:

- a named paediatric diabetes specialist nurse;
- ongoing care by a multidisciplinary paediatric diabetes care team that includes:
  - individual care plans for routine and exceptional circumstances, reviewed and updated regularly;
  - a case-management approach, escalating contact and visits for those at higher risk, be that short or longer-term;
  - routine checks and regular contact at home, school or in a clinic;
  - access to advice at times of unplanned need via 24-hour telephone access;
  - tailored and structured education that is adapted to the child's level of development and the family's learning and decision-making style;
- direct access (and access via the local team) to further expertise for specific issues, including co-morbidities, managing early complications, psychological or psychiatric support, and youth worker support – particularly for black and minority ethnic children;
- peer group support and training for parents and teenagers;
- culturally-specific advice and support, as well as the use of interpreters or bilingual health workers, telephone or face-to-face, for those who use a language other than English;
- targeted advice or access to services such as smoking cessation, sexual and reproductive health.

25 NICE. Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults, July 2004
In addition to key performance indicators as specified previously, key measures should include:

- user satisfaction, for example:
  - accessibility of a diabetes specialist nurse and wider service for planned and unplanned contact;
  - awareness of care plan;
  - rating of holistic care;
- school attendance and education time lost for diabetes-related reasons.

**Education and support for children and families**

All young people should have specific health promotion on:

- smoking cessation;
- healthy eating and weight management;
- alcohol misuse;
- substance misuse;
- mental health and emotional wellbeing;
- sexual and reproductive health.

**Service reconfiguration**

Nearly 2,500 people under 19 years of age in London have diabetes; over 80% have type 1 diabetes.

To provide sufficient expertise, we need a critical mass of staff that can:

- share experience;
- provide peer support and cover for training time;
- provide capacity for an extended hours services.

It is proposed that PCTs specifically commission services for children, adolescents and young adults on a sector-wide basis. These services could be:

- a single-team service;
- a networked service of several teams. For example, the north central London model which caters for 650 patients;
- teams in a network based in hospital or the community.
Each service should use a case-management approach and provide a case manager for each patient to deliver:

- support for the child and family at diagnosis – enabling them to avoid admission unless for diabetic ketoacidosis or at the family’s request;
- personalised care for the child or young person and their family;
- a care plan agreed with the child or young person and their family, which is regularly reviewed and updated;
- arranged routine checks conducted by the case manager or other members of the team;
- telephone or email contact between face-to-face visits and appointment reminders;
- liaison with the child or young person’s GP;
- case management level review with escalation and de-escalation as required. Escalation to a higher risk category should trigger increased contact and a case review by peers in the service. Those in the highest risk category should be reviewed by another London service;
- referral to other professionals, where appropriate, such as psychology or further specialist medical advice;
- written information and tailored education for patients and families;
- culturally-specific structured education as and when appropriate to patients and families at all stages from diagnosis. For example, some information immediately and more detail (especially about complications) three to six months later;
- interpretation services;
- transition to adult services at the appropriate time.

Diabetic specialist nurses play a pivotal role in children’s diabetes and most children’s diabetes services have paediatric diabetic specialist nurses. These nurses support young people with diabetes, providing telephone or email contact and home or school visits as needed.
Reducing emergency admissions

Proactive community care can reduce emergency admissions and lengths of stay. Each service should have:

- regular education and peer-group meetings;
- audit and review meetings;
- a mechanism for reviewing high-risk or complex cases on a regular basis;
- extended hours helplines staffed by local team members;
- drop-in clinics on Saturday mornings;
- a continuous subcutaneous insulin infusion (CSII) pump service.

Workforce requirements

Children and adolescents should be cared for by professionals with a specialist paediatric role. This strengthens the case for establishing clinical networks, possibly on a sector basis, in order to share expertise.

The following professionals are required:

- dedicated diabetes specialist nurses – paediatrics trained or with training and experience to be able to tailor care to people aged 19 or under;
- dedicated dietetics;
- paediatric medical expertise;
- paediatric and adult diabetes expertise;
- dedicated psychology input direct to patients and families, or as advice to other team members;
- relevant administrative staff.

Joint working

Children’s care needs to be collaboratively planned across multiple PCTs and providers. This requires

- shared governance, protocols and clinical pathways;
- an overnight helpline with notification to a local or network team the following morning, provided across the networks to be co-ordinated at a pan-London level.
7.4 Inpatient care

Diabetes is the cause of 12-15% of hospital-based deaths nationally; unfortunately the level in London is higher given the high-risk population. Much of the diabetes care provided in hospitals is sub-optimal, and there are adverse outcomes on patient morbidity or length of stay in a significant proportion of cases. This considerably increases the cost of providing healthcare for those with diabetes.

The model of care proposes an adequately resourced, specialist multidisciplinary diabetes team in hospitals to provide clinical leadership and ensure all aspects of inpatient diabetes services are co-ordinated (see appendix 5).

This should incorporate all the principles previously outlined, including:

• support and information for the person with diabetes and a care plan for managing their diabetes during their hospital stay;
• training and support for staff who look after inpatients with diabetes, with:
  – training guidelines;
  – easy access to multidisciplinary specialist opinion where required;
  – access to highly specialised foot care in secondary care and on a timely tertiary referral basis where necessary.

The inpatient team may assume a facilitative training role with ward teams, parallel to the role of the intermediate diabetes team in tier one and tier two care.
7.5 Pre-pregnancy and antenatal care

Many areas of London have high rates of gestational diabetes and pregnancies in women with diabetes due to the ethnic mix of their populations. The number of pregnant women with type 2 diabetes in London is increasing and the majority of these women are looked after solely in primary care. Many women are poorly prepared and take medications that are contraindicated in pregnancy.

Commissioners need to ensure there is adequate resourcing of the multidisciplinary specialist teams to:

- identify women with diabetes who are planning a pregnancy and make a timely referral to specialist services for optimisation of diabetes prior to conception;
- provide services for those who become pregnant;
- ensure the detection, management and subsequent follow-up of women with gestational diabetes.26

7.6 People with severe mental illness and diabetes

In the UK, two per cent of people will experience severe mental illness at one time in their life. These conditions are most likely to include psychotic illnesses such as schizophrenia and manic depression. Those living with severe mental illness are significantly more at risk of developing major physical health-related issues as a consequence of their mental illness.

One in five people with a severe mental illness has diabetes. This is in part due to the lifestyle they are often forced to lead because of their socio-economic circumstances, the impact of some medications and the way their mental health condition is managed. Significantly higher incidences of diabetes and other long-term conditions translate into rates of premature death which are up to three times higher than the general population.

On average, those with severe mental illness die between 10 to 15 years earlier. Managing people with severe mental illness and diabetes requires expertise and, without that, the length of stay in mental health hospital beds is significantly extended. It is essential that people with severe mental illness registered on primary care QOF registers are assessed for diabetes as part of the annual physical health check and that clinicians are aware of the interactions with lifestyle and medications.
8 Key enablers for successful delivery

8.1 Intermediate diabetes team

Every PCT or network should have an intermediate diabetes team to facilitate and support primary care, ensure co-ordinated community services and aid integration with secondary care.

Clinical leadership provided by a consultant diabetologist, GP champion and diabetes specialist nursing should be part of every intermediate diabetes team (figure 12). This leadership will be vital for ensuring services are integrated – moving towards working across a clinical pathway, in a patient-centred way.

The intermediate diabetes team should deliver the following services:

- co-ordinating access to:
  - community insulin starts;
  - patient education;
- direct access to diabetes specialist dietician;
- direct access to specialist podiatry;
- direct access to psychological support, techniques and mentors.

- support for GPs and practice staff in tiers one and two to enable them to provide high-quality essential and extended care. Functions of the intermediate diabetes team should include:
  - email and telephone support for practices;
  - organising and/or delivering training for primary care professionals;
  - practice-based joint clinical consultations;
- integrated proactive management of people with early complications. e.g. those detected with early retinopathy by retinal screening;
- community nurse support.

In addition to supporting practices to deliver tiers one and two care, the intermediate diabetes team will provide tier three care in community-based settings such as polyclinics. The number and type of community settings should be determined locally where there is a value-added, patient benefit in terms of quality or access.

The intermediate diabetes team should have appropriate administrative support and protected time for learning service improvement, research and development, and evaluation. Locally relevant service objectives and clinical enhancements should be discussed and agreed collaboratively.
Figure 12: The intermediate diabetes team specialist functions

- GP Lead
- Diabetes consultant
- Diabetes specialist nurse/nurse consultant
- Psychological support/mental health
- Pharmacists
- Podiatry
- Diabetes specialist dietitian

Training, facilitation, peer review, research and development
Joint practice-based clinics

Joint practice-based clinics are a key component of the intermediate diabetes team service. The primary role of these clinics is to train, facilitate and support GP practice teams to manage the care of people with more complex needs.

Clinical consultations should involve practice staff committed to the long-term care of people with diabetes and who provide continuity of care, and the diabetes specialist nurses with medical consultant support (see figure 13). The visit would normally involve a ‘virtual clinic’ focusing on high-risk or more complex patients. A visit from the medical consultant every six months will enable further training and development in the practice.

High-risk patients will be identified and proactively reviewed by the intermediate diabetes team and practice team.

Figure 13: Managing joint practice-based clinics

Joint practice-based clinics in tiers one and two

- Nurse-led consultations every two to three months
- Consultant visit every six months
- Advice given in practice
- Supports practice to manage people with more complex conditions, preventing referral to specialist care.

Multidisciplinary community clinic
- fewer patient referrals

Multidisciplinary specialist clinic
- fewer patient referrals
Figure 14: Identification of high-risk patients

- Podiatry
- Retinal screening
- Practice
- Other e.g. hospital discharge

Review by intermediate care team with practice

High-risk patient
8.2 Dietetic support

Dietetics plays a crucial role in managing diabetes. The model of care proposes that:

- all individuals diagnosed with type 1 diabetes and gestational diabetes are referred to a diabetes specialist dietician;
- practice staff are trained to provide basic dietary advice and structured group education;
- dietetic leadership should be available and accessible to people with diabetes at diagnosis and throughout the pathway, meeting Department of Health, Diabetes UK and National Institute for Health and Clinical Excellence (NICE) guidance;
- a dietary education package be developed by the dietetic service for use by all GP practice teams in their reviews to help address the education gap that results from no annual dietetic review;
- practice reviews identify people with complex problems. These people may be referred to specialist services;
- more community infrastructure, such as support workers and trained lay people, be developed. This reflects the government’s vision of sustainable communities and the Choosing Health white paper.

A rigorous, dietetic-led quality assurance programme, including competencies, is essential to ensure accuracy and consistency of the advice that is provided.

Culturally-sensitive dietetic advice should be available to all Londoners. PCTs and networks must work together to commission education services to ensure access to culturally appropriate advice across London.

For more information, see British Dietetic Association guidelines.

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28 The British Dietetic Association
8.3 Local networks

The Department of Health defines a clinical network as “connections across disciplines which provide integrated care across institutional and professional boundaries, raising clinical quality and improving the patient experience.”

Local diabetes managed clinical networks need to be at the centre of the delivery of clinical care.

The primary purpose of the network is to contribute to reduced morbidity and mortality associated with diabetes. It will also ensure that the service standards required by the PCT are being met. To fulfill the requirements of world-class commissioning and have effective engagement with clinicians, PCTs will have a lead commissioner who will be involved with, and work alongside, the clinical network.

The clinical network must have high-level specialist, medical and nursing, and primary care input. The focus must be on safety, quality and effectiveness, including patient experience and access. The network also requires a management lead, in addition to clinical leadership.

To reduce inequalities in health outcomes from diabetes, all care pathways need to improve access to services for hard-to-reach and high-risk communities and ensure ongoing evaluation of outcomes. This will be monitored and facilitated at a pan-London level. Some programmes may need to be co-ordinated at a sector or pan-London level.

A local diabetes managed clinical network will achieve these aims through:

- enabling the provision and governance of effective high-quality patient centered care;
- supporting the development of integrated management to ensure an integrated service for people with diabetes from primary and specialist care and from other services as required, including social service and voluntary sector provision;
- facilitating integrated care pathways across different settings and tiers provide care to at least the minimum level recommended in the Diabetes National Service Framework;
- ensuring collaboration at sector level to ensure that care systems are integrated across PCT and provider boundaries to maximise efficiency.

The commissioning guide section of this document contains details of the generic pathway and specialised pathways that were drawn up to accompany the model of care. These are available in appendix 3 but readers are strongly advised to read the commissioning guide before accessing the care pathways and adapting for local use.
A commissioner-led clinical network should support the establishment of local care pathways, either developing their own or adapting existing pathways.

- preventing type 2 diabetes;
- identifying people with diabetes;
- supporting self-management and collaborative care planning;
- improving the sense of wellbeing for those with diabetes;
- clinical care of adults with diabetes – type 1 and type 2;
- clinical care of children and young people with diabetes, including transition care;
- managing diabetic emergencies;
- care of people with diabetes during admission to hospital;
- diabetes and pregnancy;
- detecting and managing long-term complications.
Aspirations for care should be developed in line with the Diabetes National Service Framework\textsuperscript{29} and with the key performance indicators listed in this guide. An action plan with clear performance management and governance to deliver on these aspirations should be developed by the clinical network and it should be regularly monitored.

Local measures of quality need to be collected and reviewed on an ongoing basis and shared with clinicians to provide impetus for improvement. All London GP practices and PCTs should sign up to the National Diabetes audit which will generate local reports to inform this process.

The local diabetes managed clinical network should review performance data on a regular basis and focus on areas of improvement, developing and testing interventions to assist commissioners and providers. To do this, networks should proactively form partnerships with voluntary and charity organisations and local authorities.

Clinical networks should facilitate access to health records for all members of the healthcare team and for people with diabetes. To some degree, these solutions may need to be driven at pan-London level, however local clinical networks also have a key role.

Monitoring network effectiveness

Monitoring the effectiveness of the network is crucial to ensure most efficient use of resources and to ensure the network is outcomes-focused. Network assessment should be an iterative process.

More information is available on the Care Services Improvement Partnership website\textsuperscript{30} and from National Diabetes.

There are a number of tools available to measure outcomes. The commissioning guidelines in this document set these out in detail; however they focus on PCT/practice-level data. Information could be collated and used for setting local targets with constituent PCTs in a network. Detail on potential metrics for diabetes may be found at appendix 6.

“The NHS has often made the mistake of thinking it can change healthcare outcomes on its own. It cannot. The NHS must work with its partners – London boroughs, the Greater London Authority and the Mayor’s office, the voluntary and private sectors, and the higher education sector – to implement this framework.”

Healthcare for London, A Framework for Action

\textsuperscript{29} Department of Health. A national service framework for diabetes: standards, 2001

\textsuperscript{30} www.integratedcarenetwork.gov.uk
8.4 A London Diabetes Board

While London faces specific problems providing diabetes and long-term condition care, there is much to learn from models elsewhere within and outside the UK. New approaches to raising the quality of diabetes care and reducing inequalities need to be tested collaboratively and, where effective, implemented in London.

It is proposed that a pan-London diabetes board with clinical specialist, commissioner, primary care and user input be established to monitor the progress of delivery of diabetes care (and possibly other vascular long-term conditions) and enable:

- accredited training and competencies for health professionals in diabetes care – appropriate to the needs of London’s population including those required for collaborative care planning;
- reduced health inequalities, targeting those at higher risk due to ethnicity, deprivation or lower health literacy;
- improved access for hard-to-reach communities through social marketing, commissioned at a pan-London level (co-ordinated with vascular risk social marketing);
- co-ordinated evaluation and dissemination of best practice to address common problems in London;
- together with maternity care, pan-London social marketing initiatives, focused on the importance of health for women of fertile age, particularly women with obesity and/or diabetes. With a mobile population this health promotion is best delivered at a pan-London and national level;
- responsive learning from patient reported outcome measures (PROMs) pilots on diabetes care in London;
- web-based support for people with diabetes – this could build on traditional chronic disease support. Internet programs have also been developed for diabetes education and their potential should be explored;
- children’s and adolescent care is co-ordinated over a larger sector. Some clinical services such as 24/7 telephone advice for children may need to be commissioned at a pan-London level;
- IT solutions and records sharing drive forward co-ordination of shared medical records.

This structure should allow and facilitate the ability for learning from the local level and sharing across London.

Governance

High-quality diabetes care needs to be structured and integrated with shared goals and governance. Governance should occur across the system and along the whole care pathway – irrespective of organisational boundaries. A clinical network should contribute to effective governance; the network should scrutinise data collected and ensure there is user input. Pan-London benchmarking against other PCTs across London and England will be necessary.
8.5 Training and support

Primary care

Training is an essential requirement if primary care practitioners are to manage a significant proportion of the diabetes workload effectively.

Care users identified training as a particular need to help overcome differences in service quality between practices. Specialist teams also welcome this development to ensure a high standard of care is maintained when care is transferred from secondary to primary care settings.

Commissioners need to ensure there is sufficient capacity to manage diabetes in primary care, as follows:

- At least one GP and one practice nurse in each GP practice must be trained to certificate level in diabetes care or similar (or evidence of competency to show that this is not required). In addition, one trained healthcare assistant per team is recommended.
- Appropriate succession planning should be in place to ensure turnover of staff in primary care does not destabilise care for people with diabetes. Succession planning should ensure new post-holders have the appropriate expertise – and this should be reflected in the personnel specification for the post.
- Healthcare assistants caring for people with diabetes must be competent to undertake all data collection, take blood and urine tests, measure height and weight, measure waist circumference and perform a basic foot examination.
- Staff caring for people with diabetes must have training and resources in collaborative care planning.
- Diabetes trained primary care staff should ensure a minimum level of ongoing diabetes training is incorporated in their continuing professional development. Such training should be defined and quality assured according to the needs of individual PCTs.
- Basic training should also be available to primary care health professionals who are not directly involved in the delivery of diabetes care.
- Intermediate diabetes teams should have specific responsibility for ensuring the quality of ongoing training for primary care staff.
- Joint practice-based clinics develop and review ‘learning contracts’ and advise on the structure of diabetes care within the clinic.

Shared arrangements can be put in place across a cluster of practices where necessary.
Intermediate diabetes team and specialist team

Specialist teams will require training in:
- diabetes management (accredited training) and significant clinical experience in diabetes care;
- care of more complex diabetes including clinical mentorship;
- care planning;
- facilitation skills to allow more effective support of staff in other tiers;
- designing, delivering and evaluating education programmes;
- leadership skills for GPs, diabetes specialist nurses and medical diabetes consultants.

Furthermore, specialist teams require a sufficient planned case load to ensure their skills are maintained. There should be adequate and suitable arrangements to provide mentorship and supervision for all clinical staff.

Assessing competency

Training programmes and the assessment of competencies are essential and very important to users. A valid practical approach to this should be taken, and appropriate training programmes and assessments of competency developed across the care pathway. To some degree this will be determined locally, but with increasing emphasis on developing patients’ self-management, care planning and the specific issues of diabetes care in London, NHS London should develop pan-London training requirements and competency assessments.

These might include:
- training designed to ensure competency to deliver essential diabetes care including care-planning;
- training designed to support extended primary care services;
- training for the specialist teams in training, facilitation and quality assurance.

“The consistency of patients’ experience ranges depending on the GP’s knowledge of diabetes, the availability of a consultant and the medication and education offered. This amount of variation leaves patients feeling that the quality of service they receive is too variable.”

Person with diabetes
8.6 Integration between specialist teams in community and hospital

Ideally, the same specialist team should work in the community and in the hospital with shared learning, development and governance. This team needs to be adequately resourced, rather than shifting resources from one setting to the other.

A recent joint Royal Colleges report commended this approach, pointing to the need for leadership from doctors – and commitment to continuous improvement year-on-year, driven by collaboration and learning.

In some areas, integrating hospital and community teams may not be possible due to insufficient resource or expertise. Nevertheless, a fully-integrated hospital and community specialist team is vital for adequately structured care.

8.7 Achieving integration at all tiers – steps for implementation

1. All healthcare professionals in each setting should have access to, and a working knowledge of, defined primary, secondary and tertiary care pathways – with clear roles specified.

2. Involvement with the intermediate diabetes team must be obligatory for practices offering diabetes care and for all secondary care providers to ensure integration and cohesion across the service.

3. Agreed governance arrangements must be obligatory for all practices offering diabetes care.

4. The infrastructure for service delivery – including professional training and facilitation of primary care – must be established on a sufficient scale to meet clinical governance requirements. This must be in place before any substantial shifts occur in the settings where patient care is provided.

5. Where expertise in certain primary care practices is insufficient, even for essential diabetes care, the practice and the intermediate diabetes team will need to give a high priority to the development of the skills and expertise. GP and specialist leadership will be vital to enabling this to happen.

“For patients to really benefit from the new approach to settings of care, hospital and community teams need to merge to ensure that the patient sees the right person, at the right time, in the right setting. This will require an innovative approach to collaboration across organisational, and possibly professional, boundaries in some areas.”

*Teams without walls* [31]

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9 Assessing effectiveness

It is proposed that data on the quality of diabetes care is collected consistently across London – to share with PCTs and diabetes networks and connect areas that can learn from one another where achievement has varied. All London GP practices and PCTs should sign up to the National Diabetes audit.

9.1 Data on clinical quality

The following two measures were considered to be the most important indicators of effective diabetes management.

The proportion of the population on the diabetes register who are monitored (via the QOF reporting process) as having:

1. blood pressure less than 145/85 mmHg;
2. HbA1c less than 7%.

Other indicators of effective management are:

- the number of people who have their blood pressure measured and who also have their HbA1c measured;
- the proportion of those eligible who are offered retinopathy screening and the proportion who attend.
9.2 Data on diabetes outcomes
It is critical to monitor the impact of care pathways over time by measuring the number of people:
• requiring renal replacement therapy;
• with loss of vision attributable to diabetes;
• with amputation attributable to diabetes.
Activity on renal replacement therapy and amputation is currently recorded and reported as hospital episode statistic (HES) data without necessarily attributing diabetes as a cause. Commissioners and acute trusts will need to establish a principle where attribution to diabetes is recorded appropriately. The HES recording template allows for this. Loss of vision data would need to be acquired.

9.3 Data on patient experience
Commissioners will need to collect data on the proportion of people newly-diagnosed with diabetes who are offered structured education – and the proportion who attend.
There will also be a number of PROMs pilots in diabetes taking place in London during 2009/10.

9.4 Aspirations for diabetes care
The model of care will improve diabetes care such that the NHS in London aspires to, by 2012:
• reduce the gap in recorded prevalence versus the estimated expected prevalence by half – in each PCT;
• achieve a minimum performance in the national upper 25th centile for the percentage of patients on the diabetes register achieving an HbA1c of less than 7% and a blood pressure of less than 145 mmHg;
• measure HbA1c in all people with diabetes who attend for a blood pressure check;
• ensure that 90% of those eligible to attend retinopathy screening do so;
• offer structured education to people who are newly diagnosed with diabetes, with at least half attending.
Progress on these aspirations should be monitored on a quarterly basis, with a focus on annual confirmation of outturn and shared learning. If QOF reporting changes, these recommendations will be amended to include new data reporting.
This section sets out guidelines and recommendations for commissioners to improve diabetes care in London. This includes:

- using a systematic approach to diabetes data collection;
- improving performance to achieve at least the minimum level required on key measures, whilst minimising exception reporting;
- establishing a pan-London diabetes board.

This commissioning guidance primarily focuses on adults with type 2 diabetes. Specialist care will also need to be commissioned for:

- people with type 1 diabetes;
- pregnant women with diabetes, or women planning a pregnancy;
- children and adolescents with diabetes.

Some guidance for these cases is provided in this document.

**In this section we discuss**

- Model of care and pathways
- Priorities for commissioners
- Funding diabetes services
- Performance issues
- Next steps
10 Model of care and care pathways

The new model of care (set out in the preceding chapter) provides the framework for delivering a world-class diabetes services for all Londoners. The following commissioning guidelines advise how to embed the new model of care, adapt recommended care pathways for local use and, in doing so, improve diabetes care and reduce health inequalities in the capital.

- The generic pathway for people who are newly diagnosed with diabetes, and the four specialised care pathways were described in the model of care, chapter two. The pathways are also provided in simple diagrammatic form at appendix 3.

- A step-by-step guide, Integrated pathway outline care map, has been developed for each pathway to assist PCTs with its practical implementation (see appendix 7).

- A separate guide has been developed for commissioners who wish to adapt the care pathways for local use. The guide, Localising care pathways, is available at appendix 8. The guide can also be used when adapting pathways for other long-term conditions.

Recommendation one

PCTs are advised to adopt the Healthcare for London diabetes model of care and use it to inform the commissioning of local diabetes services, recognising the importance of collaboration, networks and service integration along the care pathway. They are also advised to designate an executive director to oversee this work.

Recommendation two

PCTs should adopt the generic diabetes care pathway and the care pathways for specialised care as set out in the appendices accompanying this commissioning guide, adapting them for local use where necessary.
11 Priorities for commissioners

11.1 Key elements

There are different combinations of models of care and commissioning mechanisms across London. While some PCTs may already be delivering the Healthcare for London model of care, it is not always necessarily being delivered in full.

There are 10 key elements of the model which should be reflected in future service planning and funding. These elements are listed opposite. PCTs should assess current service provision and plan a strategic shift in care, where required.

1 Care is patient-centred and integrated.
2 Local service development is informed by user involvement.
3 People with diabetes receive care in a setting where minimum standards of essential diabetes care can be provided.
4 People with diabetes receive effective education to self-manage their condition, and there is a focus in collaborative care planning.
5 Integrated care pathways that cross organisational boundaries are developed.
6 Primary care professionals providing diabetes care receive training, development and support, including training on care planning.
7 An intermediate diabetes team is developed with clinical leadership provided by medical and nursing diabetes specialists and a GP champion.
8 There is adequately resourced specialist provision of clinical care in community settings (tier three) and hospital settings (tier four).
9 Improvements in quality of care are measured. These measures drive the process of improvement.
10 An effective commissioner-led local diabetes network is established, with representation from primary and secondary care providers and users, responsible for overseeing quality and contributing to effective governance of diabetes care across the local area.
11.2 The diabetes service commissioning model

A diabetes service commissioning model has been developed to complement the model of care. This commissioning model is outlined in figure 16 and summarises the commissioning approach for the different tiers of care delivery in the model of care for adults with diabetes. It is based on the long-term conditions model that will be familiar to commissioners.

All practices should provide essential care as per the general medical services (GMS) and personal medical services (PMS) contract and QOF. It is expected that all practices will reach tier one at an early stage in the implementation of the new model – and PCTs should support practices to achieve this. The intermediate diabetes team should provide care where there is a gap in service capacity. However, there may be practices which, after a sustained period of support and training, are still not able to provide safe tier one care. Alternative arrangements should be made to enable people with diabetes registered with that practice to receive their diabetes care elsewhere.

Practices seeking to provide tier two care should similarly be supported, though not all practices are expected to provide tier two care. Practices providing tier two care will need to retain links with the intermediate diabetes team, as part of integrated working along the care pathway. Where practices do not provide tier two care, patient clinical needs beyond tier one will be managed by the intermediate diabetes team. Individual PCTs may choose to commission all tier two care from an intermediate diabetes team or an external provider.

The key elements for commissioners are explained in detail below. Commissioners must work with local service providers and users when implementing changes to the care pathway, and maintain an ongoing dialogue with both to ensure changes result in improved services.
Figure 16: The diabetes service commissioning model

<table>
<thead>
<tr>
<th>Clinical responsibility</th>
<th>Setting</th>
<th>Providers</th>
<th>Contracting mechanism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant diabetologist</td>
<td>Hospital</td>
<td>Specialist care in hospital</td>
<td>Payment by results (PbR) plus additional funding to cover pathway services</td>
</tr>
<tr>
<td>GP and consultant diabetologist and/or nurse specialist</td>
<td>Community</td>
<td>Community service provider and specialist</td>
<td>Contract with community service provider for direct patient service provision at tier two (where provided) and tier three, plus additional funding to cover services provided at tiers one and two</td>
</tr>
<tr>
<td>GP supported by intermediate diabetes team</td>
<td>GP practice (alternatively home or care home)</td>
<td>GP(s) and practice nurses and other staff employed by the practice</td>
<td>GMS/PMS contract (including QOF) plus Local Enhanced Service (LES) for tier one or tier two care provided in primary care setting upon successful delivery of targets</td>
</tr>
</tbody>
</table>

Patients move up and down the levels as their condition dictates.
11.3 Patient-centred care

Successfully implementing the diabetes model of care, using recommendations set out in this guide, will result in more patients with less complex needs being supported closer to home by primary and community care services.

It is estimated that around 80% of care for people with diabetes can occur at a primary or community setting if staff are appropriately trained and supported.

Tier one care should be provided in primary care by appropriately skilled GPs, practice nurses and healthcare assistants in accordance to standards set out in a Local Enhanced Service (LES) agreement. The LES funds primary care providers to deliver a standard of care beyond that funded through the GMS/PMS contract and existing QOF mechanisms.

An exemplar LES has been created to accompany this commissioning guide for adaptation to local use by PCTs as required (see appendix 9).

As PCTs have differing arrangements with their primary care providers on funding a range of enhanced services and individual commissioning approaches, a fixed remuneration for London has not been established in the exemplar LES. Where this model has already been adopted, current practice indicates that remuneration is in the range of £20-£60 per patient per annum where LES quality targets have been achieved. Some PCTs apply a sliding-scale, rewarding practices if they manage a greater proportion of patients. The reason for this approach is that it is difficult to increase the proportion of individuals achieving any of the given targets as the mix of patients becomes more complex.

Most patients with type 2 diabetes can be managed in primary care, with referral along the care pathway to the intermediate diabetes team or direct to the specialist team in a hospital setting, according to clinical need. Patient choice must be included in the commissioning arrangements for diabetes care. This will require some local form of recompensing for community services to ensure that when patients want to access a diabetes service in a different location, funds still flow to that service. This would also be the case if GPs were to provide a service to patients registered with other practices.

Recommendation three

PCTs should put mechanisms in place to support and reward primary care professionals for delivering high-quality care at tiers one and two.
11.4 Establishing an intermediate diabetes team

Establishing an intermediate diabetes team in every borough is fundamental to implementing the model of care for adults with diabetes. The team will

- support primary care professionals to provide tier one and tier two care;
- act as trainers and facilitators;
- provide tier two care where required.

The team will also

- support the development of high-quality primary care services;
- ensure ongoing accreditation of primary care providers;
- manage complex cases that do not need to be seen in an acute setting;
- provide a clinically secure mechanism for outpatient care from the acute sector to the community and primary care settings.

The number of staff required in the team will vary according to the number of patients relocated from the acute sector and the pattern of tiers one and two delivery in primary care and community settings. It is not possible to give definitive guidance on the number of whole-time equivalent roles needed in each category on a pan-London basis. PCTs will need to determine this locally with their service providers.

Different elements of the team may be managed either by the provider arm of the PCT (or an autonomous provider organisation), a community service provider or by an acute trust. It is important to build integrated daily working, and consistent and clear clinical and managerial governance arrangements into service agreements.

Commissioners should ensure that sufficient expertise is available to provide the infrastructure of the intermediate care team and that it includes specialised staff, such as specialist diabetes dieticians.

Recommendation four

Every PCT or network should have an appropriately resourced intermediate diabetes team to facilitate and support primary care. The intermediate diabetes team should comprise the following professional expertise:

- consultant diabetologist;
- nurse specialist or nurse consultant;
- GP champion or lead;
- podiatrist;
- dietician.

And ideally:

- psychologist;
- pharmacist.

It should be clinically-led by the GP champion, consultant diabetologist and nurse specialist.
11.5 Retention of specialist skills in acute providers

Patients with more complex care needs will be cared for in the acute sector. Acute services will continue to be funded through the payment by results (PbR) mechanism. The PbR tariffs were originally assessed on the basis of clinical dependency levels and have been uplifted annually since their introduction. Consideration will need to be given to appropriately reimbursing providers who no longer see the full case-mix of diabetes outpatients and, at the same time, have higher clinical demands due to the condition of the patients that are referred to secondary care.

Commissioners should ensure integrated working along the care pathway so that there is full collaboration between the acute providers and those in primary and community settings. This collaboration needs to include lateral networking across tier four, ensuring local consultant staff receive support and professional development from other professionals.

It has not been possible to accurately estimate the level of funding that should be applied to the shift in care. Local PCTs and providers will need to negotiate the pace of change and the additional funding required to support specialist-level acute service provision. This process will be facilitated by creating six sector-based commissioning centres, where a consistent funding model will be applied for acute organisations providing services to a number of PCTs.

It is essential that specialist skills are maintained in the acute setting so patients with complex diabetes needs can be managed effectively. Joint working with other specialties such as maternity, paediatrics, renal and general medicine is also supported. Support for diabetes inpatients also needs to be developed and maintained.

Recommendation five

In the absence of new national tariffs, PCTs should negotiate a local uplift with acute providers that reflects:

- the rate of movement of outpatient-based activity to community and primary care services;
- the negotiation of support from acute-based specialists to the whole care pathway in terms of clinical governance, professional education and direct patient care delivery;
- the funding of possible joint appointments across organisations to support the pathway.

Recommendation six

PCTs should share a common approach to commissioning acute diabetes services across the organisational boundaries shared with acute providers.
11.6 Education for people with diabetes

Across London, less than 20% of people with diabetes attend user-education and self-management workshops. The user group reported that poor access to education was a significant issue. In some parts of London there is restricted access to patient education, so only a proportion of newly-diagnosed people have access to services – resulting in a long waiting period.

There are well-established education programmes available, notably DESMOND and DAFNE (see appendices 10 and 11), and commissioners should also consider using patient segmentation techniques, as used in social marketing, to assess the particular needs of their diabetes population. Section 2.2 outlines the levels of access to education in each PCT in 2006/07.

No area in London performs well on diabetes education and some face particular challenges from a population with many different cultural needs. Commissioners need to address local issues and improve access to education. Local user groups and expert patient programmes will be helpful in informing, shaping and possibly delivering education. Specific focus should be given to engaging hard-to-reach groups, particularly those related to different ethnicity, culture and deprivation. The third sector may be another source of education provision.

Recommendation seven

PCTs should work together to commission sufficient, quality-assured and appropriate education and training programmes to ensure all people with newly-diagnosed diabetes are offered access to such programmes within three months of diagnosis. Take-up rates should increase to at least 50% by 2010/11.
11.7 Raising the bar on performance

The case for change sets out London’s poor performance on a range of diabetes indicators compared with the rest of England. The indicators are markers of likely disease progression and of serious future clinical complications. The negative impact of poorly-managed diabetes on commissioning budgets will be increasingly significant for PCTs, as the demand for services and complication rates involving expensive treatments increases.

It is important that needs across the whole care pathway are considered in commissioning diabetes services. Resources must not be shifted from one part of the care pathway to another where this may have an adverse effect on the quality of care.

11.8 Services for children and young people with diabetes

Commissioners should consider creating sector-wide networks for services for children and young people with diabetes, where services are not already organised in this way. A network approach will enable clinical expertise to be shared in a number of professional fields, a joint out-of-hours rota, and sharing of protocols and learning.

Recommendation eight

Services for children, adolescents and young adults should be specifically commissioned and PCTs should consider establishing sector-wide networks for these services.
12 Funding diabetes services

The diabetes commissioning model on page 62 outlines available funding mechanisms. Individual PCTs will need to interpret this model according to their existing approach to funding primary and community care services. This guide describes a funding approach that will deliver the new model of care. The practicality of adopting a pan-London care pathway funding approach from 2009/10 was considered and its development was informed by the Department of Health.

12.1 Barriers to care pathway funding in 2009/10

Establishing a pan-London approach to funding care pathways was considered impractical for the following reasons:

1 Outpatient activity recording

Recording diabetes-related outpatient activity varies under endocrinology, diabetology and general medicine specialties in acute centres and it is not possible to differentiate diabetes specific activity with any degree of accuracy. As a movement of diabetes activity from acute settings to community and primary care settings is anticipated, an appropriate first step will be to establish a systematic recording process across all PCTs and service providers in 2009/10 to inform the possibility of care pathway funding from 2010/11 onwards.

2 Community-based activity

Similar to outpatient activity, direct diabetes care may be recorded under different specialties. This may vary according to who sees the patient – it may simply be a ‘head-count’ in a block contract (especially for care provided by allied health professionals such as dieticians or podiatrists) or may not be recorded at all.

3 Hospital-based inpatient care

Inpatient care is recorded more accurately as PbR funding relies on the existence of a rigorously-recorded patient episode. However, admissions as a result of the complications of diabetes are often not recorded as such, even though the condition can be added as secondary information. This means that the extent to which expensive care for renal disease, cardiac disease, blindness and surgery for amputations as a complication of diabetes cannot be estimated with accuracy at present.

According to the Department of Health, information collection on activity in a community setting needs to be systematically improved before it can be used to establish community-based tariffs for activity on a national basis. Early indications from the Department of Health are that there will be a national tariff for community-based diabetes care that could be incorporated into a

Recommendation nine

A systematic approach to data collection should be incorporated in service agreements with providers across all PCTs or networks in 2009/10.
locally-defined care pathway tariff in the next two to three years. PCTs in London may pilot or shadow-monitor a locally-estimated tariff for defined elements of the diabetes care pathway – but they would need to establish a rigorous approach to data collection during 2009/10.

12.2 Funding mechanisms

Before a national tariff is established, or accurate care pathway tariffs are available, funding a whole diabetes care pathway is not possible without inherent risk. A pragmatic approach to funding the service over the next two to three years is suggested on the following page and will vary according to the tier of care (figure 17).

Any service agreement will need to be outcomes-based, using PCT-wide targets to inform the outcomes for different parts of the care pathway. As a general principle, remuneration for both the practice and intermediate diabetes team should be based on the proportion of care that is being delivered in the practice and community setting – and on demonstrating appropriate skills and competence to deliver the level of care and measures of quality. An exemplar LES is available in appendix 9 and basic service specification for generic diabetes care is available in appendix 3.

It is expected that all GP practices will achieve tier one status by 2010/11, with appropriate training and support from the intermediate diabetes team – and that a proportion will have reached tier two. Practices that cannot offer essential care to acceptable standards by 2010/11 (as monitored through governance and performance management measures), should not manage care of people with diabetes.

12.3 Polyclinic approach to costing services

Healthcare for London’s polyclinic project has produced a tool for costing services to be relocated to a polyclinic for use by PCTs. This tool can be used to define diabetes care costs in a community or primary setting. This approach is appropriate for moving diabetes services from an acute setting to a community environment and may be adopted by PCTs ahead of a national tariff, where a more sophisticated approach to funding services is desired than the existing methods allow. We recommended that PCTs revisit the polyclinic costing guidance.

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32 Polyclinics financial modeling tools were provided to all commissioners in London.
<table>
<thead>
<tr>
<th>Tier</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Essential care</td>
<td>GMS/PMS contract and QOF payment mechanism, as current.</td>
</tr>
<tr>
<td>Tier one</td>
<td>GMS/PMS contract and QOF payment as per essential care, plus additional LES funding upon successful delivery against conditions and targets set out in local LES for tier one diabetes care.</td>
</tr>
<tr>
<td>Tier two</td>
<td>GMS/PMS contract and QOF payment as per essential care plus additional LES funding upon successful delivery against conditions and targets set out in local LES for tier two diabetes care or service level agreement (SLA) with community service providers (whether PCT, APO, independent sector, acute trust or third sector) for direct patient service provision where delivery by parts of primary care is not possible.</td>
</tr>
<tr>
<td>Tier three</td>
<td>SLA with community service providers (whether PCT, APO, independent sector, acute trust or third sector) for direct patient service provision in a community setting (for patients not appropriately managed in tier one and two) and to include direct education and facilitation for primary care staff.</td>
</tr>
<tr>
<td></td>
<td>In addition, a separate arrangement with acute providers to deliver clinical governance, education and training, some patient support in community, and advice to primary care.</td>
</tr>
<tr>
<td></td>
<td>Alternatively, this element may be included in community service provider SLA funding and sub-contract arrangements between community and acute providers, or vice versa, if community services are provided entirely from an acute trust. The contractual arrangement will depend to a great extent on which organisation employs the staff who work in the community-based service.</td>
</tr>
<tr>
<td>Tier four</td>
<td>All direct patient activity paid for via PbR mechanism. Additional funding will have been negotiated to cover tier three responsibilities carried out by acute clinicians. Local negotiation must include recording diabetes on HES records, even if the patient is admitted under another specialty for a non-related reason. Expansion of requirements for managing inpatients with diabetes admitted for any reason are set out in the National Diabetes report, <em>Improving emergency and inpatient care for people with diabetes</em>.</td>
</tr>
</tbody>
</table>

Figure 17: Tier funding mechanisms
12.4 Recording information to support commissioning

PCTs are striving to deliver world-class commissioning, emphasising the need for information-driven commissioning. The model of care for diabetes and the implementation requirements are generally compatible with world-class commissioning. However, information to support diabetes care commissioning needs to improve in the short-term.

PCTs in London are required to disaggregate ‘diabetes’ from the ‘other medicines’ category of world-class commissioning finance and activity planning. As a result, Healthcare for London workstreams are now identified separately on London submissions and PCTs are expected to assess the future level of activity and funding for diabetes provision. Through the contracting process, commissioners will develop mechanisms with providers to ensure more accurate recording of diabetes activity in future. This approach has been developed by NHS London to link strategic change to investment and activity shifts, and to monitor the direction of travel.

Commissioners and providers will need to have a clearer understanding of activity and costs associated with diabetes in approaching a national piece of work to produce specific diabetes tariffs for different settings or parts of the care pathway.

Read codes to support monitoring of tiers one and two delivery by primary care providers are set out in the exemplar LES for local adaptation at appendix 9. These are 66AS (annual review completed) and 66AP (diabetes practice programme). Read codes for the setting of care should be recorded electronically (66AU – hospital; 66AP – GP practice or 66AQ – shared care). The international classification of disease (ICD) coding system for inpatient activity offers an extensive range of codes for diabetes in its various presentations. However, where diabetes is not the primary reason for admission it is often not recorded, even if it is the underlying cause (for example in renal disease). As the existing information on HES records is incomplete, it is not possible to predict the rates of complications as a direct result of diabetes. In establishing the new model of care and care pathways, it is important to monitor the impact of managing the disease and rate of progression on clinical complications. This will be important underpinning information if, in future, an accurate care pathway funding approach is required.

Recommendation 10

Service agreements with acute providers should include recording diabetes on HES records, even if the patient is admitted under another specialty for a non-related reason.
13 Performance issues

13.1 Diabetes proxy indicators
The range of proxy indicators most commonly used to assess performance is the QOF assessment mechanism for primary care provision. Data is submitted annually and is used nationally to benchmark delivery. This indicator set was used to inform the case for change.

Each of these indicators has relevance to patient care; however those that are most critical to patient management have been identified, acknowledging that it is not practical to focus on the full range of indicators here in equal depth on a day-to-day basis.

13.2 Key measures of clinical quality
Establishing a London-wide target for PCTs will reduce health inequalities across London. PCTs should view the performance target as one for the whole PCT, not for individual practices.

The upper 25th centile of the all-England performance for 2006/07 should be applied, in principle, to those indicators that have the most critical relevance to management of diabetes. It should also be noted that the level of exception reporting varies significantly in, and between, PCTs on QOF monitoring of diabetes proxy indicators (see appendix 12).

PCTs should observe a maximum exception reporting limit of three per cent in each PCT, acknowledging acceptable variations between practices. Where practices are reporting exceptions beyond the three per cent maximum, the PCT should work with the practice to understand the reasons behind it and to introduce measures to reduce it where possible.

The results for the set of diabetes indicators for 2006/07 are provided for each PCT in London at appendix 13.

The exemplar LES (appendix 9) uses the PCT-wide targets. PCTs may wish to set individualised targets for each practice, depending on their starting point. For an example of how a PCT has approached setting differential targets for practices see appendix 14.

Commissioners should note that from 2009/10, the way that blood glucose is measured and recorded may change by national agreement. If this occurs, service specifications will need to reflect this change (see appendix 15). People with diabetes will need to receive education to understand the new system for monitoring their condition.

As outlined in the model of care (chapter two), below are key measures of clinical quality in assessing diabetes care overall. These targets are based on QOF indicators. PCTs are advised to use performance at the upper 25th centile as the minimum target for care to be achieved whilst maintaining an average maximum exception reporting limit of three per cent in the PCT.

1. blood pressure less than 145/85 mmHg (DM 12) minimum 80% achievement by 2010/11;
2. HbA1c less than 7% (DM 23, previously 7.5% DM 20). Note that at 2006/07 levels, the national upper 25th centile was equivalent to 71% of patients achieving HbA1c of 7.5% or less.
PCTs should perform-manage the following additional measures of clinical quality:

- number of patients who have their blood pressure measured and who also have HbA1c measured (ideally should be the same number);
- by 2010/11, 90% of those who are eligible for and offered retinopathy screening should attend;
- the gap between recorded prevalence versus estimated expected prevalence should be reduced by half in each PCT by 2010/11;
- all newly-diagnosed patients should be offered structured education within three months of diagnosis and at least half to attend by 2010/11.

Some of these measures are monitored at present. Data on the numbers of people on the diabetes register who have had blood pressure and HbA1c screening recorded are readily compared via the QOF process.

Retinopathy screening is also recorded. The recorded prevalence and estimates of expected prevalence are available from sources such as QOF submissions, LHO and the Yorkshire and Humber Public Health Observatory (YHPHO). Recorded patient education activity is not standardised and in many areas does not happen at all. Education for users and carers is very important, and PCTs must put systems in place to capture the numbers offered structured education, within what period following diagnosis and the percentage taking it up.

Please note: New proposals from the Department of Health for reviewing clinical indicators in the QOF were subject to public consultation in 2009. The outcome of the consultation may impact on indicators from April 2009.

The key measures of clinical quality set out in this section will be reviewed once any changes to QOF indicator designation are known.

Recommendation 11

PCTs should attain the following levels of achievement in the key QOF measures of diabetes clinical quality by 2010/11, while maintaining a maximum exception reporting limit of three per cent across the PCT:

- blood pressure less than 145/85 mmHg (DM 12) minimum 80%;
- HbA1c less than 7% (DM 23).

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33 The latest comparative analysis of performance against these indicators is due to be published on the Yorkshire and Humber Public Health Observatory website.

34 www.yhpho.org.uk
13.3 Key measures of diabetes outcomes

The following measures are of key importance, especially when used over the longer term to assess effectiveness of disease management:
- number requiring renal replacement therapy;
- number with loss of vision attributable to diabetes;
- number with amputation attributable to diabetes.

PCTs must ensure that service agreements with providers record attribution to diabetes where appropriate in HES data. As accurate baseline data does not currently exist, PCTs will be expected to use the first year of data collection as the baseline year and assess progress against this baseline in successive years.

13.4 London-wide monitoring

Working with the newly-formed commissioning for quality network London, PCT commissioners and NHS London, 10 key priority indicators have been developed to reflect all Healthcare for London workstreams. For diabetes, there will be one key aggregate indicator to reflect an overarching measure of clinical quality, which is an amalgam of two of the clinical quality indicators:
- The number of people with diabetes in primary care with HbA1c less than 7% and blood pressure less than 145/85 mmHg in the top 25th centile of national performance on QOF scores.

Another reflects diabetes outcomes, and is an amalgam of two of the diabetes indicators:
- All HES data on renal replacement therapy and amputation to include attributing co-morbidities to the primary presentation.

The third reflects the introduction of PROMS pilots for long-term conditions (to include diabetes):
- All NHS organisations eligible to take part in the long-term condition PROMS pilot to take part in the study.

Performance against the London-wide indicators will be monitored and regularly reported to the CQN and a pan-London diabetes board.

Recommendation 12

PCTs, through the commissioning process, should work with acute providers to improve and standardise the recording of diabetes as a co-morbidity on HES systems. This will allow PCTs to assess numbers of diabetic patients requiring renal replacement therapy and amputation attributable to diabetes in order to establish a baseline by 2010, against which they monitor progress in successive years. PCTs should work with local authorities to set up systems for assessing the numbers of people with visual loss attributable to disease.
13.5 Acknowledging variations in performance

As outlined in the case for change, there is significant variation across London in performance on diabetes indicators. As PCTs will each start from a different baseline, it will be more challenging for some PCTs to reach the upper 25th centile (the minimum target for performance) for some indicators by 2010/11.

There is also a variation in performance of GP practices within a PCT. Figure 18 illustrates the range of practice results for one diabetes indicator. Due to the different starting points of practices, PCTs may choose to set differential targets for the first one to two years of monitoring. As well as accommodating different starting points for practices, PCTs need to support those practices with particular needs or which have a challenging task in delivering the outcomes required. The possibility of decommissioning diabetes care should only be considered if, after the PCT has given intensive support and training, performance fails to improve sufficiently.

Governance arrangements should be established across the pathway.

Figure 18: Example of spread of results for individual practices by PCT – DM 7 (percentage of people with diabetes having neuropathy testing)

Each circle is one practice in a PCT. For a full set of data underpinning these charts see appendix 13.
14 Next steps

14.1 Workforce and education group

Workforce for London – A Strategic Framework published by the People and Organisational Development (POD) directorate of NHS London in September 2008 recognised the directorate’s role in supporting programmes such as Healthcare for London, and in the ongoing development of both the existing and future workforce. The POD directorate will establish an ongoing support programme to develop the workforce to meet the needs for diabetes care in local health communities. The workforce plans will be created in partnership with commissioners of education and workforce development.

This work will inform development of the professional education and accreditation aspects of local enhanced service (LES) agreements. POD will take responsibility to develop London-based courses, these will include care planning as a foundation skill throughout 2009/10. In the interim, professional education should be accessed via existing mechanisms (see appendix 16).

14.2 Care planning – Year of Care and Co-creating Health

Year of Care and Co-creating Health are approaches to diabetes care planning that are being piloted in various parts of the UK. Care planning will be an essential component of care for those with long-term conditions by 2010, and should be considered as part of planning the implementation of the new diabetes model from 2009/10. Learning arising from these approaches, and Department of Health guidance, should inform commissioning. A pan-London diabetes board will consider the outcomes of these projects to inform delivery of care planning in future.

14.3 Patient reported outcome measures (PROMs) pilots

Diabetes will be included in the Department of Health’s pilot phase of the development of PROMs from 2009. PCTs will be offered the opportunity to take part in the pilot, which is to be co-ordinated by NHS London. To date, PROMs have largely been applied to assess the impact of elective interventions from a patient’s perspective. Developing PROMs to assess the impact of long-term conditions and their management will require a considered approach. The pilot phase of PROMS will inform future planning for long-term conditions across London. National Diabetes is also piloting a project in London on patient outcomes.

14.4 National Diabetes’ London-based website ‘Noticeboard’

National Diabetes will host a website as an information exchange for all those involved in providing or commissioning diabetes care in London. This will provide a platform to connect those who have developed innovative approaches to care delivery, are doing formalised research, or those who want specific information, in a quick and simple way.
14.5 London clinical and business support agency

London PCTs are establishing an organisation called Commissioning Support for London (CSL) from April 2009. This organisation will incorporate a variety of commissioning support functions, together with the Healthcare for London programme. Currently, individual PCTs have their own diabetes performance data based on quarterly QOF reporting and quarterly acute activity reporting. National benchmarked data from the QOF process is not available until at least six months after the end of the financial year. In order to have more accessible data, and compare progress across London in a way that is more closely aligned to ‘real-time’, the CSL will need to produce pan-London reports on diabetes performance and activity. This will enable debate about progress in different parts of London and shared learning on what works and what does not work.

14.6 Pan-London diabetes board

Currently there is no mechanism for overseeing diabetes care across London. There is a clear need for a forum that enables providers and commissioners to come together to assess how the development of diabetes care is progressing, informed by activity and performance data. There are other potential advantages – including monitoring performance across London, driving best practice and high-quality care pathways through local clinical networks, providing opportunities for sharing best practice, learning from different experiences and identifying where a pan-London intervention by PCTs or NHS London is required. In addition, each of the areas of developmental work in this section of the commissioning guide will require pan-London co-ordination.

An early issue for the pan-London diabetes board would be establishing sector-wide paediatric diabetes support networks to provide out-of-hours expertise 24 hours a day, seven days a week. At present there is insufficient specialist expertise available in individual organisations to deliver this type of service. A focus on the management of fertile women with obesity and/or diabetes is also required.

Recommendation 13

Regular reporting should be conducted on diabetes activity, QOF and quality data to monitor the performance of PCTs, with results fed back to local clinical networks and PCTs.

Recommendation 14

PCTs should approve the creation of a pan-London diabetes board.

35 www.diabetes.nhs.uk
36 www.health.org.uk
1 PCTs are advised to adopt the Healthcare for London diabetes model of care and use it to inform the commissioning of local diabetes services, recognising the importance of collaboration, networks and service integration along the care pathway. They are also advised to designate an executive director to oversee this work.

2 PCTs should adopt the generic diabetes care pathway and care pathways for specialised care as set out in the appendices accompanying this commissioning guide, adapting them for local use where necessary.

3 PCTs should put mechanisms in place to support and reward primary care professionals for delivering high-quality care at tiers one and two.

4 Every PCT or network should have an intermediate diabetes team to facilitate and support primary care. This team should comprise the following professional expertise:
   - consultant diabetologist;
   - nurse specialist or nurse consultant;
   - GP champion or lead;
   - podiatrist;
   - dietician.
   And ideally
   - psychologist;
   - pharmacist.
   It should be clinically led by the GP champion, consultant diabetologist and nurse specialist.

5 In the absence of new national tariffs, PCTs should negotiate a local uplift with acute providers that reflects:
   - the rate of movement of outpatient-based activity to community and primary care services;
   - the negotiation of support from acute-based specialists to the whole care pathway in terms of clinical governance, professional education and direct patient care delivery;
   - the funding of possible joint appointments across organisations to support the pathway.

6 PCTs should share a common approach to commissioning acute diabetes services across organisational boundaries shared with acute providers.

Summary of recommendations
7 PCTs should work together to commission sufficient, quality assured and culturally-appropriate education and training programmes to ensure all people with newly-diagnosed diabetes are offered access to such programmes within three months of diagnosis. Take-up rates should increase to at least 50% by 2010/11.

8 Services for children, adolescents and young adults should be specifically commissioned and PCTs should consider establishing sector-wide networks for these services.

9 A systematic approach to data collection should be incorporated in service agreements with providers across all PCTs or networks in 2009/10.

10 Service agreements with acute providers from 2009/10 should include recording diabetes on HES records, even if the patient is admitted under another specialty for a non-related reason.

11 PCTs should attain the following levels of achievement in the key QOF measures of diabetes clinical quality by 2010/11:
   - blood pressure less than 145/85 mmHg (DM 12) minimum 80%;
   - HbA1c less than 7% (DM 23).
   This is to be achieved while maintaining a maximum exception reporting limit of three per cent across the PCT.

Note: Targets will be revisited by the pan-London board if the current QOF targets change for 2009/10.

12 PCTs, through the commissioning process, should work with acute providers to improve the recording of diabetes as a co-morbidity on HES systems. This will allow PCTs to assess numbers of diabetic patients requiring renal replacement therapy and amputation attributable to diabetes in order to establish a baseline at the end of 2009/10, against which they monitor progress in successive years. PCTs should work with local authorities to set up systems for assessing the numbers of people with visual loss attributable to disease.

13 Regular reporting should be conducted on diabetes activity, QOF and quality data to monitor the performance of PCTs; with results fed back to local clinical networks and PCTs.

14 PCTs should approve the creation of a pan-London diabetes board.
Appendix 1
London Health Observatory analyses of diabetes prevalence, future projections, mortality and screening

Appendix 2
Diabetes user group: priorities for action

Appendix 3
Case study: Diabetes intervention and prevention programme

Appendix 4
Diabetes care pathways

Appendix 5
Improving emergency and inpatient care for people with diabetes

Appendix 6
Metrics for diabetes

Appendix 7
Integrated pathway outline care map

Appendix 8
Localising care pathways

Appendix 9
Local enhanced service (LES) agreement – exemplar

Appendix 10
Delivering the national education programme, DESMOND – diabetes education and self-management for ongoing and newly-diagnosed

Appendix 11
Delivering DAFNE – dose adjusted for normal eating – course

Appendix 12
Diabetes indicators including and excluding exceptions

Appendix 13
Diabetes indicators for PCTs in London

Appendix 14
Setting differential targets for practices

Appendix 15
Reporting on glycated haemoglobin

Appendix 16
Education for primary care health professionals in diabetes care

Other examples of diabetes models of care, on which this guide is based, are available. These include Bolton PCT, Leeds PCT, NHS Scotland, Cumbria, Bexley Care Trust, Enfield PCT, Tower Hamlets PCT and NHS Westminster.