



**Essex County Council, Thurrock Borough
Council, Southend-on-Sea Borough Council
Health Overview and Scrutiny Committees**

Scrutiny Review: Implementing the Diabetes National Service Framework

November 2006

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Contents

Key Findings	1
1 Introduction	6
1.1 Diabetes	6
1.2 National Service Framework for Diabetes	7
1.3 National Diabetes Support Team	9
1.4 Wider Context.....	10
1.5 Objectives of this Scrutiny Review	11
2 Our Approach	11
3 Findings	12
3.1 Building Capacity: Developing Diabetes Networks.....	12
3.2 Prevention of Type 2 diabetes.....	14
3.3 Identification of people with diabetes.....	15
3.4 Empowering people with diabetes	17
3.5 Clinical care of adults with diabetes	19
3.6 Clinical care of children and young people with diabetes	22
3.7 Management of diabetic emergencies.....	24
3.8 Care of people with diabetes during admission to hospital.....	25
3.9 Diabetes and pregnancy	26
3.10 Detection and management of long-term complications.....	28
Appendix One: What is Diabetes?	31
Appendix Two: Public engagement and witness sessions	33
Appendix Three: National screening for diabetes	35

Appendix Four: Structured Patient Education in Diabetes	37
Appendix Five: Emerging Technologies.....	40
Appendix Six: Documentary Evidence	43
Appendix Seven: Glossary	47

Executive Summary

It is estimated that up to 12,600 people in Essex may have undiagnosed diabetes and that up to 45,000 residents in the county are living with diabetes, with the figure set to rise due to an increase in obesity.

Diabetes is a long-term condition, which has far reaching implications for people living with it and their families and carers. Average life expectancy is reduced in people with Type 1 diabetes by at least 15 years and by 5 years for men and 7 years for women with Type 2 diabetes¹.

The exact cost of diabetes to the NHS is unknown but it is likely to cost the Essex health economy between 5-10% of NHS expenditure and at least 10% of NHS hospital expenditure.

The Essex, Southend-on-Sea and Thurrock Health Overview and Scrutiny Committees have carried out a review of diabetes services in Essex involving NHS staff, patients and diabetes experts. This report sets out their key findings and recommendations for improving services in the county.

Key Findings

A number of key findings have emerged from the review. The views of patients and those working to deliver diabetes services underpin these findings.

Prevention and Diagnosis

The number of people living with type 2 diabetes is expected to rise and up to 12,600 people in Essex may already have developed it and not yet been diagnosed.

The panel identified some gaps across the county in the prevention and diagnosis of diabetes. In particular they are concerned that:

- There is a need to raise the public awareness of diabetes, its symptoms and effects;
- Screening of high risk groups should be offered and there is a need to review the case for an opportunistic screening/national screening programme; and
- Prevention programmes should explicitly link with obesity strategies, and physical exercise and heart disease.

¹ YPHO Yorkshire and Humber Public Health Observatory, Diabetes: *key facts*. March 2006 available at www.diabetes.nhs.uk/downloads/YHPHO_Diabetes_key_facts.pdf

Information & Education

Structured education is essential for people with diabetes to improve their knowledge, skills and confidence to enable them to self manage their condition. It is central to improving patient care and a cost effective intervention in terms of delaying or preventing some of the complications that can occur in people living with diabetes. There are several examples of good patient education programmes across the county but the panel had some concerns:

- That not all areas have structured education programmes underway;
- That programmes did not recognise the need to deliver education in different ways to suit individual learning styles;
- That there was not sufficient capacity and resourcing to provide education for all those who could benefit; and
- That further work is needed to roll out patient held records in all areas.

Children's Services

The panel recognise that there are some good examples of children's services including a DVD for teenagers living with type 1 diabetes that was developed in Mid Essex and the clinic for adolescents in Colchester. However, serious concerns were raised across the county by parents, and healthcare professionals. Areas identified as needing further development included:

- Recruitment and retention of Paediatric Diabetic Specialist Nurses;
- Out of hours and emergency care;
- Support for parents and carers;
- Access to psychology, podiatry, and education services;
- Support during transition to adult services; and
- Work with schools.

Hospital Care

A number of patients raised concerns about the standard of hospital care for people living with diabetes. The panel was pleased to learn that networks are planning to improve hospital care and that some are already training hospital staff and providing access to link nurses and dietitians. However, concerns remain that patient care is sometimes compromised, leading to longer hospital stays, by:

- Not recording diabetic status of patients;
- Inappropriate food and medication regimes;
- Lack of knowledge about diabetes among hospital staff; and
- Lack of information to patients.

Funding and Capacity

Patients and NHS staff raised concerns that the capacity of some services was not sufficient to meet the needs of all patients. In addition to patient education and paediatric services there were particular concerns about equitable access to the following services:

- Psychologists;
- Dietitians;
- Podiatry; and
- Diabetes Specialist Nurses (DSNs)

Key Recommendations

The panel is proposing the following recommendations:

	Lead Responsibility	Monitoring arrangements	Commissioners	Providers	Public Health	Patient's Groups	LEA	Joint activity	Networks ²
Prevention & diagnosis									
Raise awareness of diabetes, explicitly linking it to obesity, exercise and heart disease.	Networks	To be confirmed	✓	✓	✓	✓	✓	✓	✓
Ensure screening is available on self-referral.	Commissioning organisations	To be confirmed	✓	✓					✓
Introduce screening for relatives and high-risk groups	Commissioning organisations	To be confirmed	✓						✓
Lobby the Department of Health to review the case for opportunistic screening or a national screening programme.	Networks	To be confirmed	✓		✓	✓			✓

² There are 5 diabetes networks in Essex responsible for ensuring the implementation of the *National Service Framework for Diabetes*.

	Lead Responsibility	Monitoring arrangements	Commissioners	Providers	Public Health	Patient's Groups	LEA	Joint activity	Networks
Information and education									
Expand capacity for patient education	Commissioning organisations	To be confirmed	✓						
Improve the availability of information for families and carers	Commissioning organisations	To be confirmed	✓	✓					
Ensure basic information about diabetes is available at the point of diagnosis for all patients	Commissioning organisations	To be confirmed	✓	✓		✓			
Clinical care of adults with diabetes									
Clear plans should be developed to address any gaps in capacity, including in podiatry, psychology, and dietetics	Commissioning organisations	To be confirmed	✓	✓	✓	✓	✓	✓	✓
Develop Essex care pathways	Networks	To be confirmed	✓	✓	✓	✓		✓	✓
Develop commissioning arrangements to ensure that service improvements are effectively delivered	Commissioning organisations	To be confirmed	✓						
Expand provision of appropriate training for NHS staff	Networks	To be confirmed	✓	✓					

	Lead Responsibility	Monitoring arrangements	Commissioners	Providers	Public Health	Patient's Groups	LEAs	Joint activity	Networks
Children and Young People									
Establish an Essex County wide working group to identify areas for improvement and a timetable for action	Networks	To be confirmed	✓	✓	✓	✓	✓	✓	✓
Ensure that schools raise awareness of diabetes as part of their work to promote healthy lifestyles.	LEAs	To be confirmed	✓	✓	✓		✓		
Ensure school nurses can deliver consistent quality information about diabetes	Commissioning organisations	To be confirmed	✓	✓	✓	✓	✓	✓	✓
Care of people with diabetes during admission to hospital									
Improve quality of hospital care to ensure fewer complications for patients with diabetes (and, potentially shorter hospital stays).	Commissioning organisations	To be confirmed	✓	✓		✓			✓

The panel recognises that the current changes in the NHS, particularly PCT and SHA reorganisation will impact on the speed with which these recommendations can be implemented. They will request an action plan from each network by December 2006 with a view that significant progress will be made by June 2007.

1 Introduction

1.1 Diabetes

In Essex County, as nationally, around 3% of the population, up to 45,000 people are living with diabetes³. This figure is expected to grow, fuelled by a rise in obesity. Diabetes is a long-term condition, which has far reaching implications for people living with it and their families and carers (see **appendix one**). These range from the need to adopt a suitable diet to possible long-term complications such as aggravated coronary heart disease, blindness or amputation. Average life expectancy is reduced in people with Type 1 diabetes by at least 15 years and by 5 years for men and 7 years for women with Type 2 diabetes⁴. There is also an inevitable impact on the families of people with diabetes. The cost of diabetes to the NHS is unknown but it is likely to cost the Essex health economy between 5-10% of NHS expenditure and at least 10% of NHS hospital expenditure⁵.

Figure 1 below shows recent diabetes prevalence figures for PCTs in the Essex SHA area.

Prevalence of diabetes

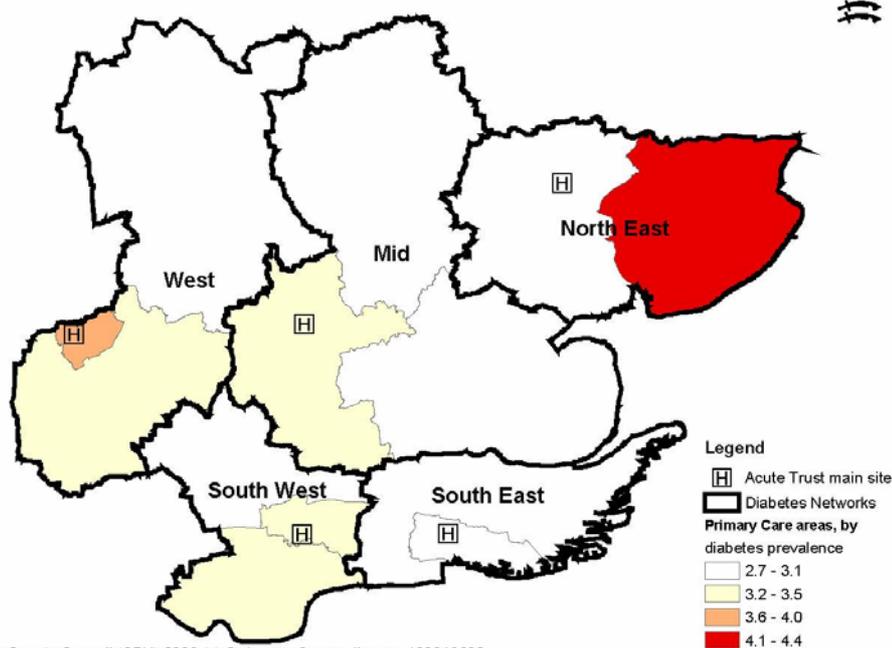


Figure 1: Prevalence of Diabetes in Essex County⁶

The highest prevalence is in Tendring at 4.4%, this is likely to be due to the high proportion of older people in this area. The lowest figures are for

³ See *Local Delivery Plan 2004/2005*. Essex Strategic Health Authority at www.essex.nhs.uk/documents/framework/localdeliveryplanjune04.pdf

⁴ YPHO Yorkshire and Humber Public Health Observatory, *Diabetes: key facts*. March 2006 available at www.diabetes.nhs.uk/downloads/YHPHO_Diabetes_key_facts.pdf

⁵ See for example www.diabetes.org.uk/infocentre/reports/in_the_UK_2004.doc.

⁶ Data from: Quality and Outcomes Framework (QOF) for April 2004 - March 2005, England. Numbers on QOF disease registers, and unadjusted prevalence rates, by Primary Care Trust

Uttlesford, Basildon PCT and Brentwood, Billericay and Wickford PCTs, all at 2.7% prevalence.

There are serious concerns, nationally and internationally, about the rising number of people diagnosed with type 2 diabetes, the quality of care for people living with diabetes and the growing burden of the disease. There are concerns not just about the implications of the disease for individuals with the condition but also the significant direct and indirect financial implications of the disease.⁷

In England there have been a series of National Service Frameworks (NSFs) looking at health issues such as cancer, and coronary heart disease. These have set out standards for improving services for treating these diseases. The *National Service Framework for Diabetes*⁸ provides the framework for this scrutiny review.

1.2 National Service Framework for Diabetes

In 2001 the Department of Health (DH) published the NSF for Diabetes and, in January 2003, a *Delivery Strategy*⁹. 12 national standards for improving diabetes care were set out in these documents (see figure 2 below).

⁷ World Health Organisation. Diabetes Action Now Booklet. Available at www.who.int/diabetes/BOOKLET_HTML/en/print.html

⁸ Department of Health, *National Service Framework for Diabetes*. 2001. Available at: <http://www.dh.gov.uk/assetRoot/04/05/89/38/04058938.pdf>

⁹ Department of Health, *National Service Framework for Diabetes: Delivery Strategy*. 2002. Available at

National Service Framework for Diabetes Standards to be reached by 2013

1. The NHS will develop, implement and monitor strategies to reduce the risk of developing Type 2 diabetes in the population as a whole and reduce the inequalities in the risk of developing Type 2 diabetes.
2. The NHS will develop, implement and monitor strategies to identify people who do not know they have diabetes.
3. All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, patients and carers should be fully engaged in this process.
4. All adults with diabetes will receive high-quality care throughout their lifetime, including support to optimise the control of their blood glucose, blood pressure and other risk factors for developing the complications of diabetes.
5. All children and young people with diabetes will receive consistently high-quality care and they, with their families and others involved in their day-to-day care, will be supported to optimise the control of their blood glucose and their physical, psychological, intellectual, educational and social development.
6. All young people with diabetes will experience a smooth transition of care from paediatric diabetes services to adult diabetes services, whether hospital or community-based, either directly or via a young people's clinic. The transition will be organised in partnership with each individual and at an age appropriate to and agreed with them.
7. The NHS will develop, implement and monitor agreed protocols for rapid and effective treatment of diabetic emergencies by appropriately trained health care professionals. Protocols will include the management of acute complications and procedures to minimise the risk of recurrence.
8. All children, young people and adults with diabetes admitted to hospital, for whatever reason, will receive effective care of their diabetes. Wherever possible, they will continue to be involved in decisions concerning the management of their diabetes.
9. The NHS will develop, implement and monitor policies that seek to empower and support women with pre-existing diabetes and those who develop diabetes during pregnancy to optimise the outcomes of their pregnancy.
10. All young people and adults with diabetes will receive regular surveillance for the long-term complications of diabetes.
11. The NHS will develop, implement and monitor agreed protocols and systems of care to ensure that all people who develop long-term complications of diabetes receive timely, appropriate and effective investigation and treatment to reduce their risk of disability and premature death.
12. All people with diabetes requiring multi-agency support will receive integrated health and social care.

Figure 2: National Service Framework for Diabetes standards

The Department of Health also set out the rationale for these standards, key interventions and implications for service planning. The NSF is a 10 year plan but there are 2 early national performance targets:

- By 2006, a minimum of 80 per cent of people with diabetes to be offered screening for the early detection (and treatment if needed) of *diabetic retinopathy* as part of a *systematic programme* that meets national standards, rising to 100 per cent coverage of those at risk of retinopathy by end 2007.
- By March 2006, PCTs need to ensure that practice-based registers and systematic treatment regimens cover the majority of patients at high risk of coronary heart disease, particularly those with hypertension, diabetes and a body mass index (BMI) greater than 30¹⁰.

In addition, the National Institute for Clinical and Health Excellence (NICE) has issued guidance on the use of structured patient education programmes and these will need to be introduced across the NHS from 2006¹¹.

A national delivery plan was developed to help local NHS organisations implement the NSF. Establishing diabetes networks underpins delivery of service improvements with NHS organisations being asked to work together to achieve the standards.

It is important to note that the NHS is still in the early stages of delivering the NSF standards and it will take time for the NHS to deliver the necessary service improvements. This report sets out:

- Progress already made across the Essex Strategic Health Authority (SHA) area, particularly in developing networks and strategies for implementing the Diabetes NSF;
- Areas of good practice noted by the panel; and
- Key areas where further development is needed.

1.3 National Diabetes Support Team

The National Diabetes Support Team (NDST) has a complex role as it seeks to work with local organisations, involving both service users and providers, to provide guidance, support and co-ordination to enable effective implementation of the Diabetes NSF. Developing effective relationships with all those in the local diabetes community is an essential requirement if the work is to be carried forward positively and productively. This is underpinned by the NDST promoting an environment and culture of collaboration and team

¹⁰ See *National Service Framework for Diabetes*, Department of Health, at www.dh.gov.uk/assetRoot/04/05/89/38/04058938.pdf.

¹¹ NICE, *Guidance on the use of patient-education models for diabetes*. 2003 Available at <http://www.nice.org.uk/page.aspx?o=TA60>

working with everyone, both service providers and users, to help deliver the NSF. It focuses on three core areas:

- Knowledge;
- Communication; and
- Leadership and organisational development¹².

It provides networks with a range of resources from web forums on issues such as patient education to self-assessment questionnaires. Regional managers work closely with the networks in their area, supporting them in developing the effectiveness of their networks to enable the effective implementation of the Diabetes NSF.

1.4 Wider Context

Efforts to improve diabetes services across the county must be understood in the context of other issues affecting the NHS, particularly recent and ongoing reforms to NHS systems and the recent focus on managing long-term conditions as an effective way of both improving people's quality of life and delivering cost effective services. Issues that will need particular consideration include:

- Patient choice;
- Practice based commissioning;
- Community services White Paper, *Our health, our care, our say*¹³;
- PCT reorganisation;
- Long-term conditions agenda;
- Public health agenda, especially the focus on smoking and obesity;
- Local Delivery Planning; and
- Local Area Agreements.

Improving diabetes services is one of many priority areas for the NHS and the competing demands of different priorities is a challenge for delivering service improvements. Witnesses spoke of financial constraints and concerns of a short-term focus rather than 'investing to save' through funding preventative interventions such as patient education programmes.

¹² See www.diabetes.nhs.uk/The_Team/Core_functions.asp.

¹³ Department of Health (2006) *Our health, our care, our say: a new direction for community services*. Available at www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4127453&chk=NXIecj

1.5 Objectives of this Scrutiny Review

This scrutiny review set out to look at the implementation of the NSF, using the two national targets and the 12 standards as a framework for the project.

Key objectives are:

- To investigate how the NSF for diabetes was introduced and is being delivered across Essex.
- To identify any differences in implementation of the NSF across Essex and what actions are being taken to remedy any deficits in service delivery by the relevant agencies (e.g. NHS organisations, local authorities and voluntary groups).
- To make recommendations for improving delivery of the NSF.

2 Our Approach

Members held a training session on March 2005. Ms Tracy Slater, Regional Manager at Diabetes UK attended this meeting.

The training session was followed by a period of desk based research and interviews with key partners representing the 5 diabetes networks, and the range of services provided.

A short online questionnaire was designed to capture views from people living with diabetes or caring for people living with diabetes. The panel would like to thank all 151 people who completed the questionnaire wrote in to share their experiences of their local diabetes services. Whilst these people may not be representative of patients across Essex County they have helped inform this review and highlighted issues worthy of particular praise or concern.

Members of the panel and supporting officers also attended a number of local meetings to obtain views on diabetes services. The panel held 4 witness sessions to hear evidence from local NHS colleagues and patients representatives. Details of these meetings are set out in **appendix two**.

The panel is particularly grateful for the expert advice that was provided throughout the study by:

- Ms Tracy Slater, Eastern Regional Manager, Diabetes UK
- Councillor Barrie Taylor, Chairman of Westminster Council Health Overview and Scrutiny Committee

A stakeholder workshop was held on 10 March 2006 and attended by over 40 patient representatives and healthcare professionals from across Essex. This

event enabled the panel to test their key findings and begin to develop recommendations.

3 Findings

3.1 Building Capacity: Developing Diabetes Networks

In Essex SHA there are 5 diabetes networks charged with ensuring implementation of the NSF:

- *South West Essex* - Billericay, Brentwood and Wickford (BBW), Basildon, and Thurrock PCTs and Basildon and Thurrock NHS Foundation Trust;
- *South East Essex* - Southend-on-Sea PCT, Castle Point and Rochford PCT and Southend Hospital Trust;
- *Mid Essex* - Witham, Braintree and Halstead Care Trust, Chelmsford and Maldon and South Chelmsford PCTs and Mid Essex Hospital Trust;
- *West Essex* – Uttlesford, Epping Forest and Harlow PCTs and Princess Alexandra Hospital Trust; and
- *North East Essex* - Colchester PCT, Tendring PCT, and Essex Rivers Hospital Trust.

Figure 3 below shows the Essex diabetes networks, current PCT boundaries and location of the acute trusts.

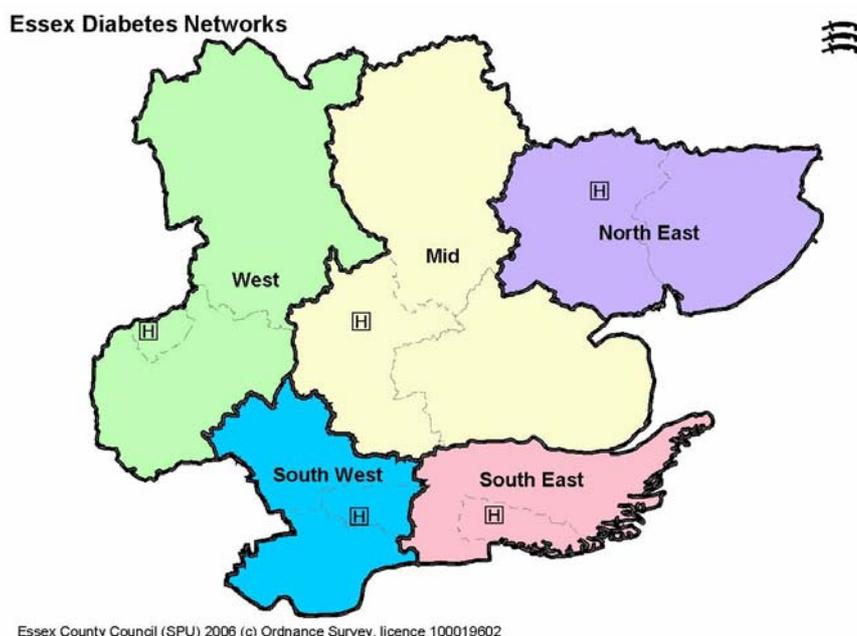


Figure 3: Essex Diabetes Network Boundaries

3.1.1 Examples of good practice

Each network is developing differently according to local needs and historic patterns of resourcing and service delivery. It is clear that there cannot be a 'one size fits all' model for diabetes networks. . From autumn 2006 there will be 5 new PCTs, which will reflect the boundaries and existing working relationships of the 5 networks. This may provide an opportunity to further strengthen diabetes networks and improve their capacity to deliver service improvements in the County. However, there are some particular strengths in the networks:

- The Essex Strategic Health Authority ran a series of themed workshops for network members over the past year. These workshops were provided in conjunction with the NDST in response to requests from the networks.
- Mid Essex has had a Diabetes Clinical Network Manager in post since May 2005. Patients are well represented on the network and the network Chair is also the lead on long-term conditions.
- South East Essex is working hard to engage GPs and has Diabetes as one of its major workstreams within the Long Term Conditions (LTC) Transformation agenda and the nominated project lead is both part of the Network and the LTC transformation group in South East Essex. The Diabetes Strategy sub-group of the Network has become the project group for this workstream.
- West Essex network has close links with the long-term conditions group.
- South West Essex has recently held a network conference involving professionals and service users in looking at aspects of service improvement such as patient held records and patient education.
- North East Essex has 2 diabetes facilitators in place (one each for Colchester and Tendring PCTs). These have been instrumental in developing seamless care between primary and secondary services.

3.1.2 Key areas for development

Each network has developed in response to local pressures, historic patterns of service delivery and the needs of local people. The networks will also face common challenges including:

- Developing relationships within the new NHS structure in Essex;
- Handling constraints in delivering service improvements given the current financial climate in the NHS;
- Developing commissioning arrangements in line with Practice Based Commissioning; and
- Ensuring partners sign up to detailed action plans and deliver their commitments.

3.2 Prevention of Type 2 diabetes

Standard One: *The NHS will develop, implement and monitor strategies to reduce the risk of developing Type 2 diabetes in the population as a whole and reduce the inequalities in the risk of developing Type 2 diabetes.*

Type 1 diabetes cannot be prevented and many of the risk factors for Type 2 diabetes (e.g. increased age, ethnicity, family history) cannot be altered. Family history is a key risk factor with the risk of developing type 2 diabetes increasing 3-fold if one parent is affected, 4-fold if a sibling is affected and 7-fold if both parents are affected¹⁴. Although these risk factors cannot be altered they can help identify people at greater risk, which could ensure earlier diagnosis.

There are also risk factors that can be modified:

- Obesity (Body Mass Index of 30+);
- Large waist circumference - over 80cm for women and over 94cm for men (90cm for South Asian men)¹⁵; and
- Physical inactivity.

The increase in type 2 diabetes reflects the increase in obesity and prevalence could be reduced through effective interventions to tackle obesity.

Reducing obesity is a key area for action identified in *Choosing Health*¹⁶ and is a priority in the Essex Local Area Agreement¹⁷. Each network has identified local obesity strategies as the key mechanism for preventing type 2 diabetes.

Given the links between smoking and increased risk of CHD and other complications from diabetes; smoking cessation programmes can also contribute to the prevention of diabetes related complications.

3.2.1 Key areas for development

Tackling obesity and smoking are *Choosing Health* priorities for each network. They are also priorities in the Essex Local Area Agreement, which covers the Essex County Council area. It is clear that work to tackle obesity is the cornerstone of any efforts to prevent people developing type 2 diabetes. This work is part of the wider public health agenda and a detailed consideration of

¹⁴ YPHO Yorkshire and Humber Public Health Observatory, *Diabetes: key facts*. March 2006 available at www.diabetes.nhs.uk/downloads/YHPHO_Diabetes_key_facts.pdf

¹⁵ See Diabetes UK, *Are you at risk of diabetes?* Available at www.diabetes.org.uk/risk/index.html

¹⁶ Department of Health (2004) *Choosing Health: making healthy choices easier*. Available at www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4094550&chk=aN5Cor

¹⁷ The Essex LAA will not involve Southend or Thurrock who will be developing their own LAAs over the coming year.

local obesity strategies is beyond the scope of this review. However, it is possible to identify some areas for development:

- There is limited public knowledge of diabetes, including its symptoms, management and the seriousness of the condition. This has been recognised by some networks, including South West Essex who plan to improve education and awareness of risk factors.
- It is not clear how explicitly local obesity strategies are targeting groups at high risk of developing diabetes.

3.2.2 Recommendations

Raise awareness of diabetes making explicit the links to obesity, heart disease and exercise.

3.3 Identification of people with diabetes

Standard Two: The NHS will develop, implement and monitor strategies to identify people who do not know they have diabetes.

Target: By March 2006, PCTs need to ensure that practice-based registers and systematic treatment regimes cover the majority of patients at high risk of coronary heart disease, particularly those with hypertension, diabetes and a body mass index (BMI) greater than 30.

The early identification of people with diabetes can help prevent complications associated with the disease. This can be done by ensuring that effective management of the disease can begin as early as possible.

The rapid onset of Type 1 diabetes means that only a small proportion of people remain undiagnosed for any length of time. Children and young people with Type 1 diabetes can become ill very quickly and some develop such high blood glucose levels before they are diagnosed, that they present with diabetic ketoacidosis (DKA). The earlier diagnosis of Type 1 diabetes could prevent some of the deaths resulting from DKA.

Type 2 diabetes may be present for several years before diagnosis and nearly half of those identified as having Type 2 diabetes will already have developed complications, such as diabetic retinopathy, diabetic neuropathy or cardiovascular disease.

Many people are living with undiagnosed type 2 diabetes. It is estimated that only 72% of those with diabetes are registered with diabetes. If Essex has a similar proportion of people living with undiagnosed diabetes this would be equivalent to about 12,600 people. People with type 2 diabetes may be

diagnosed years after developing it. Indeed, 50% of people with type 2 diabetes have complications *on diagnosis* that could have been prevented if they had been diagnosed earlier¹⁸. Given that effective management of diabetes can reduce the likelihood of developing long-term complications the panel were concerned that everything that can reasonably be done is done to identify people with diabetes as early as possible.

We were told that opportunistic testing of the general population (e.g. during GP appointments or when donating blood) was not possible as there is currently no national screening programme for diabetes as diabetes does not meet all the criteria for establishing a screening programme (**see appendix three**). The panel welcomes the fact that the National Screening Committee (NSC) will review this decision in 2006.

We believe this should be considered as a high priority for early screening. There is support for interventions with high risk groups to reduce the risks of individuals developing diabetes and identifying those that have the disease. There are a number of models available nationally that allow PCTs or networks to calculate the expected prevalence of diabetes in a given locality. That is, how many people you would expect to have diabetes given the characteristics of the population. Every GP practice should have a practice register in place by March 2006 identifying patients with diabetes. Significant discrepancies between the levels of recorded incidence and expected prevalence may indicate a high proportion of people with 'hidden' or undiagnosed diabetes.

3.3.1 Examples of good practice

There is no systematic approach to identifying people with diabetes. However, there is some good practice across the county:

- South East Essex has developed a self-assessment diabetes risk questionnaire for distribution in the community;
- West Essex has protocols for following up people with impaired fasting glucose tolerance;
- Some GP practices in the Mid Essex network with populations in high risk groups are offering annual reviews for people with impaired glucose tolerance;
- North East Essex network is working with practice staff to educate them about identification and READ coding (clinical coding) of the practice population to better support them in identifying patients at risk;
- The North East network has undertaken some work on local prevalence using the prevalence model developed by the Yorkshire and Humber Public Health Observatory;

¹⁸ YPHO Yorkshire and Humber Public Health Observatory, Diabetes: *key facts*. March 2006 available at www.diabetes.nhs.uk/downloads/YHPHO_Diabetes_key_facts.pdf

- The South West Essex network is supporting practices with low numbers of patients on the diabetes register to look at how they are identifying people at risk.

3.3.2 Key areas for development

Few networks appear to have used public health information to undertake detailed prevalence modelling which could help focus interventions through the identification of people at high risk of developing diabetes.

- The Mid Essex network has identified prevention as a key work area for 2006.
- The new General Medical Services (GMS) contract Quality and Outcomes Framework (QOF) provides an opportunity to ensure effective use of GP registers to identify people with diabetes.
- Networks could seek to develop local guidelines for targeting high risk groups for screening.
- Identifying areas where recorded prevalence is not in line with expected incidence could help target action in achieving this standard.

3.3.3 Recommendations

Commissioners should seek to ensure that diabetes screening is available to close relatives of people with diabetes.

Commissioners should ensure screening is available on self-referral.

3.4 Empowering people with diabetes

Standard Three: All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, patients and carers should be fully engaged in this process.

Target: All PCTs to have structured education programmes which met NICE criteria in place from 2006.

I was told 3 to 4 years ago I have the disease and am more confused now about the services I receive and how to obtain them (especially diet) than I was in the beginning – Help – Help – Help. Patient, South West Essex

The provision of information, education and psychological support to empower patients and enable them to be active partners in managing their diabetes has been recognised as the cornerstone of diabetes care. There is evidence that when patients understand their condition and how to manage it they have better blood glucose control, weight and dietary management, engage in more physical activity and have improved psychological well being¹⁹.

The importance of information and education has been repeated again and again at patient's groups, witness sessions and in the questionnaire responses we received. 30 of the 150 respondents to our questionnaire highlighted the need for more information or education about diabetes and the services available to them. Many patients we spoke to told us about the value of structured education programmes in improving their quality of life and management of their condition. Further information about structured education problems and evidence of their effectiveness is set out in **appendix four**.

3.4.1 Examples of good practice

There are many examples of good practice across the 5 diabetes networks, including:

- Mid Essex is providing the X-PERT programme to people with type 2 diabetes and a generic Expert Patient Programme is provided in each PCT area.
- The North East Essex network have set up a patient held records pilot using an A5 sized pack containing individual patient information and details of local services. The pack contains space for including a named Health Care Professional and a Personal Care Plan. Witham, Braintree and Halstead Care Trust are also participating in this pilot.
- West Essex have a pilot scheme of five *Dose Adjusted For Normal Eating* (DAFNE) courses in 2005 and 2006 for people with type 1 diabetes and will be introducing the X-PERT programme²⁰ for people with type 2 diabetes from early 2006. The network also has a personal record pilot.
- South East Essex is running DAFNE courses and is running a structured education programme for people with type 2 diabetes which is evidence based and follows NICE guidance.
- South West Essex is also developing patient held records using an expandable credit card format.
- South East Essex has recently elected a patient representative as the Chair of the network and all networks have patient

¹⁹ See Department of Health, *National Service Framework for Diabetes: Standards 2002*. Available at <http://www.dh.gov.uk/assetRoot/04/05/89/38/04058938.pdf> p22.

²⁰ A structured education programme (see appendix 4).

representation, or are in the process of recruiting patient representatives.

3.4.2 Key areas for development

However, there remain gaps in the provision of patient education and patient care records. Examples include:

- Some networks are still establishing structured patient education programmes. Mid Essex has not yet agreed on which structured education programme to offer to people type 1 diabetes. It is piloting the BERTIE Programme and will be comparing its outcomes with those likely to be achieved with DAFNE. It will make a decision on which to pursue at the end of 2006, after evaluation of the pilot.
- The North East network has delivered a locally developed patient education programme *Living with Diabetes*. Whilst this has been well received by patients there are concerns that it might not meet NICE criteria and the network hopes to be able to fund a recommended programme such as *Diabetes Education and Self Management for Ongoing and Newly Diagnosed* (DESMOND) or X-PERT along with DAFNE.
- There are concerns that not everybody who could benefit from structured education will receive it because of cost and capacity issues across the networks.
- Not all networks have introduced patient held records.
- It is not clear that networks have personalised care plans in place although there are commitments to achieve this.
- Patient education programmes may not always reflect different learning styles. Information and education should be available in ways that suit individuals rather than in a 'one size fits all' approach.

3.4.3 Recommendations

Commissioners should expand the capacity for patient education.

Improve the availability of information for families and carers.

Ensure appropriate information about diabetes is available to all patients at the point of diagnosis.

3.5 Clinical care of adults with diabetes

Standard Four: All adults with diabetes will receive high-quality care throughout their lifetime, including support to optimise the control of their

blood glucose, blood pressure and other risk factors for developing the complications of diabetes.

*My diabetes care is very good. I have my eyes checked once a year. I see a doctor twice a year and I have a Diabetic nurse I can ring any time. **Patient, South East Essex***

*I am extremely pleased with the service offered at Broomfield Hospital. I have recently started injecting insulin and the care and education given is excellent. **Patient, Mid Essex***

*GPs don't have enough knowledge in diabetes – it would be nice to have a GP who understands the condition. **Patient, South East Essex***

*I have not seen a dietitian for 16 years. **Patient, South West Essex***

*[The service] is improving – but there is still a lack of cohesion – the service is not properly integrated. **Patient, North East Essex***

Providing high quality care for people with diabetes can help avoid or delay the development of microvascular complications. This section sets out just some of the good practice happening across the County and key areas that have been identified by NHS staff, patients and carers as needing further development.

3.5.1 Examples of good practice

It is still early in the implementation of the NSF and service improvements will continue over the next few years across all the networks. There are already examples of good practice that can be shared:

- Mid Essex has introduced a tiered model of care. This comprises:
 - Tier 1 – GP practices which undertake most patients' annual reviews;
 - Tier 2 – multidisciplinary clinics provide a 'one-stop shop' in each PCT area for people with routine type 2 diabetes requiring advice, insulin therapy or group education; and
 - Tier 3 – hospital based services which focus on services for people with type 1 diabetes, pregnant women with diabetes, children and people with type 2 diabetes requiring specialist care.
- South East Essex is looking at how practice based commissioning could facilitate the development of a primary care diabetes referral clinic assessment service. The network has carried out some clinical audit of services. The Diabetes Service Nursing Service has a resource pack detailing care pathways and guidelines.
- North East Essex is developing patient centred care pathways and is seeking to reduce referrals to secondary care. They have introduced nurse led and multidisciplinary clinics and have

successfully reduced waiting times. There are plans to further develop these clinics and to introduce joint posts in primary and secondary care.

- West Essex has guidelines in place for the diagnosis and management of diabetes and has developed multi-disciplinary working at Princess Alexandra NHS Trust and an intermediate care clinic in Harlow. Primary care based clinics have been developed in Epping Forest and Uttlesford.
- South West Essex is working to deliver more services in a primary care setting

3.5.2 Key areas for development

Each network has plans for developing its services and specific areas for development are identified in other sections of this report. However, some areas for development are worth noting here:

- Mid Essex plans to continue to develop and refine its tiered care pathway - for example people with type 1 diabetes have asked to be treated in tier 2 services.
- North East Essex includes Tendring PCT which has the fourth highest incidence of diabetes in England and the highest in the Essex SHA area at 4.4%. This is thought to be due to the large proportion of elderly residents and represents a huge challenge to delivering diabetes care to all patients in the area.
- South West and South East Essex are continuing to develop their primary care based services and specify a clear pathway for all patients.
- West Essex has complicated referral pathways with some patients travelling to London or Addenbrooke's for secondary care treatment. This is a challenge for developing relationships between primary and secondary care across the network and different models of care have been developed in each area.
- Views differ but limited access to psychology services has been reported across the county. Long-term conditions are associated with increased risk of depression and patients may be particularly vulnerable around the time of diagnosis.
- Insulin pumps and other new therapies, such as inhaled insulin therapy, present a challenge for all networks. Further information on insulin pumps is set out in **appendix five**.
- Non-specialist NHS staff do not always have enough knowledge of diabetes to advise patients; this is a particular concern at the point of diagnosis.

3.5.3 Recommendations

Develop consistent Essex Care Pathways.

Develop commissioning arrangements to ensure that service improvements are effectively delivered.

Expand the provision of diabetes training for NHS staff (including hospital staff). For example, the Certificate in Diabetes Care from Warwick University is a multidisciplinary course that could be delivered by locally trained tutors.

3.6 Clinical care of children and young people with diabetes

Standard Five: All children and young people with diabetes will receive consistently high-quality care and they, with their families and others involved in their day-to-day care, will be supported to optimise the control of their blood glucose and their physical, psychological, intellectual, educational and social development.

Standard Six: All young people with diabetes will experience a smooth transition of care from paediatric diabetes services to adult diabetes services, whether hospital or community-based, either directly or via a young people's clinic. The transition will be organised in partnership with each individual and at an age appropriate to and agreed with them.

They [the school] need more understanding. They seem to think diabetic people should care for themselves. My son is 8 and no one at school keeps their eye on him. Parent. South West Essex

[There are] not enough paediatric diabetes nurses Patient, South West Essex

The 2002 National Paediatric Diabetes Audit estimated 522 children in Essex were living with diabetes²¹. Around 90-95% of children have type 1 diabetes. Numbers of children with type 2 diabetes remain very small but are rising. The provision of high quality care for children with diabetes is essential to ensure effective blood glucose control and help children learn to manage their

²¹ Diabetes UK, *The National Paediatric Diabetes Audit: results from the audit year 2002*. Available at <http://www.bsped.org.uk/professional/diabetesuk/NationalPaediatricAudit.pdf>

condition and avoid or delay the onset of many of the complications associated with diabetes.

3.6.1 Examples of good practice

There are some examples of good practice, including:

- Mid Essex has produced a DVD aimed at young people with type 1 diabetes.
- 24-hour access to paediatric diabetes specialist nurse on a children's ward for diabetic emergencies in Mid Essex.
- A monthly adolescent clinic for young people aged 12-18/19 is held in Colchester.
- An endocrinologist at Mid Essex Hospitals Trust is identifying children with type 2 Diabetes.
- The South East Essex paediatric diabetes team offer an adolescent transitional clinic; under 5 toddler support and education group; a local diabetes support group called Daisy; and access to a psychologist.

3.6.2 Key areas for development

We are concerned that children's diabetes services across the county need to be improved. This concern has been reflected in discussions with NHS staff and parents and carers of children living with diabetes. We recognise that many areas have been identified by the diabetes networks as needing further development and that some action is already underway. For example West Essex has set up a working group to make recommendations for improving children's services.

- Some networks are planning to develop structured patient education for children and young people. For example the South East Essex network has plans to introduce this based on a curriculum being developed by Addenbrooke's Hospital.
- There is a need to work more closely with schools. Whilst Mid Essex has undertaken some work with teaching assistants enabling them to give insulin to very young children, the lack of knowledge about diabetes in schools has been identified by parents and NHS staff across the county. For example North East Essex has identified that school nurses do not always have enough knowledge about diabetes.
- Numbers of paediatric Diabetic Specialist Nurses vary across the county. In particular, South West Essex have identified recruitment and retention difficulties. These nurses are central to the care of children with diabetes and the Royal College of Nursing recommends a caseload of 70 children per whole time equivalent paediatric diabetes specialist nurse²². None of the networks

²² See Royal College of Nursing (2006) *Specialist Nursing Services for Children and young People with Diabetes*. Available at

currently achieve this but the shortage is particularly acute in South West Essex with only 0.5 whole time equivalent paediatric DSN for 258 children.

- Access to podiatry and psychology services also varies greatly across Essex county.
- West Essex has no dedicated service team for children's diabetes services, with staff also having other roles.
- Transition services vary across the county, as does the age at which young people are transferred to adult services. In particular, there are few transition clinics and it is not clear that there is any follow up on young people after they move to adult services.
- Concerns have also been raised about managing emergencies and out of hours care for children. 24-hour access to specialist advice varies across the county and is an area where there could be improvement.
- Children are frequently admitted to hospital because of a lack of community provision and expert emergency services.

3.6.3 Recommendations

Establish an Essex County wide working group to identify areas for improvement and a timetable for action.

Ensure that schools raise awareness of diabetes as part of their work to promote healthy lifestyles.

Ensure school nurses have the skills and competencies to deliver consistent quality information on diabetes.

3.7 Management of diabetic emergencies

Standard Seven: The NHS will develop, implement and monitor agreed protocols for rapid and effective treatment of diabetic emergencies by appropriately trained health care professionals. Protocols will include the management of acute complications and procedures to minimise the risk of recurrence.

Acute complications of diabetes can result from very high blood glucose resulting from a lack of insulin, or from very low blood glucose levels. These are potentially life-threatening complications and need to be avoided where possible and effectively managed when they arise.

http://www.rcn.org.uk/publications/pdf/specialist_nursing_services_for_children_and_young_people_with_diabetes.pdf

All networks have policies in place for dealing with adult diabetic emergencies. Actions to prevent them are included in the general management of diabetes and have been considered in relation to other standards.

3.8 Care of people with diabetes during admission to hospital

Standard Eight: *All children, young people and adults with diabetes admitted to hospital, for whatever reason, will receive effective care of their diabetes. Wherever possible, they will continue to be involved in decisions concerning the management of their diabetes.*

*If you are taken into hospital, they don't know enough about diabetes and tell you to do what you think, which is OK if you are able to. **Patient, North East Essex***

People with diabetes are admitted to hospital twice as often and stay twice as long as those without diabetes. They occupy one in ten acute hospital beds²³. The Diabetes NSF notes that the quality of care received by people with diabetes whilst in hospital can be compromised²⁴. People with diabetes have identified the following concerns:

- Failure to record and consider patients' diabetes;
- Inadequate knowledge of diabetes among hospital staff;
- Inappropriate amounts and timings of food and inappropriate timings of medication;
- The lack of information provided;
- Delays in discharge resulting from their diabetes, especially when diabetes was not the original reason for their admission.

Witnesses and members of local patients' groups told us of real concerns about the level of knowledge about diabetes amongst non-specialist hospital staff. We heard of patients whose blood glucose levels would become uncontrolled during hospital stays leading to delays in discharge. Concerns were raised that hospital meals were not effectively meeting the needs of people living with diabetes. There are also concerns about the communication between hospitals and GPs.

3.8.1 Key areas for development

Most networks have recognised that there are areas of inpatient care that need to be improved for patients with diabetes and are taking action to rectify this. For example:

²³ See Diabetes NSF <http://www.dh.gov.uk/assetRoot/04/05/89/38/04058938.pdf>

²⁴ As above

- A Mid Essex network sub-group will be looking at hospital care in 2006. The network has already identified a need to improve communication and IT systems.
- West Essex may carry out an audit of hospital care in 2006.
- South West Essex has included actions to promote better communication between the diabetes team and ward staff in their draft implementation plan.
- North East Essex has introduced link training to ensure staff on wards understand diabetes and a DSN visits wards daily when a patient requires it.
- South West Essex says ward staff are encouraged to refer patients with diabetes to the diabetes specialist team and there is a diabetes nurse link system in place to help facilitate this.

3.8.2 Recommendations

Improve hospital care to ensure shorter stays and fewer complications for patients with diabetes. This will include ensuring that:

- **A patient's diabetes is recorded on admission;**
- **Where possible, medication is kept by the patient;**
- **Dietary and medication requirements are understood by patients and staff; and**
- **Catering facilities provide adequate facilities for people with diabetes.**

3.9 Diabetes and pregnancy

Standard Nine: *The NHS will develop, implement and monitor policies that seek to empower and support women with pre-existing diabetes and those who develop diabetes during pregnancy to optimise the outcomes of their pregnancy.*

One consequence of the increasing number of younger people diagnosed with type 2 diabetes is that it affects women during their reproductive lifetime²⁵. Women with pre-existing diabetes are much more likely to require a caesarean section, lose their baby either during pregnancy or after birth, or have a child with congenital malformations, than women who do not have diabetes²⁶. The risks can be reduced if near-normal blood glucose levels are achieved before and around the time of conception, throughout pregnancy and during labour.

²⁵ YPHO Yorkshire and Humber Public Health Observatory, Diabetes: *key facts*. March 2006 available at www.diabetes.nhs.uk/downloads/YHPHO_Diabetes_key_facts.pdf

²⁶ See CEMACH *Pregnancy in women with type 1 and type 2 diabetes: 2002-2003*. 2005 www.cemach.org.uk/publications/CEMACHDiabetesOctober2005.pdf

Some women develop gestational diabetes, particularly those from minority ethnic groups. These women are more likely to have large-for-dates babies, a risk that can be reduced by reducing maternal hyperglycaemia. Even women whose blood glucose levels revert to normal after delivery have an increased risk of developing Type 2 diabetes later in life.

The importance of tight glucose control for women during pregnancy is highlighted in the NSF and specialist services are provided in each of the 5 Essex NHS Hospital Trusts.

3.9.1 Examples of good practice

Given the limited availability of information from the networks, particular examples of good practice against this standard are difficult to identify, especially with regard to how the service is patient-focussed.

The Princess Alexandra Trust provides a service jointly run between the Diabetes and Women's Health Departments that includes:

- Nominated lead consultants from each directorate;
- A diabetes link midwife;
- One designated place and time to run the ante-natal diabetic clinic;
- Support out of hours;
- Effective communication with the GPs (unified letter/clinic record pro forma sent on the same day to the GP);
- Agreed standards and detailed guidelines for screening and management during pregnancy and labour²⁷

The South East Essex diabetes team offer jointly run antenatal clinics for women who are pregnant and are diabetic or develop gestational diabetes. Women also have access to follow-up support from a diabetes midwife and diabetes specialist nurse.

3.9.2 Key areas for development

This review has not looked in detail at maternity services and none of the questionnaire responses or patients we met with have commented specifically on these services. It is clear that each network provides specialist services and has guidelines in place for these services.

NICE is developing clinical guidelines for diabetes in pregnancy, due to be published in November 2007. The panel will not be making specific recommendations about improving services for managing diabetes in pregnancy in advance of these guidelines. However, not all networks have audited clinical outcomes and this could be a key area for further work.

²⁷ Note from Deborah Gunn-Roberts, Head of Corporate Services, The Princess Alexandra Hospital NHS Trust. (10th October 2005).

3.10 Detection and management of long-term complications

Standard Ten: *All young people and adults with diabetes will receive regular surveillance for the long-term complications of diabetes.*

Standard Eleven: *The NHS will develop, implement and monitor agreed protocols and systems of care to ensure that all people who develop long-term complications of diabetes receive timely, appropriate and effective investigation and treatment to reduce their risk of disability and premature death.*

Standard Twelve: *All people with diabetes requiring multi-agency support will receive integrated health and social care.*

Target: By March 2006, a minimum of 80 per cent of people with diabetes to be offered screening for the early detection (and treatment if needed) of *diabetic retinopathy* as part of a *systematic programme* that meets national standards, rising to 100 per cent coverage of those at risk of retinopathy by end 2007.

Target: By June 2006, 70% of people offered screening between April 2005 and March 2006 will have received it.

*The monitoring service provided at the local surgery with blood tests and check up by the practice nurse is first class. **Patient, South East Essex***

*The retinal screening programme is excellent. If it had been in operation 20 years ago, it may have prevented my mother's blindness. **Patient, South East Essex***

People with diabetes are at risk of developing serious and potentially life threatening complications. Regular surveillance for and effective management of these complications can help reduce the risk of blindness, amputation and premature death. Further information about the complications of diabetes is set out in **appendix one**.

There are 2 national targets regarding diabetic retinopathy screening for 2006, which are described above. Although there have been some data collection problems, the Strategic Health Authority reports that 89% of patients had been offered screening across Essex by March 2006, and that all PCTs and networks had hit the target.

The Strategic Health Authority also estimates that across Essex 80% of patients who were offered screening, actually received it (June 2006 target).

Only Epping Forest PCT, in the West Area Network did not hit this target, achieving 59%.²⁸

They have achieved the target through different mechanisms:

- Mid Essex has contracted with Suffolk West Retinal Screening Programme to provide a service that visits GP practices or nearby venues to provide screening.
- North East Essex is hoping to move to a digital screening system to be provided in community optometrist premises, rather than GP practices.
- South West Essex has a centralised screening programme.
- South East Essex has awarded a new contract for provision of screening in the community that will ensure 100% coverage.
- In West Essex, Uttlesford is using the Suffolk West service. Epping Forest and Harlow are negotiating with a new provider.

Other important aspects of surveillance and treatment of long-term complications include annual health checks, access to podiatry services and effective multi-disciplinary working particularly with social care.

3.10.1 Examples of good practice

People with diabetes told us they valued their regular health checks. 23 of the 100 positive comments we received in our questionnaires about diabetes services were about 6 monthly or annual checks.

- Mid Essex has a part time DSN exclusively for people in residential or nursing care homes.
- South East Essex has developed guidelines for microalbuminuria screening, cholesterol management and blood glucose monitoring for all people with diabetes. It also provides care for people in residential and nursing homes through diabetes community nursing and is working to educate staff in these homes about diabetes.
- North East Essex also uses a link nurse system for nursing homes and is working with Anglia Ruskin University to provide training for social care workers.
- All networks have guidelines in place for treating long-term complications such as treating myocardial infarction with insulin therapy.
- In South West Essex the wider long-term conditions network is developing an integrated assessment of health and social care needs. It is seeking to ensure effective services are provided to hard to reach groups including those in residential homes, travellers and prisoners.

²⁸ Information from Sarah Mossop, Essex Public Health Screening Co-ordinator. (June 8th 2006)

3.10.2 Key areas for development

Areas for further work include:

- The South West network has identified actions for improving detection and management of complications in its draft implementation plan. Actions will include: reducing retinopathy, nephropathy, impaired renal function and risk of coronary heart disease (CHD), limb complications, foot ulceration and surveillance for depression and other common problems.
- Access to dietitians varies across the county. 10 of our questionnaire respondents raised concerns about this.
- Access to podiatry services is variable. 8 of our questionnaire respondents said this was an area of concern.
- There is room for improved working with social care as part of wider work to tackle long-term conditions that could benefit patients across all networks.

3.10.3 Recommendations

Clear plans should be developed to address any gaps in capacity, particularly in relation to podiatrists, psychologists, Diabetes Specialist Nurses, and dietitians.

Appendix One: What is Diabetes?²⁹

Diabetes mellitus is a chronic condition in which the amount of glucose (sugar) in the blood is too high because the body cannot use it properly. Glucose comes from the digestion of starchy foods such as bread, rice, potatoes, chapatis, yams and plantain, from sugar and other sweet foods, and from the liver, which makes glucose.

In order to use glucose properly the body needs insulin. This is a hormone produced by the pancreas that helps the glucose to enter the cells where it is used as fuel by the body. The main symptoms of untreated diabetes can include increased thirst, increased urination (especially at night), extreme tiredness, weight loss, genital itching or regular episodes of thrush, and blurred vision.

There are two main types of diabetes. These are:

- *Type 1 diabetes*
- *Type 2 diabetes*

In addition to these main types of diabetes, there is also gestational diabetes. Some pregnant women have such high levels of glucose in their blood that they cannot produce enough insulin to absorb it all. This affects less than 1 in 20 pregnant women. Gestational diabetes usually disappears after the baby is born but women who develop it are more likely to develop Type 2 in later life.

Type 1 diabetes develops if the body is unable to produce any insulin. This type of diabetes usually appears before the age of 40 and is most commonly diagnosed in children or young adults. It is treated by insulin injections and diet, regular exercise is also recommended.

Type 2 diabetes develops when the body can still make some insulin, but not enough, or when the insulin that is produced does not work properly (known as insulin resistance). This type of diabetes usually appears in people over the age of 40, though in South Asian and African-Caribbean people it often appears after the age of 25. It is treated by diet and exercise alone or by diet, exercise and tablets or by diet, exercise and insulin injections. Type 2 may go unnoticed for years in a patient before diagnosis, since the symptoms are significantly milder and can be sporadic. However, severe complications can result from untreated type 2 diabetes including renal failure and coronary artery disease.

The main aim of treatment for both types of diabetes is to achieve blood glucose and blood pressure levels as near to normal as possible. If diabetes is not treated it can lead to many different health problems.

²⁹ The information in this appendix is adapted from the Diabetes UK website which can be found at <http://www.diabetes.org.uk/diabetes/index.html>.

It is important to keep a check on blood pressure to prevent problems such as heart disease, stroke, angina and poor circulation. Blood pressure should be checked regularly and kept at the right level. This means eating a healthy diet, maintaining a healthy weight, stopping smoking and avoiding stress.

Blood flow problems can lead to nerve damage in the hands and feet. About 1 in 10 people with diabetes get foot ulcers, which can cause serious infection. Blood flow problems can also cause blindness, cataracts and retinopathy (damage to the back of the eyes). Over time, excessive urination and damage to blood vessels can damage the kidneys. Diabetes can lead to impotence in many men, a symptom that may be treated with medication. Pregnant women with diabetes are at increased risk of miscarriage and stillbirth. If their blood-sugar level is not carefully controlled in the early stages of pregnancy there is also an increased risk of the baby developing a serious birth defect. Pregnant women with diabetes will usually have their antenatal check-ups in hospital or in a diabetic clinic, where doctors can keep a close watch on their blood-sugar levels and control their insulin dosage more easily.

Diabetes affects over 2 million people in the UK and there may be many more people who have the disease but do not know it yet. 90% of people with Diabetes have Type 2 Diabetes and over 80% of these people are overweight. In 2000, the Audit Commission reported that by 2010 the number of people with Diabetes in the UK would double due to age, obesity and lack of exercise from the then base of 1.3 million.

Appendix Two: Public engagement and witness sessions

Members of the panel and officers attended the following events:

- Regional Diabetes UK Roadshow, Lakeside (10th November 2005)
- Chelmsford Diabetes UK (15th November 2005)
- Colchester Service User Group (18th November 2005)
- Basildon Diabetes UK (1st December 2005)
- Basildon PPIF (2nd December 2005)
- Chelmsford Health Watch (7th December 2005)
- Basildon Healthy Heroes (10th January 2006)

The following people attended panel meetings to give evidence and the panel is grateful for their contributions, which were invaluable:

7th December 2005

- Irvine Turner, Chairperson, Colchester Service Users Group; and
- Malcolm Jacobs, Chair of Chelmsford PPI Forum.

12th December 2005

- Mike Gogarty, Director of Public Health, Colchester PCT;
- Margaret Gray, Senior Health Promotion Strategist, Southend PCT;
- Tracy Slater, Eastern Regional Manager, Diabetes UK;
- Chris Birbeck, Clinical Governance Manager, Essex Strategic Health Authority;
- Bill Downs, Chair of Chelmsford Diabetes UK;
- Liesel Park, Representative for the South East Essex Health Economy;
- Sheila Smyth, Primary Care facilitator/Diabetes Specialist Nurse, Tendring; and
- Debbie Cook, Eastern Region Programme Manager, National Diabetes Support Team.

13th December 2005

- Paul Davison-Holmes, Member of Diabetes Committee;
- Maria Berridge, South West Essex Long-term Conditions Project Manager;
- Alexis Hodgkins, Diabetes Specialist Nurse, Community Team Castle Point and Rochford and Southend-on-Sea PCTs; and
- Terry Chapman, Chair of Basildon and Thurrock Healthy Heroes.

16th December 2005

- Linda Jewsbury, Chelmsford PCT and Mid Essex Diabetes Network;
- Irene Guidotti, Podiatrist, Mid Essex Diabetes Network;
- Shelagh Newman, Diabetes Paediatric Nurse, Essex Rivers;

- Aidan Thomas, Chief Executive, Epping Forest PCT;
- Jane Tadman, Nutrition and Dietetics and Chair of West Essex Area Diabetes Network; and
- Paula Wilkinson, Chief Pharmacist at Chelmsford PCT and Witham Braintree and Halstead Care Trust.

Appendix Three: National screening for diabetes

The National Screening Committee (NSC), which makes recommendations to ministers on what should be screened, has looked at the issue of screening for Diabetes Mellitus in adults. Its position as at May 2005 was that 'general population screening should not be offered', a position that will be reviewed again in 2006³⁰. In 2000, the NSC also looked at screening for Diabetic Retinopathy and recommended a national screening programme which is being implemented³¹.

The NSC has recently defined screening as:

A public health service in which members of a defined population, who do not necessarily perceive they are at risk, or are already affected by, a disease or its complications, are asked a question or offered a test to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of disease and its complications³².

In considering potential screening programmes the NSC applies 22 criteria which include:

- All the cost-effective primary prevention interventions should have been implemented as far as practicable.
- The distribution of test values in the target population should be known and a suitable cut off level defined and agreed.
- There should be agreed evidence based policies in place, covering which individuals should be offered treatment and the appropriate treatment to be offered.
- The benefit from the screening programme should outweigh the physical and psychological harm (caused by the test, diagnostic procedures and treatment).
- The opportunity cost of the screening programme (including testing, diagnosis and treatment, administration, training and quality assurance) should be economically balanced in relation to expenditure on medical care as a whole (i.e. value for money).³³

³⁰ National Electronic Library for Health. Available at <http://libraries.nelh.nhs.uk/screening/viewResource.asp?mr=10&offset=30&dg=&searchText=&attributeText=Health+Policy&categoryID=&attributeOptionID=&keywordID=14216&uri=http%3A//libraries.nelh.nhs.uk/common/resources/%3Fid%3D60985>

³¹ Second Report of the UK National Screening Committee.
www.nsc.nhs.uk/pdfs/secondreport.pdf

³² National Screening Committee. 2nd Report of the National Screening Committee
www.nsc.nhs.uk/pdfs/criteria.pdf <<http://www.nsc.nhs.uk/pdfs/criteria.pdf>>

³³ NSC. March 2003. Criteria for appraising the viability, effectiveness and appropriateness of a screening programme.
www.library.nhs.uk/screening/ViewResource.aspx?resID=59772&tabID=288

The assessment of diabetes showed it did not meet all criteria and a national screening programme was not recommended. Key reasons included:

- High risk or population level primary prevention interventions have never been fully implemented.
- Day-to-day variability in individuals blood glucose levels 'creates an indistinct separation between people with and without diabetes'. The report concluded that 'urinalysis for glycosuria' has a 'low sensitivity'³⁴.

The NSC does not appear to have considered selective screening on particular groups such as minority ethnic groups with a higher than average prevalence, or family members of those who have diabetes. It does not rule out the contribution focussed screening could make.

The government is trying to improve health prevention through a focus on self-assessment. This would enable people to consider their own health as a whole and could lead to more people with undiagnosed diabetes being diagnosed and treated appropriately.

Further evaluation is taking place in line with this broader approach. The NSC has integrated the screening for Diabetes with screening of those at higher risk of heart disease and stroke and has set up a pilot 'Diabetes, Heart Disease and Stroke Prevention Project'³⁵. After interim results in November 2005 the NSC is now combining cardiovascular disease and diabetes into a Risk Assessment and Control Programme. This is likely to make recommendations that improve the understanding of the combination of risk factors at the primary care level and lead to more effective identification of conditions at that level.

Developments in Essex

Networks in Essex are undertaking some work to identify people with diabetes. Notably, the South East Diabetes Network has just released a self-assessment questionnaire to the general population. This questionnaire is intended to make the public more aware about Diabetes, and encourage people to self refer for testing where appropriate.

³⁴ Wareham *Evaluation of Type 2 Diabetes Mellitus Screening against the NSC Handbook Criteria*, Department of Public Health and Primary Care, Cambridge, 2001 available at: <http://libraries.nelh.nhs.uk/screening/viewResource.asp?categoryID=5525&uri=http%3A//libraries.nelh.nhs.uk/common/resources/%3Fid%3D60981>

³⁵ Diabetes, Heart Disease and Stroke Prevention Project (DHDS). www.screening.nhs.uk/diabetes

Appendix Four: Structured Patient Education in Diabetes

DAFNE (Dose Adjustment for Normal Eating) and DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) programmes provide a nationally-led, evidence based approach for adults with type 1 and type 2 diabetes. These packages are recommended by the DH because they respectively meet NICE (National Institute for Clinical Excellence) criteria and are being evaluated nationally. Other programmes may not meet the criteria and are not being evaluated nationally.

The NICE Health Technology Appraisal on patient education models defines structured education as 'a planned and graded programme that is comprehensive in scope, flexible in content, responsive to an individuals clinical and psychological needs and adaptable to his or her educational and cultural background'.³⁶ We are currently awaiting publication of a structured patient education self assessment tool which will enable networks to assess whether their education programmes meet NICE criteria.

The NICE Health Technology Appraisal noted evidence that structured education within intensification of treatment in type 1 diabetes produced worthwhile improvement in glycaemic control, reduced complications and was likely to be cost effective. Much of this evidence was based on research in Germany. An economic evaluation modelling UK and German data suggested that DAFNE would pay for itself in 4 years³⁷. For type 2 diabetes, the Cochrane review on 'Group based training for self management strategies in people with type 2 diabetes mellitus'³⁸, stated that 'such training is effective by improving blood glucose levels, glycated haemoglobin and diabetes knowledge and reducing systolic blood pressure levels, body weight and requirement for diabetes medication'.

Witnesses have told us about the value of Education Programmes, both in terms of their impact on quality of life through reducing higher risk behaviour but also in helping patients avoid complications at later stages.

Tracy Slater (Diabetes UK) has told us that a range of delivery styles e.g. DVDs and online training could be developed in the future to meet individuals' needs and which would also fulfil NICE requirements.

³⁶ From: 'Structured Patient Education in Diabetes'. Diabetes UK and DH. June 2005

³⁷ Shearer A, Bagust A, Sanderson D, Heller S, Roberts S. 'Cost effectiveness of flexible intensive insulin management to enable dietary freedom in people with Type 1 Diabetes in the UK'. *Diabetic Medicine* 2004; 21(5).

³⁸ Deakin T, McShane CE, Cade JE, Williams RDRR. *The Cochrane Database of Systematic Review* 2005. Issue 2.

NICE criteria

NICE has set out criteria for structured education programmes. They should:

- Have a structured curriculum;
- Have trained educators;
- Be quality assured; and
- Be audited.

Children and Young People

NICE guidance recommends that children and their families should be offered timely and ongoing opportunities to access information about the development, management and effects of type 1 Diabetes. Unfortunately, there is no evaluated paediatric or adolescent structured education programme being delivered systematically in the UK. A version of DAFNE is being piloted in Sheffield and involves paediatric nurses, dietitians and teachers at a local school.

Approved Schemes

DAFNE (Dose Adjustment for Normal Eating)

DAFNE is a skills based education programme where adults learn how to adjust their use of insulin to suit their food choices, rather than having to work their diet around their insulin doses. This is an intensive 5-day course. The main areas of the course are:

- Nutrition topics;
- Insulin dose adjustment at mealtimes and special circumstances (exercise, illness);
- Hypoglycaemia;
- Annual review; and
- Pregnancy.

DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed)

This is a new structured group education programme for people living with type 2 diabetes. The programme supports people in identifying their own risks and how to respond to them by setting their own behavioural goals. The course takes 6 hours and is delivered in full-day or half-day sessions. The curriculum includes:

- What diabetes is;
- Main ways to manage diabetes;
- Diabetes consequences/personal risk;
- Monitoring and taking action;
- Food choices;
- Physical activity;
- Stress and emotion; and
- Screening and annual clinics.

Practice in Essex

Adults

The NDST and the SHA are highlighting the need to use programmes that meet the NICE criteria such as DAFNE and DESMOND, programmes which are being adopted by most of the Essex Diabetes Networks. There are other programmes in use and these are working towards meeting the NICE criteria for Structured Education. Evidence from witnesses and attendance at local diabetes patient groups indicate that the need and demand for structured education far outstrips current capacity.

Mid Essex and West Essex are utilising the nationally recognised X-PERT programme for Type 2 diabetes. This is a structured group education programme based on theories of empowerment and discovery learning. It consists of 6 weekly 2.5-hour sessions. This education programme has been evaluated using a Randomised Control Trial (RCT) involving 314 people, and has shown benefits in clinical, lifestyle and psychosocial outcomes.³⁹ The Mid Essex network is considering whether to use the Bournemouth programme, which has become known as BERTIE for people with Type 1 Diabetes. This is similar to DAFNE but it can be delivered over a 4 week period. BERTIE has also had some positive evaluation⁴⁰.

The North East Network is currently using a locally developed programme, 'Living with Diabetes', which is working towards meeting the criteria. There maybe benefits in using such packages, in terms of time accessibility, but there will be costs in showing that that they can meet criteria.

The decision on which education programme to use is often made as part of the Local Delivery Plan process and short-term resource availability is likely to be a key consideration in the decision-making process.

Children

Paediatric DSN staff in most of the networks, have indicated to us that they want to consider adapting DAFNE to use with children. This work has not started.

³⁹ Deakin TA, Cade JE, Williams DRR, Greenwood DC. 'Expert patient versus routine treatment'. *Diabetic Medicine*. 2003 (20)

⁴⁰ 'Structured Patient Education in Diabetes', Diabetes UK and DH. June 2005

Appendix Five: Emerging Technologies

Insulin pump therapy

Insulin pump therapy is a treatment, which some people with Type 1 diabetes find beneficial in terms of overall control and quality of life.

People living with diabetes have to monitor their blood glucose levels and pay close attention to their diet. Those receiving insulin therapy may also face multiple daily injections (a particular issue in the treatment of children). The lifestyle demands (e.g. carbohydrate counting, regular meal times and multiple daily injections) may impact on quality of life. Insulin and glucose intake have to be carefully balanced to avoid hyperglycaemia or episodes of hypoglycaemia, which can cause weakness, confusion, dizziness, unconsciousness and seizures. Fear of severe hypoglycaemia is common among people with diabetes on insulin therapy and as a result they may deliberately maintain high blood glucose levels or over treat the early symptoms of hypoglycaemia in an attempt to avert a severe hypoglycaemic attack⁴¹.

The panel has heard how quality of life can be improved, for some people, through using an insulin pump by gaining better control over their blood glucose levels, which can also help people avoid or delay the onset of complications.

What is insulin pump therapy?

Insulin pump therapy or continuous subcutaneous insulin infusion is a way of continuously delivering insulin into the body at a controlled rate. This allows the rate of insulin to be varied depending on a person's activity – for example it can be increased at meal times.

The insulin pump is a small mechanical device that is worn outside the body, often on a belt or in a pocket. It pumps insulin into the body through a needle or very narrow tube (cannula) under the skin⁴².

Insulin pump therapy was first introduced in the 1980s but there were early safety concerns. These now appear to have been addressed.

Access to the pump

The UK has a lower proportion of people using insulin pump therapy than many other countries. Diabetes UK puts the figure at 0.19 per cent of people with Type 1 diabetes in the UK use pumps (650) compared with about 8 per cent in the United States, 12 per cent in Sweden, and 10 per cent in Germany⁴³.

⁴¹ See <http://www.nice.org.uk/page.aspx?o=TA057>

⁴² See for example, *Insulin Pumps UK* see for example www.insulin-pumpers.org.uk/whatisapump/ or www.river2u.com/medical_instruments/insulin_pumps.htm

⁴³ See http://www.diabetes.org.uk/infocentre/state/pump.htm#_edn1

It is widely agreed that not all patients are suitable for insulin pump therapy.⁴⁴

In February 2003 the National Institute for Health and Clinical Excellence (NICE) issued guidance on insulin pump use, recommending that it be available as a treatment option for people with Type 1 diabetes in cases where:

- multiple dose insulin therapy (including insulin glargine, or lantus, when it's appropriate) has failed; and
- the person is willing and able to use insulin pump therapy effectively⁴⁵.

PCTs have a statutory obligation to provide funding for NICE recommended treatment where this is considered appropriate by the clinician and patient. Those people most suited to using the pumps will:

- Have a good knowledge and understanding of diabetes;
- Be well motivated and willing to take control of their diabetes;
- Be prepared to test blood glucose levels at least four times a day and be confident in acting on those results; and
- Have a sound understanding of how insulin, exercise and food intake affect blood glucose levels.

Pump therapy is successfully being used by a small number of children and teenagers in the UK. This means there are few paediatric diabetes teams with pump therapy expertise. A major concern for health care professionals is the lack of experience of pump use in the UK. In response to this, Pump Management for Professionals (PUMP), a network of multidisciplinary health professionals with experience in pump use has been set up, to share knowledge, run training events and to advise colleagues less experienced in pump therapy⁴⁶.

Access to pumps in the private sector

Some people purchase pumps directly from manufacturing companies, who might also provide care and nursing provision. There are no figures available on how many people are doing this and there are concerns about how they are being supported by the supplier and any NHS diabetes specialists.

Provision in Essex

Few pumps have been issued to people in Essex. However, networks have assured us that the decision to refer to a specialist centre such as Addenbrooke's for insulin pump therapy rests with the hospital consultant in line with NICE guidelines. Only the North East Network has an 'agreement, not written', for a number of pumps to be commissioned in a year. There have

⁴⁴ See http://www.diabetes.org.uk/infocentre/state/pump.htm#_edn1 and http://www.nice.org.uk/pdf/57_InsulinPumps_IFP.pdf

⁴⁵ See <http://www.nice.org.uk/page.aspx?o=TA057>

⁴⁶ See <http://www.insulin-pumpers.org.uk/support/>

been some discussions between Essex Diabetes Consultants with the SHA about the possibility of developing a specialist centre/team in Essex.

Other technologies

New technologies continue to be developed. These include inhaled insulin therapy. NICE has developed preliminary recommendations on the use of inhaled insulin for the treatment of diabetes (type 1 and 2). It is not recommending inhaled insulin except in the context of clinical studies designed to evaluate the clinical and cost effectiveness of inhaled insulin compared to injected insulin in people with uncontrolled blood sugar levels⁴⁷.

⁴⁷ See *Inhaled insulin for the treatment of diabetes (types 1 and 2) - Appraisal consultation document* available at: www.nice.org.uk/page.aspx?o=305465

Appendix Six: Documentary Evidence

Audit Commission. *Testing Times: A review of Diabetes Services in England and Wales*. 2000.

Basildon PCT Public and Patient Involvement Forum. *Minutes of 23 December 2005*.

Confidential Enquiry into Maternal and Child Health (CEMACH) *Pregnancy in women with type 1 and type 2 diabetes: 2002-2003*. 2005. Available at www.cemach.org.uk/publications/CEMACHDiabetesOctober2005.pdf

Deakin TA, Cade JE, Williams DRR, Greenwood DC. 'Expert patient versus routine treatment'. *Diabetic Medicine*. 2003 (20)

Department of Health. *National Service Framework for Diabetes: standards*, December 2001.

Department of Health. *National Service Framework for Diabetes: delivery strategy*. November 2002.

Department of Health. *National Service Framework for Diabetes: one year on*, April 2004.

Department of Health. *Improving Diabetes Services: The NSF two years on*, March 2005.

Department of Health. *Choosing Health: making healthy choices easier*. 2004.

Department of Health. *Workforce Matters: a guide to role reorganisation in diabetes care*. 2005

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

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Diabetes UK, *The National Paediatric Diabetes Audit: results from the audit year 2002*. Available at www.bsped.org.uk/professional/diabetesuk/NationalPaediatricAudit.pdf

Diabetes UK. *Local Diabetes Care: access all areas*. Accessed November 2005 at www.diabetes.org.uk

Diabetes UK and Department of Health. *Structured Patient Education in Diabetes*, June 2005

Diabetes UK and Dr Foster. *Your Local Care 2005. – A survey of Diabetes Services provided by PCTs*, October 2005.

Essex Strategic Health Authority. *Local Delivery Plan 2004/2005*. Available at: www.essex.nhs.uk/documents/framework/localdeliveryplanjune04.pdf

National Electronic Library for Health. *National Screening Committee : diabetic retinopathy screening*. Accessed 2006 at: <http://libraries.nelh.nhs.uk/screening/viewResource.asp?mr=10&offset=30&dg=&searchText=&attributeText=Health+Policy&categoryID=&attributeOptionID=&keywordID=14216&uri=http%3A//libraries.nelh.nhs.uk/common/resources/%3Fid%3D60985>

National Institute for Clinical Excellence *Guidance on the use of patient-education models for diabetes*. 2003. Available at <http://www.nice.org.uk/page.aspx?o=TA60>

Royal College of Nursing. *Specialist Nursing Services for Children and young People with Diabetes*. 2006

World Health Organisation. *Diabetes Action Now Booklet*. Available at www.who.int/diabetes/BOOKLET_HTML/en/print.html

Yorkshire and Humber Public Health Observatory (YPHO), *Diabetes: key facts*. March 2006 available at www.diabetes.nhs.uk/downloads/YHPHO_Diabetes_key_facts.pdf

National Screening Committee. *Second Report of the National Screening Committee* www.nsc.nhs.uk/pdfs/criteria.pdf

National Screening Committee. *Criteria for appraising the viability, effectiveness and appropriateness of a screening programme*, March 2003. Available at: www.library.nhs.uk/screening/ViewResource.aspx?resID=59772&tabID=288

Documents from Essex Diabetes Networks

We received a number of documents including emails from the 5 diabetes networks.

Mid Essex

- Progress on Implementing the NSF. Linda Jewsbury 4 October 2005
- Mid Essex Network – Milestones. December 2005.
- Mid Essex Hospital Trust. Guidelines for the antenatal, Intrapartum and Postnatal Management of Women with Diabetes
- Progress on NSF. Mid Essex Hospital Trust. Back up page and Website. Jane Young. 30 September 2005
- Linda Jewsbury. *Email to Glyn Jones: Prevalence data* 2 February 2006.
- Jane Young *Email to Glyn Jones: Progress on standards: 1 and 2, 7,8,9* 30 January 2006.

- Sara Arun *Email to Glyn Jones: Further information on Children's Services* 30 January 2006.

North East Essex Network

- North East Essex Network – *My Diabetes Record. Personal Records Pilot.*
- *Implementation of the Diabetes NSF in Tendring PCT and Colchester PCT.* Linda Smyth, 30 September 2005.
- Diabetes Services. Local Delivery and Planning Network. Jane Murphy. December 2002
- Essex Rivers Hospital Trust/Network. Diabetic Guidelines (Clinical). January 2005. Sent by Charles Bodmer, 27 September 2005.
- Strategic Outline Business Case. Developing and Investing in the Diabetes Service Across Primary and Secondary Care Oct 2003. Sent by Charles Bodmer, 27 September 2005.
- Diabetes and Endocrine Services. June 2005. Sent by Charles Bodmer, 27 September 2005.
- Transitional care for the adolescent with diabetes through to adult care. Shelagh Newman. April 2005. Sent by Charles Bodmer, 27 September 2005.

South East Network

- South East Essex Network – Joint Policy Statement on Microalbumin Screening in People with Diabetes. March 2005
- Southend Hospital Trust. Guideline for the Management of Diabetes. November 2004.
- Southend Hospital Trust. Patient Record Card.
- Diabetes Scrutiny Study. Progress on the NSF. Jules Martin. 30 September 2005.
- Progress towards the NSF. George Malinowski. On behalf of Castle Point and Rochford and Southend-on-Sea PCT. 30 September 2005.
- Note on Diabetes Community Nursing Services. Sent by Bryan Heap. 26 September 2005
- Southend on Sea PCT. *Annual Report of the Director of Public Health, 2004.*
- John Crofts *Email to Glyn Jones: Progress on Standards 3, 7 and 9,* February 2006.

South West Network

- South West Essex Network – Adult Diabetes Implementation Plan. Nov 2005.
- South West Essex Network – Children's Diabetes Implementation Plan. Nov 2005.
- Note: Basildon and Thurrock University Hospitals Trust. Information for Diabetes Study. Sanjay Gupta. 7 October 2005
- Note: Diabetes Services in Thurrock. Wendy Alleway 3 October 2005
- Note: Progress in Billericay, Brentwood and Wickford. John Tuppen. 29 September 2005
- Note: Progress on the NSF. Belinda Brook. 20 September 2005

- Note: Describing a Patients Contact with Health/Social Services – A multi layered approach. Sue Roberts. 2005
- Maria Berridge. *Email to Glyn Jones*. 31 January 2006
- Maria Berridge *Email to Glyn Jones*. 23 January 2006

West Essex

- Epping Forest PCT. *Note on Progress on the NSF*. Kirsty Boetcher. 30 September 2005.
- Harlow PCT. *Note on Progress on the NSF*. Lorna Burnside. 23 September 2005.
- Princess Alexandra Hospital Trust. *Note to HOSC on progress in implementing the NSF Standards*. Deborah Gunn Roberts 10 October 2005.
- Uttlesford PCT. *Note on Progress on the NSF*. John Hockey. 20 September 2005
- West Essex Diabetes Network. *Diabetes Network Terms of Reference*, November 2005. Sent by Jane Tadman.
- West Essex Diabetes Network. *Patient Journey*, January 2006. Sent by Jane Tadman
- Jane Tadman *Email to Glyn Jones: Prevalence Data for Uttlesford*, 1 November 2005.

Panel Meetings

Minutes of the following panel meetings can be found at (<http://194.72.123.51/applications/agenda/default.htm>):

- 29 March 2005
- 29 July 2005
- 10 October 2005
- 7 November 2005
- 7 December 2005
- 12 December 2005
- 13 December 2005
- 16 December 2005
- 12 January 2006
- 22 February 2006
- 10 March 2006
- 26 April 2006

Appendix Seven: Glossary

BERTIE	Bournemouth Type 1 Intensive Education Programme
CHD	Coronary Heart Disease
DAFNE	Dose Adjustment For Normal Eating
DESMOND	Diabetes Education and Self-Management for Ongoing and Newly Diagnosed
DH	Department of Health
DSN	Diabetes Specialist Nurse
GP	General Practitioner
GPwSI	GP with Special Interest
HOSC	Health Overview and Scrutiny Committee
NHS	National Health Service
NICE	National Institute for Clinical Excellence (now National Institute for Health and Clinical excellence)
NSC	National Screening Committee
NSF	National Service Framework
PCT	Primary Care Trust
PPI	Public and Patient Involvement
PUMP	Pump Management for Professionals
SHA	Strategic Health Authority
YPHO	Yorkshire and Humber Public Health Observatory
X-PERT	A structured education programme for adults with type 2 diabetes

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