

Behind closed doors?

The hidden impact of diabetes in social care

Report by the Institute of Diabetes for Older People and Novo Nordisk

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idop



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Contents

Foreword – Professor Alan Sinclair and Peter Meeus	1
Executive summary and key recommendations	2
Chapter 1: The diabetes challenge	3
Chapter 2: The cost of diabetes in social care	12
Chapter 3: Addressing the challenge	22
Conclusion	28
Appendix	29
References	30

Foreword

Diabetes is a growing challenge not just to the NHS but to the broader health and social care system. Diabetes prevalence increases with age. As our society ages, there is an ever greater need to understand the impact of the condition both on those older people with diabetes and the services set-up to deliver their care.

Originally launched in May 2008, the Institute of Diabetes for Older People (IDOP) is a non-profit making, research and academic institution, dedicated to enhancing the health and wellbeing of all older people with diabetes and related metabolic illness. The Institute is a leading voice in the field of diabetes and older people and is at the heart of the vast majority of the national work being progressed in this area of speciality.

Strategic partnerships have been established by the Institute with a host of high-profile organisations, including the Department of Health and Diabetes UK. This project in collaboration with Novo Nordisk seeks to for the first time quantify the costs of diabetes to the social care system.


Novo Nordisk is a global healthcare company with 90 years of innovation and leadership in diabetes care. Its aspiration is to change the future of diabetes. This means constantly striving to defeat diabetes by finding better methods of diabetes prevention, detection and treatment, working to deliver better outcomes for people with diabetes and for the NHS, and to improve the quality of life for those people living with the condition.

The project uses publically available datasets and discussions with leading stakeholders in social care to develop an estimate of the cost of diabetes to the social care sector. It also provides an initial exploration of the impact of diabetes related complications, such as hypos, on health and care services and also the wider impact of diabetes in social care settings, particularly on carers and broader societal costs. The report also looks at the likely rising future cost of the condition, if current trends continue.

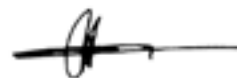
There is currently a great deal of support for integrating health and social care services with a number of initiatives and processes underway, both by Government and the Opposition, to bring organisations within the system closer together. This support is welcome and the report identifies integrated care as a key opportunity to address the diabetes social care challenge.

The report's ten recommendations include a number of mechanisms for making integration happen, particularly at a local level through the closer collaboration of health and social care commissioners. The report includes case studies of local integrated diabetes care to demonstrate how services for people with the condition can be effectively integrated and the benefits this can bring.

There is no doubt that grappling with how best to support and care for a growing number of people with diabetes accessing social care can seem daunting and overwhelming. Numbers are rising, costs are growing and commissioner budgets are stretched. This report sets out a new approach to tackling the diabetes challenge in social care, through more integrated, person-centred care where patients get access to treatment and support that improves care quality and reduces system pressures. It is an opportunity that should be seized.



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Executive summary and key recommendations

Diabetes is one of the most pressing health and social care challenges facing us today. Diabetes currently affects three million people in the UK¹ and this is expected to rise to 6.2 million by 2035². This increase will place significant pressures on the health and social care system.

To date much of the analysis of the impact of diabetes has focused on diabetes as a health only problem, costing the NHS an estimated £9.8 billion a year². This report finds that there is a growing need to re-appraise the way diabetes as a condition is prioritised, managed and resourced jointly within the health and social care system. The growing ageing population means that the number of people with diabetes in social care is set to grow rapidly, placing real pressures on local authority care budgets which are already strained and face multiple pressures.

Behind closed doors? The hidden impact of diabetes in social care finds that there are over 70,000 people with diabetes incurring local authority social care costs today, and that direct care costs from the condition amount to £1.4 billion. By 2030 it is estimated that the number of people in local authority care affected by diabetes will be 130,000 with an associated cost of £2.5 billion.

Furthermore, the impact of diabetes in social care extends beyond the direct cost of providing care for people affected by the condition. Complications associated with the condition including hypoglycaemic episodes, cardiovascular conditions and amputations place a huge burden on local health economies which will stretch the future sustainability of health and care services. More broadly, the societal and indirect costs of caring for people with diabetes include impacts on individual quality of life, lost productivity and increasing need for a broader range of state funded support.

In order to effectively address the impact of diabetes in social care, this research concludes that there is a need for a more integrated approach to managing diabetes across health and care settings for those in receipt of social care. This more co-ordinated approach to care would look to better address the needs of individuals with the condition, providing them with tailored support that improves outcomes and provides care more efficiently.

The new health and social care system presents a number of opportunities to deliver this, and with both Government and opposition parties embracing the integration agenda, there is a chance to change the way care is delivered for people with the condition to deliver improvements.

To make this a reality this research makes the following recommendations for bodies across the health and care system:

- The Department of Health should publish a new Action Plan for Diabetes which includes actions to support the integration of diabetes services across health and social care
- NHS England, in consultation with NICE, should develop a series of outcome measures for inclusion in the NHS and Adult Social Care Outcomes Frameworks to measure integrated care
- NHS England should develop a best practice portal for integrated care to showcase examples of commissioners effectively integrating services for patients, including people with diabetes
- NHS England should ensure that new incentive mechanisms, such as financial incentives and payment mechanisms, are introduced to incentivise high quality integrated diabetes care
- NICE should ensure that future iterations of the diabetes quality standard, setting out high quality care across the care pathway, cover care for people in social care settings
- Clinical commissioning groups should ensure that they are commissioning diabetes services in line with NICE guidance
- Local health and wellbeing boards should ensure that their forthcoming local integrated care plans include a focus on ensuring that people with long-term conditions such as diabetes benefit from more co-ordinated services
- Local health and wellbeing boards should ensure diabetes is appropriately prioritised in their Joint Strategic Needs Assessments (JSNA) and Joint Health and Wellbeing Strategies (JHWS)
- Local health and wellbeing boards should develop new longer term, more integrated budgets across health and social care to commission services for people with long-term conditions such as diabetes
- Local commissioners and local Healthwatch groups should review the information available to people with diabetes, and ensure that information is co-ordinated and targeted appropriately to support better self-management of the condition

Chapter 1: The diabetes challenge

Diabetes is a chronic condition which develops when the pancreas does not produce enough insulin to control blood glucose levels in the body. If high blood glucose levels are sustained this can cause irreparable damage to blood vessels and lead to further complications such as amputation, kidney failure, heart failure or stroke².

There are two forms of diabetes which can occur in patients. Type 1 is an autoimmune disease affecting approximately 10% of all those with the condition³. Type 2, which is preventable in most cases and the most common, accounts for almost 90% of those that have been diagnosed. It is most common among middle-aged and older people⁴.

Three million people in the UK have diabetes, making it one of the most common conditions in the UK¹ and an additional 850,000 people remained undiagnosed in 2012⁵. Diabetes is almost four times more prevalent than all cancers combined⁵ and accounts for nearly 15% of deaths in the UK every year⁴. People with diabetes also account for around 19% of hospital inpatients at any one time, and the length of an average stay is three days longer than for people without diabetes⁵. Diabetes therefore presents a pressing healthcare need.

Future projections for the condition indicate that the situation is likely to worsen considerably. Prevalence of diabetes has been projected to increase to 6.2 million by 2035². Brent is currently the only local area to have approximately more than 1 in 10 people diagnosed with the condition. However, if diabetes continues to increase at the current rate, six other localities are forecast to reach this rate by the end of the decade, putting significant pressures on local health and care economies⁶.

Funding diabetes care

At the local level, clinical commissioning groups (CCGs) are responsible for commissioning local health services. They will assess their local resources and allocate the national funding that they receive to local services, which will of course include diabetes care. In assessing how they prioritise and allocate their resources, CCGs will have regard to a number of national and local policy and accountability levers (such as the NHS Outcomes Framework and Clinical Commissioning Group Outcomes Indicator Set) as well as their local population needs (outlined in their joint strategic needs assessments). In relation to diabetes care, professional guidance and publications such as the NICE diabetes in adults quality standard may support CCGs to design and monitor these services in line with best practice.

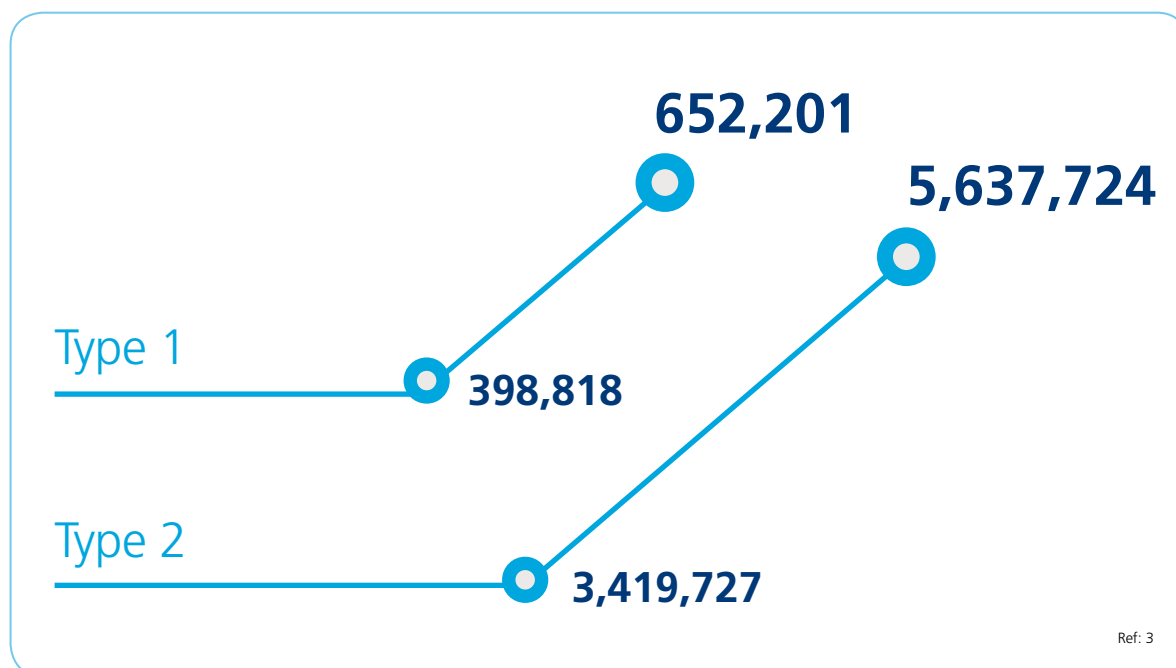


Figure 1: The rising estimated prevalence of diabetes in the UK from 2010/11 to 2035/36

Chapter 1: The diabetes challenge

Social care commissioning is undertaken by local authorities. Like their counterpart CCGs, the commissioning priorities and practices of local authorities will be driven by the relevant national and local social care policy levers, accountability arrangements and needs. These may include the Adult Social Care Outcomes Framework.

As the funding streams and commissioning arrangements for local authorities and CCGs remain separate, it is only in exceptional cases that these commissioners will pool their budgets and jointly agree priorities and services for both health and social care.

Recent guidance from Diabetes UK, outlining best practice management of diabetes needs in social care, includes what are often intertwined healthcare and social care practices. These include:

- Care planning and case management
- Guidance on adequate diet and nutrition
- Specialist health professional input
- Structured and timely appointments with medical staff

Given the nature of these needs, it is clear that active negotiation and joint funding and planning is required between both health and social care commissioners to deliver optimal services which deliver these practices. However, assessments by Diabetes UK have found that both planning and delivery of these practices is poor across the board. As such, it is clear that, with health and social care commissioners working distinctly from each other and according to their own priorities, budgets, and ambitions, people with diabetes needs will not receive the optimal and holistic care they require in social care settings. Instead, they will receive distinct care support packages to address their diabetes-related health and care needs.

Ambitions for joint funding and more integrated services are developed further, later in this report⁷.

Current service: variations in the quality of diabetes care in the NHS

Within the NHS, the quality of care being received by people with diabetes varies greatly.

Two thirds of people with type 1 diabetes (68%) and almost half of people with type 2 diabetes (48%) in England are missing out on the nine care processes recommended by NICE⁸. Poor diabetes care and management causes 24,000 avoidable deaths occur each year⁵. In addition, 100 lower limb amputations occur every week due to diabetes⁵, and people with type 2 diabetes have a two-fold increased risk of stroke within the first five years of diagnosis⁴.

A recent report by the National Audit Office (NAO) concluded that variations in the quality of care for diabetes patients cannot be explained by demand or spend alone, and are likely to be influenced by the local organisation and management of health services⁹. A report from the Public Accounts Committee (PAC) in response to the NAO report found that NHS accountability structures have failed to hold commissioners of diabetes services to account for poor performance, as there are no mandatory performance targets like those in place for other conditions, such as cancer¹⁰. It also found that information on diabetes is not being used effectively by the NHS to assess quality and improve care, and that many people with diabetes develop avoidable complications because they are not effectively supported to manage their condition¹⁰. The PAC called on the Department of Health to set out how the NHS will deliver improvements in diabetes care under the new accountability arrangements, in addition to improving integrated health and social care for people with diabetes¹⁰.

“Variation in the level of progress across the NHS... means that there is an unacceptable ‘postcode lottery’ of care, whereby the quality of diabetes care varies dramatically.”

Commons Public Accounts Committee,
November 2012¹⁰

Chapter 1: The diabetes challenge

The Government has committed to publish a Diabetes Action Plan to replace the National Service Framework for Diabetes, which has been in place for over 10 years and expired at the beginning of 2013. A number of policy levers currently seek to improve diabetes care across the NHS and public health – including the NICE quality standard, the Quality and Outcomes Framework, and the Public Health Outcomes Framework – and it is envisaged that the Diabetes Action Plan will provide an overarching, strategic plan to improve diabetes outcomes.

However, no indication has yet been provided by the Department of Health about when the Diabetes Action Plan will be published. As such, the challenge currently remains firmly with each clinical commissioning group to work with local stakeholders to improve the design, delivery and monitoring of diabetes services in their locality, and reduce variation in the quality of care provided.

Diabetes in social care settings: a rising challenge

Whilst there is wide-ranging evidence which indicates that diabetes is a pressing healthcare need which requires greater prioritisation and improvement, there is little evidence available which demonstrates the vast impact the condition has on social care.

Alongside introducing its reforms to the NHS, the Coalition Government has sought to streamline and improve the way that social care services are provided and commissioned across England. As part of this, it has published the Care Bill, which aims to reform what is, in places, archaic common law relating to care and support for adults, and support for carers.

The Bill includes provisions for safeguarding adults from abuse or neglect and describes basic care standards that contribute to the health and wellbeing of those receiving care. Importantly, high quality management of diabetes and other long-term conditions can have a significant part to play in improving the health and wellbeing of those receiving care. It can also contribute to improved outcomes against the Adult Social Care Outcomes Framework, including enhancing quality of life for people with care and support needs (domain one), delaying and reducing the need for care and support (domain two) and ensuring that people have a positive experience of care and support (domain three).

“The current economic climate means that there is likely to be little or no growth in NHS funding over the next five years.

With the significant rise in the number of people in England with diabetes, the NHS Commissioning Board [now NHS England] must therefore ensure that services for this large population are adequate, and deliver the recommended standards of care.

This will help minimise the additional costs to the NHS from complications, arising because standards are not being met.”

The National Audit Office,
May 2012⁹

These developments are set against a backdrop of transformation in the delivery of health and social care services, particularly at local authority level.

These changes include:

- Transfers of funds from the NHS to social care to support integrated care initiatives
- The development of health and wellbeing boards within local authorities, including local councillors, directors of public health, directors of adult social services and local Healthwatch representatives
- The production of joint and health and wellbeing strategies setting out health and social care priorities for localities, and feeding into and supporting scrutiny of commissioning plans

Chapter 1: The diabetes challenge

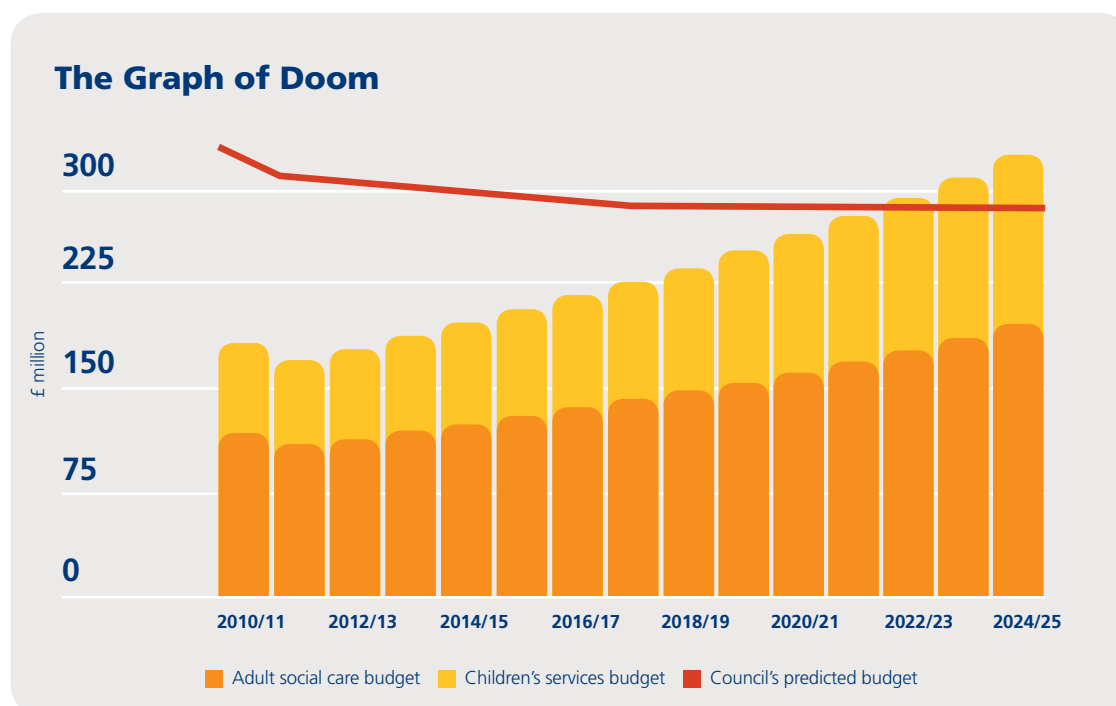


Figure 2: *The Barnet Graph of Doom*

Ref 11

These changes come at a time of rising pressures on services through a combination of increasing demand and downward pressure on care funding. This has most clearly been demonstrated through the Barnet 'Graph of Doom', developed by Barnet Council in London. The graph above illustrates that if current trends persist, the local authority will be unable to provide any services except adult social care and children's services in the next ten years.

At a time of heightened awareness about, demand on, and scrutiny of, social care services, the management of healthcare needs within a social care setting has a critical role to play in ensuring that social care can deliver high quality care to service users in a cost-effective manner.

Given the prevalence of type 2 diabetes within older age groups⁴, the cost on social care is set to be high, a cost which is only set to rise amidst the UK's ageing society. A report by the House of Lords Select Committee on Public Service and Demographic Change, published in early 2013, predicted that demand for health and social care for people with diabetes in England and Wales will rise by 45% from 2010 to 2030¹².

Whilst there is little evidence of the full cost impact that diabetes has within social care, there is some evidence available on how diabetes is managed within care homes. Research currently estimates that one in four people in care homes have been diagnosed with the condition¹³ and that one care home resident with diabetes is admitted to hospital approximately every 25 minutes due to failings in screening and training¹⁴. An assessment found that 60% of care homes with diabetes residents had no training provision, and that nearly two thirds of local authorities have not made an assessment of the needs of older people with diabetes in their area¹⁴.

Chapter 1: The diabetes challenge

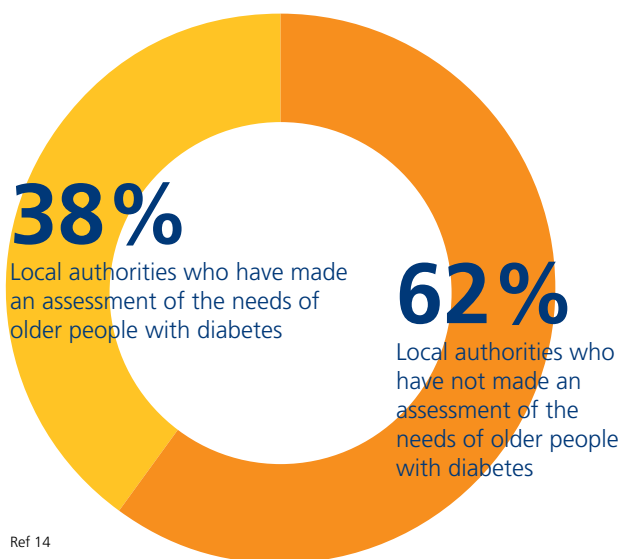


Figure 3: Percentage of local authorities who made an assessment of the needs of older people with diabetes in their local area in 2010

A report from Diabetes UK also found that in 2010 less than a quarter of care homes screened residents for diabetes on admission, and less than a third screen for the condition on an annual basis. This failing in screening means as many as 13,500 care home residents in the UK could have undiagnosed type 2 diabetes and therefore be at increased risk of complications associated with the condition¹⁴. This creates a further cost on health and social care services which result from the management and treatment of such complications which arguably could have been prevented.

This overview of care within care homes provides only a tiny segment of a far larger challenge across social care settings, which must be considered in order to gain a full understanding of the impact that diabetes has within social care.

Given the forecasts of increasing demand for social care and the increasing prevalence of diabetes – particularly within an older demographic – it is imperative to recognise the impact and costs of diabetes in social care and to consider how these costs can be addressed.

Diabetes in social care: broader considerations

Cost estimates which have been outlined so far have not provided a full assessment of the associated costs of diabetes. An older person with diabetes has an increased likelihood of frailty and multiple co-morbidities and, as a more vulnerable group, older people with diabetes and care needs have a higher prevalence of complications.

Evidence suggests that people over the age of 65 with diabetes are up to 80% more likely to become physically disabled than those who do not have the condition¹⁵. Cognitive complications of diabetes are also more common amongst the elderly¹⁶. Furthermore, many elderly diabetic people are pre-disposed to hypoglycaemia¹⁶. In addition, exercise and adapting a diet can also be more difficult for elderly people. As a result, diabetes-related complications are not only more common amongst the elderly, but they can also be harder to manage.

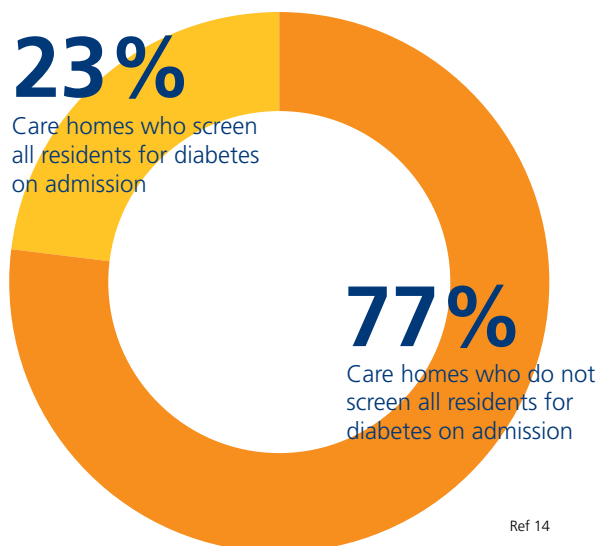


Figure 4: Care homes screening residents for diabetes needs on admission in 2010



Case Study

"We were all very upset when [one of our care home residents] got so poorly that she needed to go to hospital. Fortunately for us, the local CCG has prioritised health care provision in care homes.



The local diabetes specialist nurses, primary care team and [Home and Communities Agency] HCA have been evaluating the care we provide to our residents and have also been educating the care home staff regarding how to look after the different aspects of diabetes care.

This has included treating hypoglycaemic attacks, medication management, monitoring blood glucose and, most importantly, ensuring people with diabetes undertake some physical activity

and follow a healthy diet to reduce their chances of developing cardiovascular problems.

This work has been very valuable as we have local general practitioners, specialist nurses and educators working together with us and it is great to get the one common message in looking after residents who have diabetes. I have also completed a certificate in diabetes care and now I am the link worker for diabetes."⁷

Chapter 1: The diabetes challenge

These complications can considerably reduce the quality and length of life for older people. They also create substantial and additional health and social care costs³, through escalated care and support needs, and increased hospital admission rates. Given that estimates demonstrate that almost 80% of the NHS funding associated with diabetes is spent on the management of long-term complications⁵, it is likely that this figure will rise given an ageing population and the growing prevalence of the condition.

In developing a true picture of the impact of diabetes in social care, it is clear that the cost of managing complications and other severe co-morbidities must be considered. However, this is outside the scope of this project, but remains an opportunity for further research to build on the direct cost of diabetes outlined in more detail in the next section of the report.

Indirect costs of diabetes

Diabetes can result in a number of additional and indirect costs to the individual and the economy. This can include reduced productivity, absences from work, early retirement, welfare and disability benefits, and carer costs¹⁷.

In 2010/11, an estimated 37,000 working years were lost from deaths caused by type 1 diabetes and approximately 288,000 working years lost from deaths caused by type 2 diabetes. As such, deaths from type 1 diabetes are estimated to have lost the economy an estimated £600,000, whilst death from type 2 diabetes is estimated to have lost the economy an estimated £4.2 billion.

Productivity loss has also caused an additional cost to the UK economy. Studies estimate that 830,000 sickness days were taken during 2010/11 for type 1 diabetes patients, and more than seven million absences were taken during the same year for type 2 diabetes. This caused an estimated productivity loss of £3.8 billion for both type 1 and type 2 diabetes patients³.

Indirect costs can also be found in the number of diabetes patients who require informal care. There were an estimated 1,160,000 people with diabetes (over the age of 70 years) requiring some form of informal care in the UK in 2010/11. This equated to over 336 million hours of social care and cost an estimated £5 billion for people with type 2 diabetes³.

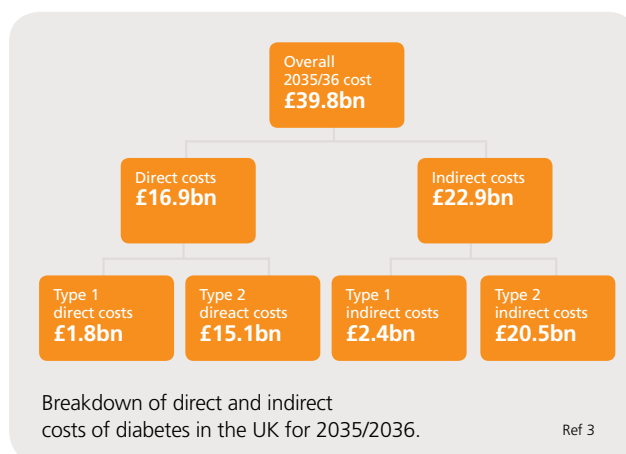
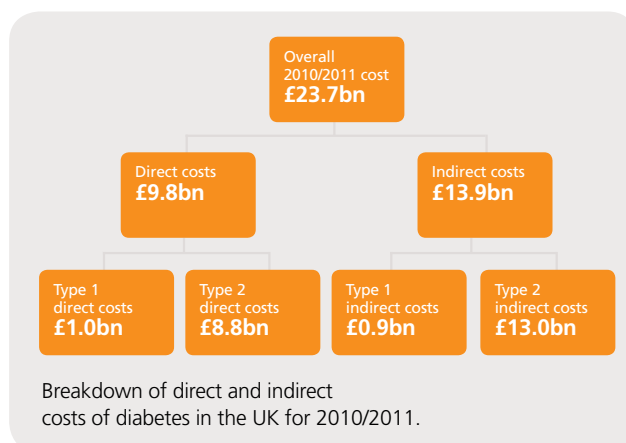
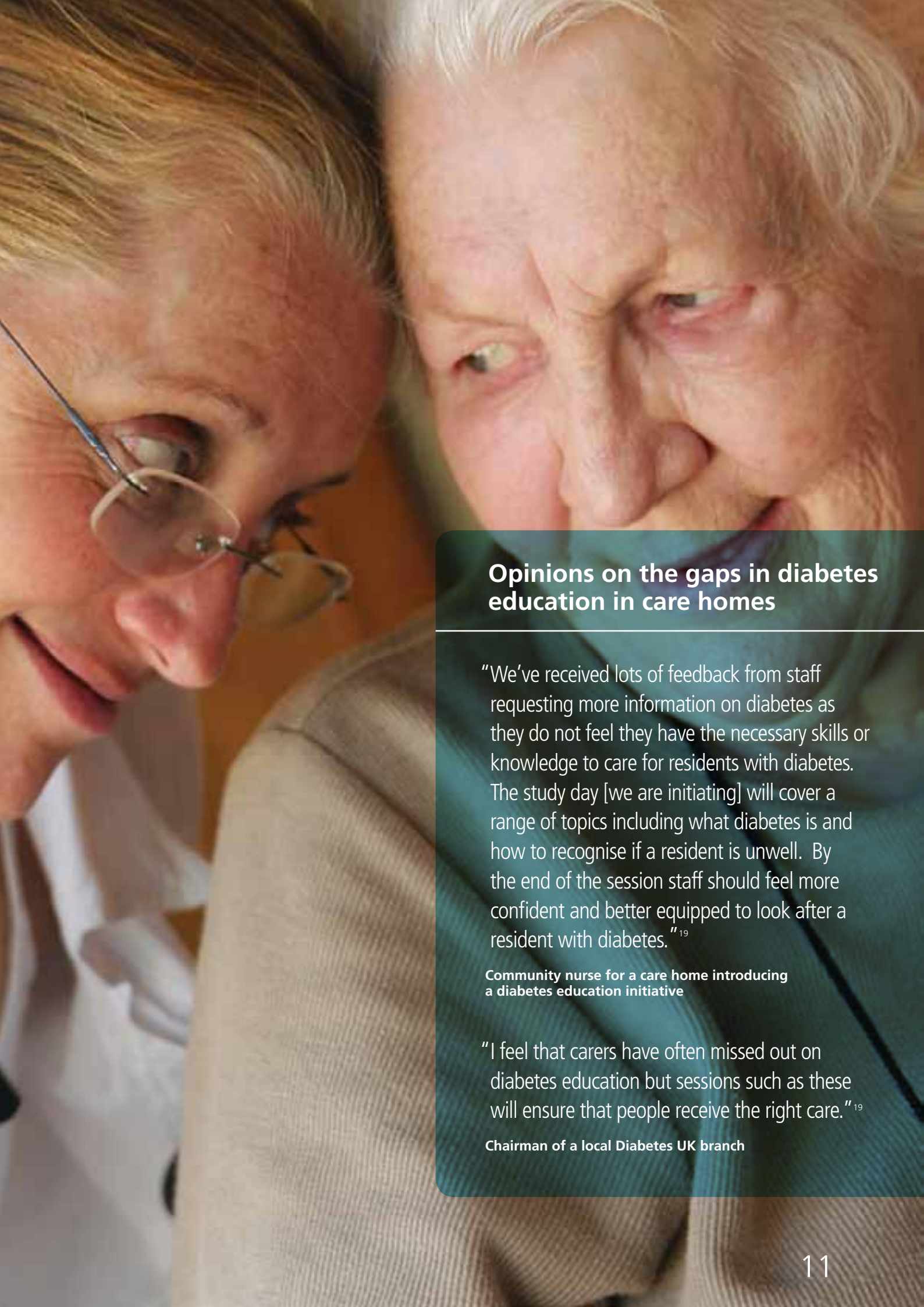


Figure 5: Predictions about escalated diabetes costs

Benefits claims constitute an additional indirect cost from diabetes. In February 2013, 22,000 claims for the Disability Living Allowance (DLA) amongst people of working age cited their main disabling condition as diabetes¹⁸.

In assessing the complete cost of diabetes to the UK – that is, adding to the direct cost of the condition as well as the costs associated with complications to indirect costs – one estimate suggests that the condition costs a total of £23.7 billion. Furthermore, estimates suggest that, with the growing prevalence of the condition, the total cost is set to rise to £39.8 billion by 2035/36². The scale of these figures underlines the imperative for high quality prevention, management and treatment of diabetes not only within the NHS, but across all care settings.



Opinions on the gaps in diabetes education in care homes

"We've received lots of feedback from staff requesting more information on diabetes as they do not feel they have the necessary skills or knowledge to care for residents with diabetes. The study day [we are initiating] will cover a range of topics including what diabetes is and how to recognise if a resident is unwell. By the end of the session staff should feel more confident and better equipped to look after a resident with diabetes."¹⁹

Community nurse for a care home introducing a diabetes education initiative

"I feel that carers have often missed out on diabetes education but sessions such as these will ensure that people receive the right care."¹⁹

Chairman of a local Diabetes UK branch

Chapter 2: The cost of diabetes in social care

According to available data sources, 519,000 people in England were using nursing, residential or home care services in 2011/12. The large majority of these were over 65 years of age, an age at which long-term conditions and multi-morbidities become increasingly prevalent – indeed it is estimated that by the age of 65, 60% of people will have one or more long-term condition²⁰.

The total cost to local authorities of providing care for people in residential, nursing and home care settings in 2011/12 was £11.3 billion. While the costs of paying for care are well understood, there is limited information on the cost of providing healthcare services in social care settings, including the cost of diabetes.

There is very little official information on the prevalence of diabetes in social care settings. While some studies have suggested that the prevalence rate in care homes may be as high as 26%²¹, the studies have been relatively small scale and have not been used to project an estimated national prevalence. However, one wider study has suggested that 20% of care home residents in the UK suffer from diabetes²². Furthermore, it is estimated that one in 20 people with diabetes incur social care costs – three-quarters of this in nursing and residential care and a further one fifth in home care²³. These demands on services are only expected to rise as the proportion of people with diabetes increases.

Using data from the Health and Social Care Information Centre, the Office for National Statistics and the Yorkshire and Humber Public Health Observatory, we have been able to produce an estimate for the prevalence of diabetes in social care settings operated and paid for by local authorities.

We estimate that in 2011/12 there were 74,069 people in residential, nursing or home care settings who had diabetes. This includes both those over 65 years of age and those aged 18-64 with mental health or physical needs and those with learning disabilities.

Over half of those with diabetes in social care settings were aged over 65 and were using home care services. Less than 10% were aged between 18 and 64 in all healthcare settings. Prevalence of diabetes is significantly higher amongst people over the age of 65 who are also the most frequent users of social care services²⁴.

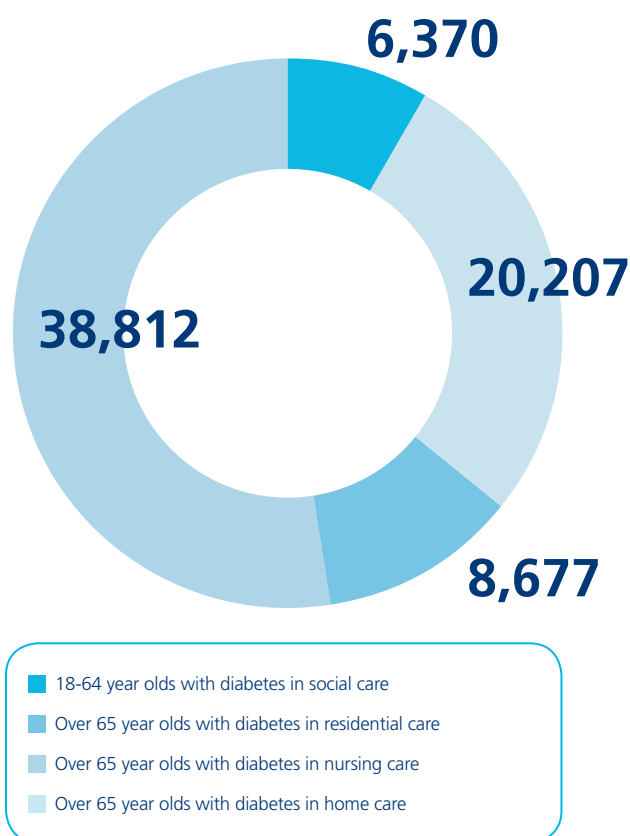


Figure 6: Our estimates: number of people with diabetes in social care settings by different social care setting in 2011/12

The number of people in social care settings with diabetes was calculated by using local authority prevalence data from the Yorkshire and Humber Public Health Observatory (YHPHO) and local authority social care population data from the Health and Social Care Information Centre (HSCIC) as part of Personal Social Services Expenditure data.

The estimate prevalence, based on population figures and the number of people from different age groups and of different ethnicities in each local authority is 14.28% across England, ranging from 23.4% to 9.98%. Figure 7 overleaf shows the variation in diabetes prevalence in social care settings across England by local authority.

Chapter 2: The cost of diabetes in social care

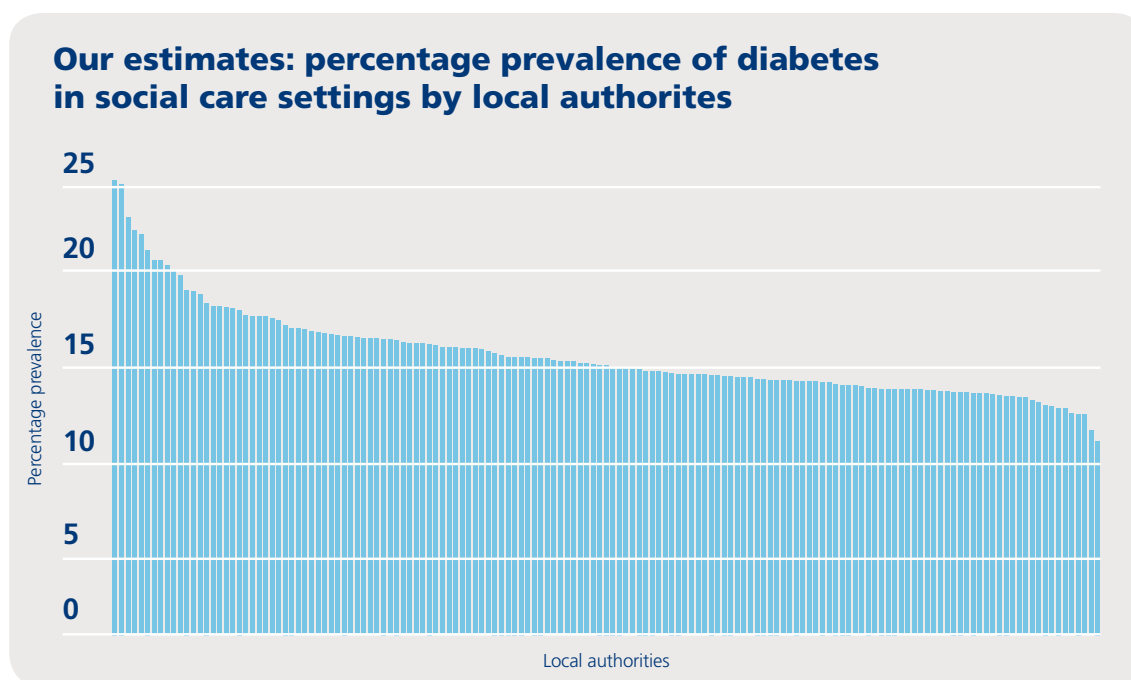


Figure 7: Our estimates: percentage prevalence of diabetes in social care settings by local authorities in 2011/12

The number of people in social care settings with diabetes was calculated by using local authority prevalence data from the Yorkshire and Humber Public Health Observatory (YHPHO) and local authority social care population data from the Health and Social Care Information Centre (HSCIC) as part of Personal Social Services Expenditure data.

Using these estimated figures and unit cost data from the Health and Social Care Information Centre, we have also been able to determine an estimate for the amount that is spent on caring for people with diabetes in social care settings. Across England, we estimate that caring for people with diabetes in social care settings costs £1.442 billion.

The largest cost was for residential care for people aged over 65 years with diabetes, costing an estimated £600 million. The smallest cost was for caring for 18-64s with diabetes across all care settings, costing an estimated £223 million.

There were significant variations between local authorities in the estimated amount spent on people with diabetes in social care.

The total amount spent on caring for people with diabetes in social care settings represents 12.67% of the total amount spent on caring for people in residential care, nursing care and home care settings across England.

The impact of diabetes complications

These figures do not take into account complications associated with diabetes, including hypoglycaemia, or abnormally low blood glucose levels. Patients with hypoglycaemia may have different symptoms such as nervousness, shaking, confusion, agitation, perspiration or altered level of consciousness. Hypoglycaemia may lead to coma, brain damage or even death if left untreated²⁵.

The average patient with type 1 diabetes experiences two episodes of symptomatic hypoglycaemia a week and 30% experience one or more episodes of severe hypoglycaemia a year. The UK Hypoglycaemia Study Group has reported rates of up to three severe episodes a year for those with diabetes for over 15 years. A patient with type 2 diabetes, on insulin for less than two years, experiences four episodes of mild hypoglycaemia a year, and 7% of those treated with sulphonylurea or on insulin for less than two years experience one or more episodes of severe hypoglycaemia²⁶. A study by NHS South Central estimated that the annual cost of emergency calls for severe hypoglycaemia is £13.6 million for England. However, this may be an underestimate as the incidence of hypoglycaemic episodes attended by the emergency services may substantially underestimate the overall numbers of episodes of severe hypoglycaemia²⁶.

People with diabetes whose condition is not appropriately managed are at risk of developing other complications including heart attacks, blindness, stroke and renal failure.



Case Study

"I'll be 78 years old at my next birthday. I've had type 2 diabetes for over twenty years and now I'm registered blind and have had a heart attack. I found it difficult to manage at home so last year I moved into [a residential home]. I like it here but I hadn't been in here long when I ended up in hospital with sky-high blood glucose levels and pneumonia. I was very frightened and I hope it doesn't happen again."⁷



Chapter 2: The cost of diabetes in social care

Unfortunately, it is not possible to separate social care costs and diabetes related care costs as there is limited data on the healthcare needs for people in social care, the costs of meeting those needs and the costs of complications resulting from a failure to meet those needs. For example, while we know that in 2011/12, 35,000 people over the age of 60 were admitted to hospital with a primary diagnosis of diabetes²⁷, it is not possible to identify those admitted specifically from social care, nor is it possible to identify those who were admitted for another reason but with diabetes as an underlying condition.

Using the estimated figures for the prevalence of diabetes in social care settings and the figures for the incidence of complications, it is possible to project the number of people in social care with diabetes who have suffered complications. The actual prevalence of diabetes complications in England and Wales, and our estimates of their incidence in social care settings are set out in Figure 8.

Diabetic complication	Prevalence of diabetes complications in England and Wales (%)	Our estimates: incidence of diabetes complications in social care settings
Angina	3.53	2,615
Myocardial infarction	0.73	541
Heart failure	2.27	1,681
Stroke	0.903	669
Renal replacement therapy	0.492	364
Minor amputation	0.153	113
Major amputation	0.087	64
Diabetic ketoacidosis (DKA)	0.427	316
Retinopathy treatment	0.479	355

Ref 28

Figure 8: Our estimates: incidence of diabetes complications in social care settings in 2010/11

The estimate number of people with diabetic complications was calculated by taking the percentage of the general diabetic population who suffer from each complication set out in the National Diabetes Audit report on complications and mortality and applying it to our estimate of the number of people with diabetes in social care settings set out in figure 6.

Chapter 2: The cost of diabetes in social care

It is estimated that treating diabetes complications accounts for 80% of the cost of diabetes to the NHS⁵.

Figure 9 sets out the costs of a range of diabetic complications to the UK, according to a recent study.

Diabetic complication	Cost (£)
Hypoglycaemia	72,178,150
Diabetic ketoacidosis (DKA)	15,957,160
Ischaemic heart disease	509,656,332
Myocardial infarction	603,069,221
Heart failure	308,157,806
Stroke	287,931,944
Kidney failure	514,066,538
Other renal costs	426,396,095
Retinopathy	57,741,842
Foot ulcers and amputations	985,600,282
Other CVD	1,654,855,114
Depression	33,209,175
Excess inpatient stays	1,822,829,640
Neuropathy	309,632,804

Ref 3

Figure 9: Estimated cost of diabetic complications to the UK in 2010/11

While there are no official data on the costs of treating diabetic complications arising out of poor disease management in social care settings, it is possible, by using these figures, to estimate the costs for certain complications. The potential costs of diabetic complications amongst people with diabetes using social care are set out in figure 10.

Chapter 2: The cost of diabetes in social care

Diabetic complication	Our estimates: cost of treating diabetic complications in social care settings (£)
Myocardial infarction	22,525,681
Heart failure	11,513,659
Stroke	10,763,542
Renal replacement therapy	35,143,542
Diabetic ketoacidosis (DKA)	595,709
Retinopathy treatment	2,156,221

Figure 10: Our estimates: cost of diabetic complications in social care settings in 2010/11

The data in Figure 10 were calculated by using the estimated cost data set out in Figure 9 and the prevalence data in Figure 8. We first calculated the cost of each complication per capita and then multiplied this figure by the estimated number of people suffering from each complication in social care settings.

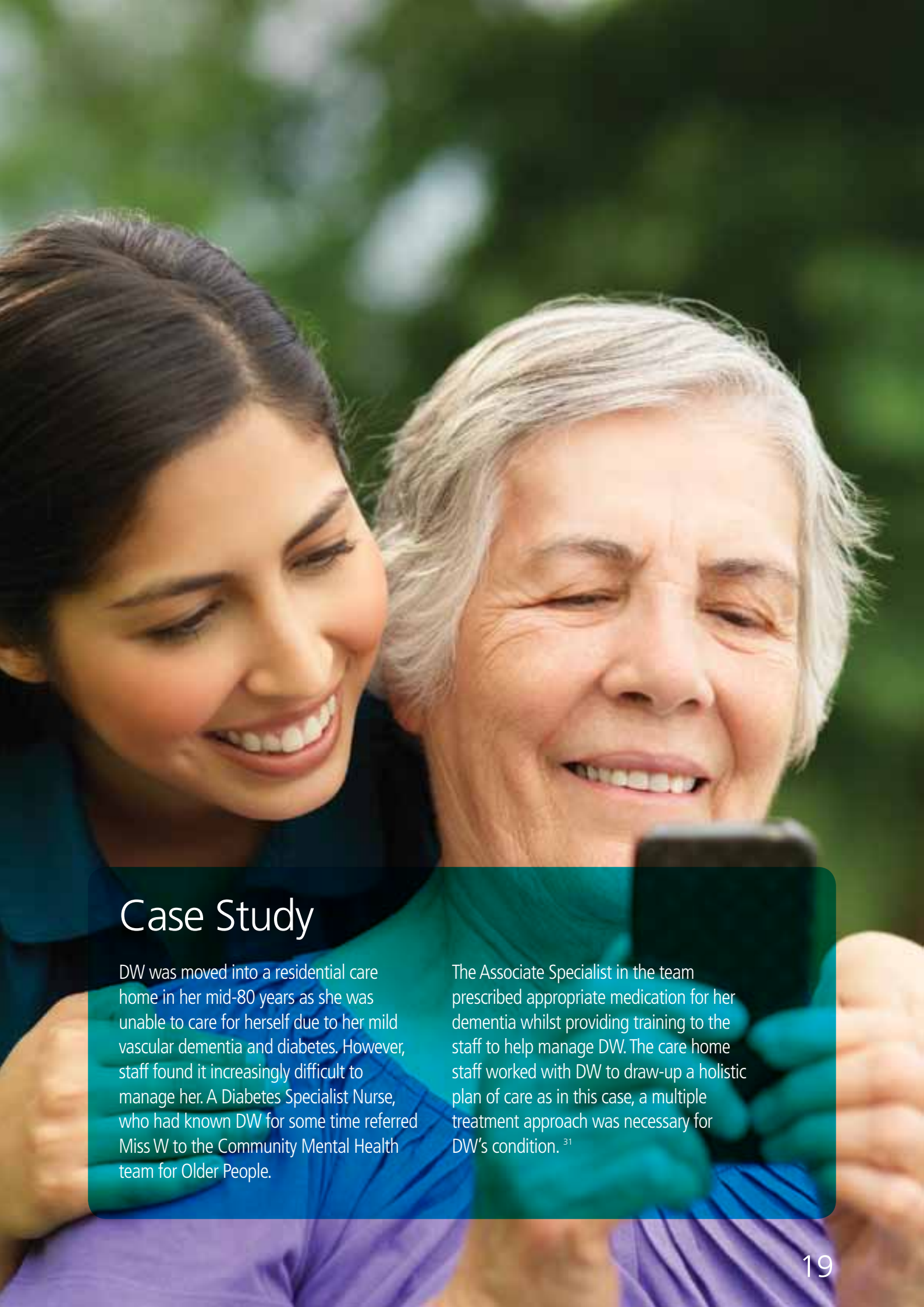
While this is only a selection of the complications of diabetes, these figures give a snapshot of the costs of poor disease management in social care settings, and indeed highlight the potential savings that can be made. In 2007, the Department of Health found that complications due to diabetes increased the cost of providing social care four-fold²³. Not only do these complications pose significant costs to health and social care services, they can be very debilitating for people with diabetes and have a serious impact on their quality of life.

It is not just formal, local authority-provided care that represents a cost to the economy. It is estimated that 1.16 million people over the age of 70 with diabetes require some form of informal care – provided by spouses or adult children – at a cost of just under £5.2 billion to the economy³. In addition, there will be social care provided by the independent sector for which there is no available usage or unit cost data.

Co-morbidities and societal costs

The challenge of diabetes should not be seen in isolation. A significant portion of people receiving local authority-funded social care, will have more than one condition, and diabetes is linked to a range of other conditions. One cohort study in Ireland suggested that up to 90% of people with diabetes, across all age groups, have at least one co-morbidity including heart disease (25%) and arthritis (16%)²⁹. Another study estimates that 75% of people with diabetes have hypertension³⁰. The total cost of diabetic cardiovascular complications – including ischemic heart disease, myocardial infarction, heart failure and stroke – to the UK is estimated to be over £3.36 billion³.

However, while the links between diabetes and cardiovascular disease are well understood, there is increasing evidence that it is linked to other diseases of old age such as dementia.



Case Study

DW was moved into a residential care home in her mid-80 years as she was unable to care for herself due to her mild vascular dementia and diabetes. However, staff found it increasingly difficult to manage her. A Diabetes Specialist Nurse, who had known DW for some time referred Miss W to the Community Mental Health team for Older People.

The Associate Specialist in the team prescribed appropriate medication for her dementia whilst providing training to the staff to help manage DW. The care home staff worked with DW to draw-up a holistic plan of care as in this case, a multiple treatment approach was necessary for DW's condition. ³¹

Chapter 2: The cost of diabetes in social care

It is estimated that diabetes increases the risk of developing dementia by between 63 and 176% depending on what stage the condition is diagnosed³². According to the Alzheimer's Society, dementia costs the UK around £23 billion a year³³. Given that recent studies suggest that higher blood glucose levels may be a risk factor for dementia, even among people without diabetes³⁴, it can be suggested that glucose control is important in reducing the risk of developing dementia.

Beyond dementia, it is estimated that 30% of all people with diabetes will have a mental health problem, such as depression or anxiety³⁵. Indeed, diabetes is thought to up to double the risk of depression³⁵. These mental illnesses present unique and difficult challenges to managing diabetes and preventing complications from developing, as well as impacting on people's quality of life. In addition, it is estimated that depression resulting from diabetes costs the UK over £33 million a year³ – this does not take into account the cost of poor self-management as a result of depression or other mental illness.

Furthermore, failure to appropriately manage blood glucose levels puts people at risk of developing hypoglycaemia. Research from the United States has found that older people, particularly those who have recently been discharged from hospital, or who are given a number of different medicines, are at increased risk of hypoglycaemia³⁶. Even mild hypoglycaemic episodes can cause extreme distress amongst older patients. Preventing hypoglycaemia enhances quality of life, boosts confidence, improves compliance with antidiabetic regimens and avoids the exacerbation of long-term complications³⁶.

Taking into account these complications and the broader societal costs of caring for people with diabetes are likely to mean that the actual true cost of diabetes on the care sector presented in this report is an underestimate of the true scale of the cost of diabetes in social care settings.

Future projections

As discussed in the previous section, the burden of social care costs on local authorities is a pressing issue. Evidence such as the 'Barnet Graph of Doom' highlights the need to reduce costs. Indeed, in light of the impact of complications on the costs of caring for people with diabetes in social care settings, identifying those with the condition and providing effective disease management is key to not only improving the quality of care, but also reducing expenditure.

Given the ageing population, and the ongoing rise in the prevalence of obesity⁸, the demand for social care from people with diabetes will increase. Using population projections from the Personal Social Services Research Unit (PSSRU) at the London School of Economics and our diabetes prevalence projections, it has been possible to estimate the future incidence and cost of diabetes in social care settings. Figure 11 below sets out the estimate number of people with diabetes in social care.

Year	Our estimates: people with diabetes in social care settings
2020	99,075
2025	111,741
2030	130,419

Figure 11: Our estimates: number of people with diabetes in social care settings from 2020 to 2030

The projection for diabetes in social care settings was calculated by applying our estimate prevalence of diabetes in social settings to projections of the future social care population provided by LSE and the Personal Social Services Research Unit.

Chapter 2: The cost of diabetes in social care

Between 2011 and 2030, we estimate that the incidence of diabetes in social care will increase by 76%. This figure could, in reality, be even higher as these figures are not age stratified.

The increase in the number of people with diabetes in social care settings will result in an increase in the cost of caring for people with the condition. In order to calculate this, we have assumed that the individual cost of caring for a person with diabetes in social care will remain the same as in 2011. Figure 12 below sets out the estimate cost of caring for people with diabetes in social care settings in the coming years.

By 2030, we estimate that it will cost over £2.5 billion a year to care for people with diabetes in social care. These figures do not take into account the costs of the complications of diabetes, which will be commensurately higher.

It is clear from these figures that diabetes is a major challenge for leaders in both health and social care, and is an issue that will not go away. It is vital that action is taken now to ensure that services are prepared to care for people with diabetes.

Year	Our estimates: cost of caring for diabetes in social care (£)
2020	1,928,829,317
2025	2,175,423,668
2030	2,539,059,982

Figure 12: Our estimates: cost of diabetes in social care settings from 2020 to 2030

The projection of the cost of diabetes in social care settings was calculated by first working out the cost of caring for each person with diabetes in social care settings using our previously calculated estimates, and multiplying by the projected social care population set out in Figure 11.

Chapter 3: Addressing the challenge

Despite the significant impact of the condition, addressing the challenge of diabetes in social care has not been a priority to date. Recent policy developments, however, do present an opportunity to better address the challenge, particularly through a focus on a more integrated approach to care.

The subject of integrated care is highly pertinent to diabetes care. The types of services which the average person with diabetes will need to access will depend on the specific nature of their condition. However, these could include screening and diagnostic tests; assessments of risk factors and complications; glycaemic control and monitoring; specialist referrals and specialist nursing; diabetes foot assessments and podiatry services; emergency admissions and acute care; social care and long-term care support. Diabetes patients should also be offered information on diet, lifestyle and exercise, as well as advice on managing their condition.

Integrated care for people with diabetes if delivered presents a series of opportunities for improvements, including:

- **Reduced system costs** – as a result of earlier intervention in the management of the condition and more co-ordinated planning enabling the earlier discharge of people with diabetes into a community setting
- **Better outcomes** – people with diabetes have greater support for the management of their condition and are able to access care and support more effectively when they need it
- **Broader benefits** – the improved management of the condition reduces pressures on family members and carers

However, there remain a number of significant barriers to better integrating diabetes care, and developing a model of care that is more individually tailored. These include:

- **Poor discharge planning** – with patients discharged from hospitals into the community either too quickly and without sufficient support, or being discharged too late following a period of de-conditioning in hospital
- **Fragmented information** – the current system for accessing information on the type of support available for patients is fragmented

- **Different care records** – the different information systems across health and social care remain a barrier to ensuring that up to date accurate information follows the patient
- **Competing incentives** – the incentives for health and social care commissioners often differ and can indeed compete against each other, preventing a more joined-up approach to diabetes care
- **Cultural barriers** – different approaches and languages in use in the health and care sectors, are an obstacle to more joined-up working
- **Budgets** – tight budgets are an ongoing challenge for health and social care commissioners. The use of one year budgets also encourages short-termist, silo-ed thinking which can result in service fragmentation

The current NHS and social care policy environment does present opportunities to address these barriers and make integrated diabetes care a reality for people with the condition. These policies include:

- **Integrated care funding** – the commitment from the Government to provide £3.8bn of integrated care funding from the NHS to social care should encourage and facilitate greater co-operation between local health and social care commissioners
- **Integrated care pilots** – the Government's integrated care pioneers, and the development by the Opposition of 'whole-person care innovation councils' presents opportunities to try different mechanisms for making integrated care a reality for people with diabetes
- **Integrated care 3millionlives programme** – this Government initiative aimed at using telehealthcare to support three million people with long-term conditions such as diabetes in the community presents a chance to bring greater support to those with care needs and diabetes
- **Local integrated care plans** – the development of local integrated care plans to allocate funds for integration locally should ensure that integration is central in local commissioning processes



Case Study

"Hello, I'm Betty, I've been a nurse on the Elderly Care Ward at the infirmary for over thirty years. More and more of the older people I look after seem to have diabetes nowadays..... We have a protocol in place now so that anyone coming in with a diabetes problem gets referred to the diabetes specialist team straight away and seen by them within twenty four hours.

This means that we can ensure the person is receiving the best care possible and also really helps us with discharge planning. We work with the specialist team and the older person to draw up a care plan for their diabetes."⁷



Case Study

Mrs T is an elderly lady who lives with her husband in a small terraced house in the city. When she was diagnosed, 14 years ago, she could still manage the stairs, did most of the cooking and attended the hospital out-patients for her heart failure and worsening arthritis.

Since then she has become increasingly immobile. She has always been overweight but, with the lack of activity and reliance on bought meals, she has put on weight and is struggling with her health. Her heart failure has deteriorated and she gets breathless on any exertion. Her diabetes is not well controlled and she takes multiple medications daily. She sleeps downstairs and spends the day alternating between the television, the radio and reading. Her husband has become her carer but he too is becoming frail.

The community nursing team became involved when Mrs T's GP became concerned that Mrs T's kidney function was deteriorating. Guidelines required some of her diabetes medications be stopped but, as her blood glucose control was already causing her symptoms, Mrs T agreed it was time to start insulin. The community nurses had the knowledge and skills to initiate the insulin and to support Mr and Mrs T in learning how to manage the injections but found achieving stable blood glucose control difficult. Kidney disease can affect how insulin works and in order to prevent potential side effects of the treatment the community nurses sought the support of their community diabetes specialist nurse colleague. This allowed weekly joint visits to Mr and Mrs T, good liaison with the GP through nurse prescribing in the home, and changes made to the insulin regimen which allowed specialist input without the need for hospital attendance while receiving best practice care³⁷.

Chapter 3: Addressing the challenge

Taking up the challenge: examples of integrated diabetes care

Whilst national initiatives are important to set the direction of the new system it will be absolutely critical that local commissioners take up the challenge of using new funds and support for integrated care to improve the services they provide for people with diabetes.

A number of local commissioners and providers have begun developing models to introduce more integrated diabetes care and deliver service improvements.

Two models highlighted below focus on improved community care for people with diabetes, including the use of integrated care pathways, service prioritisation and incentives.

The Super Six model: integrating acute and community diabetes care across South East Hampshire

Starting in November 2011, the existing community diabetes team was joined by the local hospital diabetes specialist consultant team to provide regular in depth educational support to GP practices and locality nursing teams as well as providing day-to-day advice via email and telephone. This was influenced by the need to tackle three key issues: pathway inefficiencies involving secondary care follow-up; unacceptable variations in quality of care and knowledge of diabetes and management; and the disconnect between care services resulting in fragmentation and duplication.

Specific objectives included MERIT training for 50 clinicians per year; DESMOND training for 520 patients per year; and bespoke training to meet identified local need. Since the initial service began it has delivered MERIT training for 227 clinicians; DESMOND training for 2263 people with diabetes and 35 of 53 GP practices have had education visits³⁸. Feedback has been overwhelmingly positive with 89% of patients strongly agreeing that positive benefits come from the Community Diabetes Team.

The service received a Care Integration Award in 2012, and was shortlisted for a Quality in Care award in the same year³⁹.

Chapter 3: Addressing the challenge

Community-based services, Central Manchester

Central Manchester Clinical Commissioning Group (CMCCG) has a Diabetes Local Enhanced Service (LES) to which 18 GP practices have signed up to provide additional community-based care for their patients.

Clinicians in the LES practices will initiate injectable treatments to those patients that require it in order to improve their glycaemia (blood glucose) control.

Practices have been offered a comprehensive educational programme to gain accreditation to deliver this more advanced level of care.

The X-pert patient programme course is run over six weekly, three hour sessions designed to increase the skills, knowledge and confidence of patients to manage their diabetes. The programme can improve diabetes control, increase self-management skills and improve lifestyle and quality of life. Patient and professional education is offered through the nationally accredited X-pert patient education programme and Dose Adjustment for Normal Eating (DAfNE). CMCCG is now also in the process of commissioning a structured education programme for Type 2 Diabetics.

CMCCG has also developed a project to improve the identification, prompt early diagnosis and effective management of five long-term conditions, of which diabetes is one. Diabetes Specialist Nurses from the Manchester Royal Infirmary Diabetes Centre work with a number of local practices to:

- Support them in identifying diabetic patients by screening those at the highest risk
- Optimising the care of diabetic patients
- Support practices to develop their skills and knowledge

CMCCG has identified further areas where development would improve local diabetes services and which will form the basis of future work, including:

- A structured education programme for primary care clinicians
- Funding for advanced education courses such as the Warwick course
- Variability in the standard of care delivered in primary care, specifically Quality and Outcomes Framework (QoF) and patient outcomes
- Proactive screening for diabetes, particularly in high risk populations, to support secondary prevention
- Improving awareness amongst high risk black and minority ethnic groups of the prevalence of diabetes and measures that can be taken to reduce the likelihood of the development of type 2 diabetes
- Sharing of patient records across organisations
- Increased uptake of diabetic retinal screening⁴⁰

Recommendations

Current Government policy is certainly supportive of a more integrated approach to care for people with long-term conditions such as diabetes. In parts of the country some commissioners are taking up the challenge and developing new approaches to address the rising burden of diabetes and its impact on social care services.

However, in order to ensure that such practice is adopted widely, it will be important for the following actions to be delivered by various groups across the new NHS and social care system:

- The Department of Health should publish a new Action Plan for Diabetes which includes actions to support the integration of diabetes services across health and social care
- NHS England, in consultation with NICE, should develop a series of outcome measures for inclusion in the NHS and Adult Social Care Outcomes Frameworks to measure integrated care
- NHS England should develop a best practice portal for integrated care to showcase examples of commissioners effectively integrating services for patients, including people with diabetes
- NHS England should ensure that new incentive mechanisms, such as financial incentives and payment mechanisms, are introduced to incentivise high quality integrated diabetes care
- NICE should ensure that future iterations of the diabetes quality standard, setting out high quality care across the care pathway, cover care for people in social care settings
- Clinical Commissioning Groups should ensure that they are commissioning diabetes services in line with NICE guidance
- Local health and wellbeing boards should ensure that their forthcoming local integrated care plans include a focus on ensuring that people with long-term conditions such as diabetes benefit from more co-ordinated services
- Local health and wellbeing boards should ensure diabetes is appropriately prioritised in their Joint Strategic Needs Assessments (JSNA) and Joint Health and Wellbeing Strategies (JHWS)
- Local health and wellbeing boards should develop new longer term, more integrated budgets across health and social care to commission services for people with long-term conditions such as diabetes
- Local commissioners and local healthwatch groups should review the information available to people with diabetes, and ensure that information is co-ordinated and targeted appropriately to support better self-management of the condition

Conclusion

This research has demonstrated the growing challenge diabetes presents to the social care system and the need for action to address it.

Whilst this report focuses on this challenge and sets out recommendations for tackling it, it is important to note that diabetes as a condition should not be seen in isolation. A significant portion of people accessing local authority care will have more than one condition or care need which needs to be addressed. Thus, ensuring that plans for a more integrated health and care system place the user or patient at the heart of their care, with tailored care packages and plans is absolutely critical to delivering a better future service.

There is also a clear need to focus on better prevention of diabetes as a condition through an improved public health system. A greater focus on prevention of diabetes should be a goal of the new public health system and local directors of public health, as this will deliver benefits to the more integrated health and care system, advocated here.

Finally, this report begins to set out some of the wider costs of diabetes in care settings both through complications associated with the condition and broader societal and economic costs. As the population ages more detailed research into these impacts should be considered to continue to make the case for the prioritisation of diabetes in the health and care system and to hold the Government and policymakers to account for progress in improving care for those affected.

Appendix

Methodology

There is no single recognised definition of social care, and the services provided through it are wide ranging.

This report uses the definition of social care provided by the Law Commission following its inquiry into adult social care. The Commission defined adult social care as “... support provided by local social services authorities pursuant to their responsibilities towards adults who need extra support⁴¹.”

There are three main types of costs associated with social care services:

- **Direct costs** – the cost of care for people with care needs (eg care home fees)
- **Indirect costs** – broader costs associated with those with care needs, through complications and poor care management (eg emergency hospital admissions, operations etc)
- **Societal costs** – wider costs relating to issues that may be a result of people’s care need (eg employment issues and benefits)

This paper focuses primarily on the direct costs of diabetes on social care and also provides an initial scoping of the indirect costs associated with the condition. The broader societal costs are referenced but not explored in detail.

There is a wide range of publically available data on the prevalence of diabetes and the costs of social care services. The following data sources were used to develop the findings in this report:

Diabetes data

A wealth of publically available information exists on the prevalence and activity associated with diabetes in England. This includes (but is not exclusively limited to):

- **Diabetes prevalence models for local authorities in England** – Yorkshire and Humber Public Health Observatory
- **National Diabetes Audit** – NHS Information Centre
- **Hospital admissions for diabetes and related complications** – Hospital Episode Statistics
- **Atlas of variations for people with diabetes** – NHS RightCare
- **Diabetic retinopathy screening data** – Public Health England
- **Uptake of NHS Healthchecks** – Department of Health

Social care data

There is a range of information available on the activity and cost of social care services in England. This includes:

- **Personal social services expenditure (PSSE) activity data** – Health and Social Care Information Centre (HSCIC)
- **Personal social services expenditure (PSSE) unit cost data** – Health and Social Care Information Centre (HSCIC)
- **Referrals, assessments and packages of care data (RAP)** – Health and Social Care Information Centre (HSCIC)
- **Adult social care combined activity returns (ASC-CAR) data** – Health and Social Care Information Centre (HSCIC)
- **Unit costs of health and social care** – Personal Social Services Research Unit (PSSRU)
- **Data on conditions of older people** – Institute of Public Care

Population data

The 2011 census data held by the Office for National Statistics (ONS) provides a platform to undertake population and age related analyses.

Advisory Group

On 19 September 2013, Novo Nordisk hosted a workshop to explore the issues in this report in more detail. The workshop was chaired by Professor Alan Sinclair and was also attended by the following:

- Professor Alan Sinclair, Director, *Institute of Diabetes of Older People*
- Laura Wilkes, Policy Manager, *Local Government Information Unit*
- Gillian Ford, Councillor, *London Borough of Havering*
- Lynda Gardner, Board Member, *UK Home Care Association*
- Robin Hewings, *Head of Policy, Diabetes UK*
- Gwen Hall, *Diabetes Specialist Nurse*
- Rachel Cummings, *Government Affairs, Policy and Communications Manager, Novo Nordisk*
- John Clarke, *Senior Policy and Government Affairs Advisor, Novo Nordisk*
- Richard Sloggett, *Account Director, MHP Health*
- Poonam Arora, *Senior Account Manager, MHP Health*
- Peter Wasson, *Consultant, MHP Health*

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