



THE STATE OF HEALTH CARE AND ADULT SOCIAL CARE IN ENGLAND 2013/14

Technical annex: Thematic data review of
diabetes care pathways

1. Background to diabetes

Diabetes mellitus is a long-term chronic condition where there is too much glucose in the blood because the body cannot use it properly. This occurs when either the pancreas does not produce any insulin, it produces too little insulin or there is resistance in the body to the insulin that is produced. Currently there is no known cure for diabetes, although its symptoms can be treated and the risk of adverse complications reduced by managing the condition effectively. There are two main types of diabetes and, while both are serious and lifelong conditions, they are distinctly different in terms of their causes and often their treatments.

- Type 1 diabetes is where people cannot produce any insulin and it accounts for around 10% of all people with diabetes. It is often diagnosed in childhood or during adolescence following sudden onset of severe symptoms. Current research indicates that most Type 1 diabetes results from problems with T cell lymphocytes that cause autoimmune destruction of the insulin-producing cells in the pancreas. This T cell problem is detectable before symptoms appear where there is a family history of Type 1 diabetes. Although there is currently no known prevention or cure, trials have recently begun on developing a vaccine to prevent the disease. All people with Type 1 diabetes are dependent on insulin treatment and cannot survive without it.
- Type 2 diabetes is where someone either does not produce enough insulin or the insulin produced does not work properly and it accounts for around 90% of all people with diabetes. There are a number of risk factors associated with development of Type 2 diabetes, including family history, age, and ethnic background. People are also more likely to develop Type 2 diabetes if they are overweight. Unlike Type 1, the condition tends to develop gradually, often later in life, and it can take years before people realise they are diabetic.

The third most common form of diabetes is gestational diabetes. This is a condition in which women without previously diagnosed diabetes exhibit high blood glucose levels during pregnancy and is caused when insulin receptors do not function properly. Gestational diabetes often has few symptoms and is generally diagnosed by screening during pregnancy. Untreated gestational diabetes can lead to delivery complications, seizures or even stillbirths. We have not examined gestational diabetes in this data review because the hospital episode statistics data that are currently available only provide an incomplete picture of this area. Also, the Health and Social Care Information Centre has not yet released the new maternity and children's data set. CQC will therefore return to the topic of gestational diabetes once this data is available, which will enable us to examine the topic in greater detail.

There are also other forms of diabetes, such as MODY (maturity onset diabetes of the young), but these are much rarer than Type 1 and Type 2 diabetes.

When diabetes is managed poorly, it can result in severe episodes of ill health leading to admission to hospital as well as a range of long term complications including:

- Blindness
- Heart attacks
- Strokes
- Kidney disease
- Amputation
- Depression.

There are over 3.2 million adults in England currently diagnosed as diabetic, and this figure is predicted to rise substantially in the coming years.¹ The report published by Diabetes UK, *The Cost of Diabetes* (2012) states, “Diabetes accounts for about 10% of the NHS budget and 80% of these costs are due to complications.” The trends in the population and increasing prevalence of diabetes means that treating the associated complications will become a growing burden on the NHS unless solutions can be found to improve how it is managed within the community and to better empower people to take control of their condition.

2. Our review of diabetes care pathways

As noted above diabetes is a serious lifelong condition that has a profound effect on people’s lives. Successful management of the condition depends on the information, support and quality of care provided by services across all of the sectors that CQC regulates. CQC is therefore in a unique position to monitor the quality of diabetes care along the entire pathway, including looking at how well providers are working together to deliver joined-up care to people with diabetes. There is also a wealth of information available on diabetes including the largest clinical audit programme in the world comprising the National Diabetes Audit, the National Diabetes Inpatient Audit and the National Diabetes Paediatric Audit.

CQC selected diabetes as a suitable topic to enable us to review the entire care pathway. The review is effectively split into two quite distinct phases: the first, summarised here, involves a review of available centralised information to form a national picture of the quality of care based on data analysis. The second phase, to begin in 2015, will involve inspection activities and bespoke information gathering to follow up on the findings from the data review and explore in-depth at the local level the causes behind variations in care and outcomes for different people.

This report summarises the findings from the data review – both from bespoke analysis that CQC carried out and work by other bodies.

¹ Diabetes UK - figure taken from Quality and Outcomes Framework (QOF) prevalence data for 2012/13, includes all registered diabetics aged 17 and over

3. Care in the community

Processes and treatment targets

Managing diabetes effectively in the community is essential for preventing long term complications and avoiding emergency admissions to an acute hospital. To help ensure people receive quality community care, the National Institute for Health and Care Excellence (NICE) has defined nine core care processes that all people with diabetes over 12 years old should be receiving.² While the recommendation is for checks to be completed at least annually, many people with diabetes may receive these more frequently. The checks, along with associated treatment targets where applicable, are:

- Effectiveness of diabetes treatment by measuring HbA1C³ with targets of those under 48 mmol/mol, under 58 mmol/mol and under 86 mmol/mol.
- Cardiovascular risk factors by measuring blood pressure with targets of <140/80 for those without recorded eye, kidney or vascular disease and <130/80 applied to those patients with recorded eye, kidney or vascular disease.
- Serum cholesterol with targets of <4 mmol/l and <5 mmol/l.
- Body Mass Index (BMI)
- Smoking status
- Eye screening
- Foot surveillance
- Kidney surveillance by measuring urine albumin/serum creatinine.

Results from the most recent National Diabetes Audit (2011/12) show that across England only 60% of people with diabetes received eight care processes⁴, with this falling to only 43% among people with Type 1 diabetes. The findings also showed large variation across the country with the proportions at CCG level for all people with diabetes ranging from 18.5% to 78.3%. Below CCG level, there is also known to be significant variation at GP practice level. There was a similar picture for the proportion of people who met all treatment targets,⁵ although there was less geographical variation, with a national rate of 21% (12% for Type 1) and CCG level variation from 16.6% to 27.8%. Looking only at newly-diagnosed people, the figures are even worse with only 51% of all people with diabetes receiving all eight care processes (30% for Type 1) and 19% of people meeting treatment targets (although this climbs to 20%

² For those under 12 only the HbA1C check and corresponding treatment targets are recommended as standard

³ HbA1C is 'glycated haemoglobin' and indicates how well blood glucose has been controlled over the preceding weeks

⁴ Results for eye screening were not included in the audit analysis. For under 12s completion of HbA1C measurement is counted as meeting of all processes (similarly for targets).

⁵ Where patients have achieved HbA1c ≤58mmol/mol, cholesterol <5mmol/L and their relevant blood pressure target.

for people with Type 1 diabetes). These geographical variations have been previously shown at PCT level in the work conducted by the NHS Right Care team in their Atlas of Variation.⁶

All these measures are included in the Quality and Outcomes Framework (QOF) for GP practices, covering people aged 17 years and older, although smoking cessation does not have an indicator specifically for people with diabetes. Published data was available for 2012/13 at the time we carried out this review. Results from the QOF data also show large variations at CCG level as well as underlying variations between GP practices, particularly when looking at intervention rates (i.e. including exceptions in the denominator). Achievement scores show noticeably less variation, due to differences in exception rates between practices. The 'Healthier Lives' programme at Public Health England is due to publish a new online tool this year showing variations in QOF intervention rates, along with other diabetes information, at both CCG and GP practice level.

In addition to these process checks there is also a NICE standard for people with diabetes and/or their carers to receive a structured educational programme that fulfils the nationally agreed criteria from the time of diagnosis, with annual review and access to ongoing education. Self-management is a fundamental part of effective diabetes management and structured education can empower people to do this by giving them the knowledge and skills to take better control of their condition. However, audit results for 2011/12 show very low proportions of people with diabetes recorded as being offered and attending structured education programmes.

Being offered an education programme:

Newly-diagnosed people	
Type 1	Type 2
2.2%	12%

All people with diabetes	
Type 1	Type 2
1.6%	4.5%

Attending an education programme:

Newly-diagnosed people	
Type 1	0.6%
Type 2	3.1%

All people with diabetes	
Type 1	1%
Type 2	1.4%

⁶ <http://www.rightcare.nhs.uk/index.php/atlas/diabetes/>

These low proportions for structured education are of particular concern. Empowering people is particularly important given that most people will manage their condition in their own home outside of a primary care setting, and annual check-ups may not reveal the full extent of how a person has been managing their condition in the interim. A QOF indicator for newly-diagnosed people with diabetes who have been referred to a structured education programme has now been introduced, although the 2013/14 data was not available at the time of this review.

Overall, these results not only indicate worryingly low levels of compliance with NICE standards in primary care but also wide variations across the country. Comparisons over time reported by the National Diabetes Audit indicate that although the large improvements made in diabetes care between 2004 and 2009 have been sustained, performance appears to have remained the same and there are large degrees of underlying variation. This suggests ongoing deficiencies in the quality of diabetes care within the community although, as we discuss later in the report, it can be difficult to directly link performance against these measures with rates of admission to hospital or development of complications as many of these problems may take several years to develop.

4. Emergency diabetes admissions

As part of this review CQC conducted some bespoke analysis that looked at emergency hospital admissions with a primary diagnosis of diabetes.⁷ Our analysis explored the relationship with demographic risk factors⁸ and remaining geographical variations at CCG level once the risks associated with the local population were accounted for.

The analysis

We conducted the analysis to improve our understanding of the likelihood of having an emergency admission with a primary diagnosis of diabetes, in relation to different key demographic groups nationally. We then used this understanding to create a CCG indicator comparing actual admissions for diabetes against what would be expected for each CCG given their demographic characteristics in relation to a reference group.⁹ We then compared the results for these CCG level comparisons with the results for meeting the eight care processes and treatment targets in primary care taken from the 2011/12 National Diabetes Audit.

⁷ Presence of ICD-10 codes E10-14 in the primary diagnosis field. Additionally people were identified as having diabetes based on the appearance of one of these codes at any point in their diagnostic history over the last 4 years.

⁸ Risk factors explored were; Gender, Age, Ethnicity, Deprivation, Recording of Insulin Dependency anywhere in their HES history, and Revised Charlson Index

⁹ A CCG with a large population and average characteristics was chosen as the reference group for this analysis

For this analysis we used a multivariate off-set logistic regression model for the first two steps and a more standard regression model for the third step. The analysis effectively involved a three stage process:

Stage 1 - a baseline model calculating a measure of the likelihood of a given patient having a diabetes-related emergency admission (this measure is called a 'linear predictor'). For the baseline model, the odds-ratios effectively indicate the likelihood of experiencing an emergency admission for diabetes compared to the likelihood of any non-diabetes-related emergency admission for that group (based on their characteristics in terms of the other risk factors).

Stage 2 - an offset model applying these to comparisons of CCGs to effectively standardise for the occurrence of these risk factors in the population. For the offset model, an odds-ratio is produced for each CCG. Ratios significantly higher than one indicate a CCG where people with diabetes are more likely to have an emergency diabetes admission, and odds ratios significantly lower than one indicate a CCG where this is less likely.

Stage 3 - a regression model comparing the log odds-ratio for each CCG with the CCG's results in the 2011/12 National Diabetes Audit for completion of care processes and treatment targets, both for existing and newly diagnosed people with diabetes.

An early problem encountered with this analysis was the inability to accurately distinguish between people with Type 1 and Type 2 diabetes based on diagnostic codes in Hospital Episode Statistics (HES). While coding guidelines do specify that E10 (insulin dependent diabetes) should be recorded for people with Type 1 diabetes and E11 (non-insulin dependent diabetes) should be used for people with Type 2 diabetes (with an additional Z79.4 code used separately in the record to indicate if they are currently on long-term insulin treatment), we found several people who had received different codes during separate hospital spells. For example, an individual may have been diagnosed as E11 (non-insulin dependent) on a particular admission but then a year later diagnosed as E10 (insulin dependent).

Given the significant differences between these conditions, the inability to accurately distinguish between people with Type 1 and Type 2 diabetes using hospital records alone (i.e. without linking back to the individual's primary care records as is done with the National Diabetes Audit) presents a significant impediment to reviewing care for people with diabetes using HES data alone. The most likely reason for this inappropriate use of diagnostic codes is that some people have interpreted the descriptions of insulin dependent and non-insulin dependent as referring to whether someone is currently on insulin treatment or not.

Key findings from the analysis

Results from the analysis showed that there are substantially different patterns for diabetes admissions odds-ratios depending on whether the admission is for E10 (insulin dependent) or E11 (non-insulin dependent diabetes), as would be expected given the different nature of the two types of diabetes. The difference is particularly noticeable in relation to age, with insulin dependent admissions being most prominent for younger age groups, but it also showed noticeable effects in relation to ethnicity, gender and deprivation. The main reason for this is probably because as people get older the range of co-morbidities and reasons for admission to hospital increase, thereby lowering the prominence of emergency admissions with diabetes as the primary diagnosis. It may also be due to a lack of awareness about diabetes symptoms such as Diabetic Ketoacidosis (DKA) in younger age groups, which as highlighted in the most recent National Paediatric Diabetes Audit, is resulting in almost one in five children with diabetes developing DKA before they are officially diagnosed with the condition and high rates of DKA in young people even after diagnosis. Overall, being insulin dependent was shown to significantly increase the likelihood of experiencing an emergency admission for diabetes.

More surprising results were seen for ethnicity and deprivation. The Asian ethnic group showed a lower likelihood for non-insulin dependent admissions (despite the known higher prevalence of Type 2 diabetes in this group), and deprivation had a less marked impact than might have been expected. In fact, where results for deprivation were significant, mainly those for insulin dependent admissions, they showed lower odds ratios for the more deprived Index of Multiple Deprivation (IMD) quintiles. These results may be due to a number of factors such as differences in admissions for other conditions in these groups, ethnic differences in pathogenesis of the condition, variations in quality of care, use of a broad quintile measure of deprivation, or other factors not accounted for in this modelling.

Once these demographic-based variables were accounted for, the analysis showed that significant variations in diabetes admissions across CCGs remained, which indicates potential differences in the quality of care across the country. Although no correlations were found with the National Diabetes Audit results for meeting process and treatment targets in the community, this may be due to the limitations of only using one year of audit results. Also it is possible that longitudinal studies covering many years may be required to accurately determine the effects that completing these processes and meeting targets are having on people's likelihood of admission, given the long term nature of many of the complications. As part of Phase 2 of this review we will explore further the differences seen in these results, both by demographic groups and across geographical areas.

Development of complications

The National Diabetes Audit reports on nine complications associated with diabetes. For seven¹⁰ of these, the report looked at the difference in likelihood for experiencing these complications between people with diabetes and people without diabetes, accounting for other risk factors such as age and sex. Results from the 2011/12 report¹¹ showed the following additional risk for people with diabetes for these seven complications:

Complication	Additional risk of complication among people with diabetes
Angina	75.9%
Myocardial infarction (heart attack)	55.4%
Heart failure	73.7%
Stroke	34.3%
Major amputation (above the ankle)	221.8%
Minor amputation (below the ankle)	336.9%
Renal replacement therapy (ESKD)	164.4%

The table above shows that being diabetic significantly increases a person's risk of developing all seven of these complications, with lower limb amputations and renal replacement therapy carrying the greatest additional risk. Results for Diabetes Ketoacidosis (DKA) showed that between 1 April 2010 and 31 March 2012, 10,434 people included in the 2009/2010 National Diabetes Audit were admitted to hospital for DKA with Type 1 diabetes at least once. The audit also found geographical variations in the incidence of DKA, with some areas shown to have significantly higher (and other significantly lower) than expected rates once age and sex were standardised for. Results from the 2011/12 National Paediatric Diabetes Audit indicate that while DKA admission rates remain high, there is some evidence that this may have declined slightly in some age groups, and particularly in girls, in 2011-12 compared to previous years. As with the National Diabetes Audit, geographical variations were also found for DKA rates among children and young people.

¹⁰ Retinopathy treatment and Diabetes Ketoacidosis (DKA) are excluded as these only affect people with diabetes.

¹¹ <http://www.hscic.gov.uk/catalogue/PUB12738/nati-diab-audi-11-12-mort-comp-rep.pdf>

Admissions to hospital for other conditions

As part of this review CQC conducted some bespoke analysis looking at differences in emergency hospital admission rates between people with and without diabetes for the following conditions, based on primary diagnosis and procedure codes:

- Fractured neck of femur
- Appendectomy
- Drainage of abscess
- Essential hypertension (diabetes related)
- Chronic ischaemic heart disease diabetes related)
- Acute myocardial infarction (diabetes related)
- Stroke (diabetes related)
- Chronic obstructive pulmonary disease
- Asthma
- Congestive heart failure (diabetes related)
- Peripheral vascular disease (diabetes related)
- Chronic Kidney failure (diabetes related)
- Lower limb amputation (but excluding patients with malignancies or injury/trauma) (diabetes related).

Comparisons for these conditions were also made in relation to mortality, length of stay and re-admissions (the findings for these are summarised in the 'Outcomes' section below). As can be seen from the list above, eight of these conditions are directly related to diabetes, primarily in the sense of being a long-term complication, although they were not recorded on these particular spells as being caused by diabetes (at least in the primary diagnosis field). For the purposes of this analysis, rates were standardised for age, sex, primary diagnosis and co-morbidity (using a modified Charlson score that excluded diabetes) so that results for people with diabetes were compared with similar people without diabetes. Because of the low numbers for some of these conditions, particularly in relation to mortality, and the coding issues mentioned above, people with diabetes were treated as one group and comparisons were made using four years of data (2009/10 to 2012/13).

Results showed that people with diabetes had significantly higher (worse) standardised ratios than similar people without diabetes for the vast majority of conditions we looked at. These findings broadly fit with the work others have done in this area such as the National Diabetes Audit findings on complications mentioned above. Overall, these findings show that people with diabetes are more likely to experience an emergency hospital admission than similar people without diabetes. Variation was also seen at the CCG level, both in terms of the difference between people with and without diabetes and in terms of the actual magnitude of this difference (i.e. the difference of the differences).

Care in hospital

In September 2013, the National Diabetes Inpatient Audit was conducted in hospitals across England and Wales; this was a repeat of the 2010, 2011 and 2012 audits. The audit collected information on the make-up of the teams working in hospitals that care for people with diabetes, information on the care received, and reported experiences of people with diabetes in hospital at the time of the audit. Results from the 2013 audit show that the prevalence of people with diabetes in hospitals in England has continued to rise, from 15.3% in 2012 to 15.7% in 2013. The average staffing levels per person per week generally fell: diabetes specialist nursing fell from 1.69 in 2012 to 1.66 in 2013, dietician hours fell from 0.5 in 2012 to 0.47 in 2013 and podiatrist hours fell from 0.5 in 2012 to 0.48 in 2013.

However, there was a rise in consultant hours from 0.74 to 0.78. There was also a rise in the proportion of people with diabetes visited by a member of the diabetes team to 34.5%, although this still means that nearly two thirds of those included in the audit did not receive a visit from a member of a specialist team. Where people with diabetes are in hospital for other reasons, such as elective surgery or maternity, although they are used to managing their condition themselves, their diabetes control can be upset due to their diet and routine being disturbed. Specialist nurses and dieticians can be particularly important in these cases.

On a more positive note, there was a rise in the proportion of people with diabetes receiving a foot assessment within 24 hours, although this was still only 37.6%; a rise in appropriate glucose testing to 6.4 out of 7 days and a rise in good diabetes days¹² to 4.2 out of 7. There were also falls in medication, prescription, management and insulin errors. Although with 37% of people experiencing a medication error and one in five experiencing an insulin error, there is still room for significant improvement in this area. While there were small falls in the proportions experiencing mild or severe hypoglycaemic episodes,¹³ approximately one in five still experienced a mild episode and just under one in 10 experienced a severe episode.

In terms of responses to the audit's patient survey, there was an increase in overall satisfaction from 85.7% in 2012 to 86.1% in 2013. The questions showing the lowest proportions of positive responses were 'patients reporting that staff were very good at working together as a team in managing their diabetes' (44.2%) and 'patients reporting that all or most staff looking after them knew enough about diabetes to meet their needs' (67.5%). Overall results from the audit also showed some large variation in performance between hospital trusts across all of the reported measures, although on most measures there have been gradual improvements in the national averages.

¹² A "good diabetes day" was defined as a day when the frequency of blood glucose monitoring was appropriate, there was no more than one measurement of greater than 11mmol/L and no measurement of less than 4mmol/L.

¹³ Mild defined as glucose of 3.0-3.9 mmol/L, while severe is <3.0 mmol/L

5. Outcomes – comparisons of people with and without diabetes

Length of stay

As mentioned above, for this review CQC conducted some bespoke analysis comparing admissions and outcomes for people with diabetes and similar people without diabetes for 13 individual conditions (see 'Admissions to hospital for other conditions' above). Results from this analysis showed that people with diabetes have significantly longer lengths of stay in hospital than similar people without diabetes for the vast majority of conditions we looked at. This corresponds with the findings from the work of the Yorkshire Public Health Observatory (YHPHO, now part of Public Health England) looking at variations in inpatient activity across all admissions. This found that in 2009/10 people with diabetes accounted for 19.4% more hospital bed days than would have been expected if they had experienced the same average length of stay as people without diabetes.

Emergency readmissions

Findings from our analysis showed that for all the conditions we looked at, people with diabetes had a significantly greater likelihood of experiencing an emergency readmission within a month of being discharged than similar people without diabetes. Again, this corresponds with the YHPHO work, which found in 2009/10 that people with diabetes were readmitted as an emergency within 28 days 59.1% more times than would have been expected if they had the same readmission rate as people without diabetes.

Proportion of planned day case procedures turning into overnight stays

As part of the bespoke CQC analysis comparing people with diabetes to similar people without diabetes, we compared the standardised ratio for planned therapeutic day case procedures that unexpectedly became overnight stays. Results from this showed that people with diabetes have a significantly higher (worse) standardised ratio than people without diabetes. Findings from the YHPHO work showed that people with diabetes also had a lower likelihood of being treated as a day case across all elective procedures.

Mortality

Previous research in this area has consistently shown that, overall, people with diabetes have a lower life expectancy and higher mortality rates. For example, the Diabetes UK publication *Diabetes in the UK 2010: Key Statistics on Diabetes* states that the life expectancy of someone with Type 2 diabetes is likely to be reduced, as a result of the condition, by up to 10 years, and that the life expectancy of someone

with Type 1 is likely to be reduced even further and by as much as 20 years. Results from the 2011/12 National Diabetes Audits showed that between 1 January 2012 and 31 December 2012, people with all types of diabetes were 37.5% more likely to die than their peers in the general population. Among those with Type 1 diabetes, mortality was 129.5% greater while people with Type 2 diabetes were 34.5% more likely to die. Findings from the YHPHO, covering the period April 2010 to March 2012, showed that after adjustment for case-mix, inpatients with diabetes are 6.4% more likely to die than those without diabetes.

On a more positive note, the recent Global Burden of Disease Study 2010 showed that in fact the UK has the lowest rates of early death due to diabetes of the 19 wealthy countries included in the analysis, and the 2011/12 National Diabetes Audit also suggests a continuing downward trend in additional mortality among people with diabetes.

As part of the bespoke CQC analysis comparing people with diabetes to similar people without diabetes, we compared the standardised ratio for mortality in hospital within 30 days of admission. Results from this showed that for a number of conditions we looked at, people with diabetes had a significantly higher (worse) standardised ratio than people without diabetes. However, this was not consistently the case across all the conditions we looked at.

As was the case with the analysis looking at admissions to hospital for other conditions described above, we found variations for all four of the above measures (length of stay, emergency readmissions, planned day case procedures turning into overnight stays, and mortality) at hospital trust and CCG level – both for the differences between people with and without diabetes and in the magnitude of these differences.

6. Conclusions

In relation to primary care, the results from the bespoke analysis for this review and the findings from other analyses show that there are still large numbers of people experiencing potentially preventable hospital admissions related to their diabetes and there are significant geographical variations in both hospital admissions and other measures of primary care performance. While risk of emergency admission to hospital is strongly linked to demographic characteristics, geographical variations are still apparent once demography has been accounted for. More generally, people with diabetes were shown to be significantly more likely to experience an emergency admission to hospital than people without diabetes.

Once in hospital, people with diabetes are likely to stay longer, have a greater chance of readmission and are more likely to die. Findings also indicate significant geographical and provider level variation in these outcomes. Findings from the inpatient audit also showed that despite some improvements, there are ongoing deficiencies in the quality of care for people with diabetes while in hospital and variations in quality between providers.

Overall, while this review of available data has been able to highlight differences in the experiences of people with diabetes and potential discrepancies in the quality of care, it has been unable to really expose what is causing these variations. It will therefore be important to supplement these findings with more in-depth local level assessment and information gathering during Phase 2 to build a more complete picture of diabetes care in England.