

# My diabetes, my care

People's experiences of  
community diabetes care and  
the support they are provided  
to self-manage their condition



## Our purpose

**The Care Quality Commission is the independent regulator of health and adult social care in England.** We make sure that health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.

## Our role

- We register health and adult social care providers.
- We monitor and inspect services to see whether they are safe, effective, caring, responsive and well-led, and we publish what we find, including quality ratings.
- We use our legal powers to take action where we identify poor care.
- We speak independently, publishing regional and national views of the major quality issues in health and social care, and encouraging improvement by highlighting good practice.

## Our values

**Excellence** – being a high-performing organisation

**Caring** – treating everyone with dignity and respect

**Integrity** – doing the right thing

**Teamwork** – learning from each other to be the best we can



# Contents

<b>FOREWORD</b> .....	<b>2</b>
<b>MY EXPERIENCE</b> .....	<b>3</b>
<b>SUMMARY</b> .....	<b>4</b>
<b>INTRODUCTION</b> .....	<b>6</b>
<b>IDENTIFICATION AND DIAGNOSIS</b> .....	<b>8</b>
<b>STRUCTURED EDUCATION AND SUPPORT FOR SELF-MANAGEMENT</b> .....	<b>14</b>
<b>CARE PATHWAY</b> .....	<b>21</b>
<b>PERSON-CENTRED CARE COORDINATION</b> .....	<b>25</b>
<b>CONCLUSIONS</b> .....	<b>31</b>
<b>ACKNOWLEDGEMENTS</b> .....	<b>33</b>
<b>REFERENCES</b> .....	<b>34</b>
<b>APPENDIX: HOW WE CARRIED OUT THE REVIEW</b> .....	<b>35</b>



# Foreword

The increase in the number of people with diabetes in the last 20 years has been unprecedented – the percentage of adults in England with diabetes has more than doubled since 1996. This has brought with it a significant cost in terms of people’s health and wellbeing.

It is more important than ever to address the rise in Type 2 diabetes and ensure the effective care of those with Type 1 and Type 2 diabetes. This includes supporting people with diabetes to self-manage and helping those who have been identified as at high risk of developing Type 2 diabetes to become healthier. The stakes are high, for the individuals who may experience the devastating consequences of long-term poor health and in financial terms for the NHS. When diabetes is not well-managed, it can lead to serious complications such as heart disease, kidney disease, stroke, amputations, and blindness. It is estimated that the NHS spends around £8 billion each year on treating these complications – most could be avoided or delayed by empowering people with the skills and knowledge to manage their condition.

The NHS Five Year Forward View sets out a vision for the future of the NHS, prioritising prevention and public health and breaking down the traditional divide between primary care, community services and hospitals. In the past decade we have seen how professionals in primary care and community settings are able to provide most diabetes care outside of hospitals. The NHS Five Year Forward View reaffirms this shift of services into the community alongside the enabling of people with long-term conditions to take more control of managing their health and building integrated care around them.

Improving health and managing resources better is at the core of improving quality of care. This report shows there is much that is already working well for us to learn from and build on in meeting this challenge.

**Professor Steve Field CBE – Chief Inspector of General Practice, CQC**

**Chris Askew – Chief Executive, Diabetes UK**



# My experience

I was diagnosed with Type 2 diabetes seven years ago by my GP. It was an emotionally difficult time as I was also trying to cope with other serious health issues. I was not offered any support or the attention I needed. I also felt that there was an immediate presumption and continuing presumption, that it was my fault for having developed diabetes, which made me feel even more unsupported.

I didn't receive the proper tools or education to self-manage my condition confidently, and a lot of the information I received I had to look up myself online.

When I was diagnosed, I didn't know what was happening and where to turn to. Healthcare professionals need to provide more information and support to patients. Whether that is pointing them to diabetes care websites or organisations, or just taking the time to sit them down to explain how diabetes will impact their life. We need people who are motivated and interested in providing patients joined-up diabetes care that makes them feel supported.

**Woman with diabetes**



# Summary

We conducted this thematic review to improve understanding of people's experience of diabetes care across England, and to consider how well different care services work together to deliver high-quality diabetes care.

We asked people (aged 18 to 65 years) with Type 1 and Type 2 diabetes about their experience of care. We particularly focused on the experiences of people from Black and minority ethnic (BME) populations and people with a learning disability, as people in these groups are more likely to develop diabetes and have poorer health experiences and outcomes.

We visited 10 areas to talk to commissioners, providers, and staff about how diabetes care in the community is delivered. We found variation in some aspects of care at local level, including many examples where diabetes care is working well that we encourage others to learn from.

The review found that most people's experience of community diabetes care is good overall, but care and support is not always flexible and responsive enough to meet everyone's individual needs. The extent to which services are successfully supporting people to self-manage appears limited. However we found examples where commissioners and providers have developed approaches that are working well that others can learn from.

We found that:

- Most people we spoke with received the checks recommended by the National Institute for Health and Care Excellence (NICE). Generally, people told us that they were able to discuss their care with primary care staff and they felt they received good explanations about their care.
- People at high risk of developing Type 2 diabetes were not always identified and supported to manage their risk. Several areas we visited described ways of engaging with individuals and communities to encourage uptake of health checks and raise public awareness of diabetes.
- Some people need more emotional support than they are receiving – both at diagnosis and on an ongoing basis. This was not always recognised by services or health professionals. This includes those with Type 2 diabetes where the need might be more than previously thought.
- People who had attended structured education courses felt it improved their ability and confidence to manage their condition. However, the courses were not able to meet everyone's needs and it was not always clear how the education needs of those who had not attended were being met.
- People showed a lack of awareness and understanding of their test results. Very few people had a hand-held care plan they could

take with them as they moved between services.

- Knowledge of diabetes was often lacking within some staff groups, particularly in adult social care, and in some areas diabetes training for care workers was absent. This can result in insufficient support for people who rely on others to help manage their diabetes.

Community diabetes care can be improved through building on what is good and learning from what is already working well, in particular where commissioners and services are taking a personalised approach that meets individual needs.

While we found that the care people received from services was good overall, the extent to which people are supported to successfully self-manage appears limited. This is illustrated by the lack of understanding of recent test results and treatment targets not being met. When the NHS does not support and empower people to self-manage their long-term condition it impacts on patient experience and on NHS resources. For people with diabetes this may mean that they do not have the knowledge and skills to manage their condition effectively and are more likely to experience complications as a result. All parts of the health and care system need to make self-care a real priority, for the benefit of patients and the future of the NHS.

CQC encourages **health and social care commissioners, providers and professionals** to work together to deliver an approach to diabetes care that puts people at the centre of their own care and enables them to improve their health and wellbeing and manage their diabetes effectively.

Key components of this approach are:

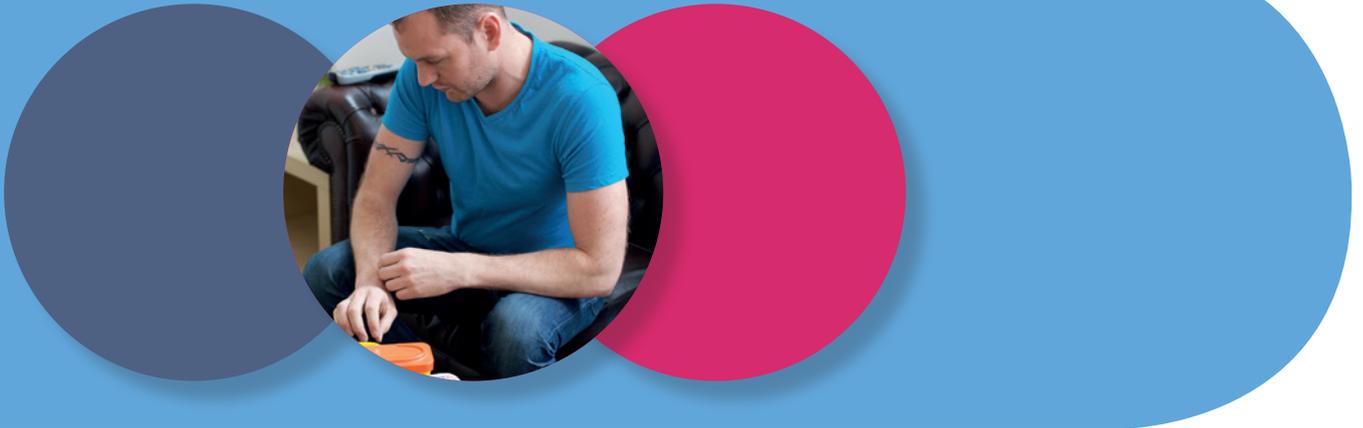
- A **local plan** for improved diabetes care through support to self-management.
- Commissioners and providers **engaging** with their whole community to **increase awareness** and understanding of diabetes and encourage **uptake of health checks**.
- Professionals engaging with people to understand their individual needs and

developing a **personalised care plan** together.

- **Emotional support** embedded in care for people with diabetes.
- Development of **education** approaches to ensure everyone, including people from BME groups and people with a learning disability, can gain the **knowledge and skills** they need.
- **Evaluation** of the effectiveness of structured education and annual review in giving people the knowledge and ability to self-manage their diabetes.
- Making better use of available **technology** to support self-management through education, motivation, and self-monitoring.
- **Training** in diabetes **for care workers** to enable them to fully support and care for people with diabetes.

CQC is committed to encouraging improvement in diabetes care. CQC will:

- Review our approach to long-term conditions, including diabetes, as part of the development of the next phase of our inspections of primary medical services and community health services.
- Support our inspection teams to develop their understanding of good and outstanding diabetes care.
- Identify and share examples of outstanding diabetes care from our inspections.
- Include data relating to diabetes care in the development of our new insight model for monitoring quality and encouraging improvement.
- Use our inspections to encourage providers of adult social care to ensure their staff have necessary capacity and capability.



# Introduction

Diabetes is a lifelong condition that causes a person's blood glucose level to become too high. In Type 1 diabetes, the body does not produce insulin and glucose levels increase, which can seriously damage the body's organs. In Type 2 diabetes, the body does not produce enough insulin, or the body's cells do not react to insulin. Type 2 diabetes is more common in older people and is often associated with obesity. In England around 90% of adults with diabetes have Type 2. When diabetes is not well-managed, it can lead to serious complications such as heart disease, kidney disease, stroke, amputations, and blindness.

Public Health England estimates that nearly 3.5 million people are living with diabetes in England. This figure is predicted to rise to 4.6 million (9.5% of the population) by 2030.<sup>1</sup>

Approximately £10 billion is spent by the NHS on diabetes each year – 10% of the NHS budget for England and Wales.<sup>2</sup> Eighty per cent of these financial costs are due to the complications associated with diabetes; these costs are likely to grow significantly as the number of people with diabetes increases. The annual cost of diabetes is predicted to rise to £40 billion by 2035/36 if things continue as they are.<sup>2</sup>

In 2012, the National Audit Office reported that NHS diabetes care was "poor, with low achievement of treatment standards, high numbers of avoidable deaths."<sup>3</sup> In their 2015 progress report, they found that progress had

been made "in reducing the additional risk of death for people with diabetes" but that "performance in delivering key care processes and achieving treatment standards, which help to minimise the risk of diabetes patients developing complications in the future, is no longer improving".<sup>4</sup>

The potential benefit of making these improvements is enormous. We know that, if sustained, even modest improvements in blood glucose levels can result in huge benefits for people with diabetes. If earlier intervention for better controlling blood glucose were applied to the UK diabetes population, in the next 25 years almost a million serious medical complications, such as blindness, amputation and kidney failure could be avoided and save the NHS £5.5 billion.<sup>5</sup> Improvements to other aspects of people's health will also result in fewer complications and reduced NHS costs.

CQC supports the strengthened focus on improving diabetes prevention as a result of the NHS Five Year Forward View. This includes the introduction of the NHS Diabetes Prevention Programme that will support people who have been identified as at high risk of developing Type 2 diabetes to become healthier. The NHS Five Year Forward View also emphasises better enabling of self-management and community support for people with diabetes. People need to have the knowledge, skills and support to manage their condition, and community-based

services underpin this. Good diabetes care equips people to manage their diabetes, minimises the risks of associated complications, and identifies and treats complications early when they occur.

## About our review

CQC's *Diabetes care pathways thematic data review of hospital admissions* highlighted that care outcomes for people with diabetes are variable and that there are significant variations in diabetes admissions across clinical commissioning group (CCG) areas.<sup>6</sup>

This review follows on from the data review. The purpose was to improve understanding of people's experience of diabetes care in community settings across England, including how well care services deliver high-quality care and reduce admissions to hospital. For the purposes of this review, 'community settings' are defined as any care provided outside of a hospital or ambulance setting. The review aimed to:

- Understand the experience people with diabetes have of receiving care, and how well are they supported by community services to achieve good outcomes.
- Highlight examples of good and outstanding community diabetes care at service and local levels.
- Identify barriers that prevent people receiving high-quality care.
- Make recommendations for services, providers and commissioners, at local and national levels so they can take action to address poor care.

This review, its findings and recommendations, aim to reflect the experiences of people with diabetes. We focused on the experience of adults aged 18 to 65 years. We know that younger working age people with Type 1 and Type 2 diabetes and people with Type 1 diabetes of all ages are less likely to receive the health checks or achieve treatment targets recommended by the National Institute for Health and Care Excellence (NICE).<sup>7</sup> Including people aged up to 65 allowed us to consider a balance of experiences of people with Types 1 and 2 diabetes, in particular how primary and community services support those with Type 2 diabetes.

We specifically looked at the experiences of people from Black and minority ethnic (BME) backgrounds and people with a learning disability. People from South Asian and Black communities are two to four times more likely to develop Type 2 diabetes than those from white backgrounds.<sup>8</sup> People with a learning disability tend to have higher rates of obesity and therefore may be at greater risk of developing Type 2 diabetes.<sup>9</sup> Both of these groups may also experience inequalities in their access to healthcare.

During the review, we looked at four key aspects of care for people with diabetes:

1. Identification and diagnosis
2. Structured education and support for self-management
3. Care pathway
4. Person-centred care coordination.

For more information on how we carried out the review, please see the appendix.



# Identification and diagnosis

## KEY FINDINGS

- People at high risk of developing Type 2 diabetes are not always identified and supported to manage their risk. Several areas we visited described ways of engaging with individuals and communities to encourage uptake of health checks and raise public awareness of diabetes.
- Some people need more emotional support than they are receiving – at diagnosis and on an ongoing basis. This was not always recognised by services or health professionals. This includes those with Type 2 where the need might be more than previously thought.

## Identification of people at high risk of developing Type 2 diabetes

Identifying people who are at high risk of developing Type 2 diabetes, and engaging with them to help them manage and reduce their risk, can delay or prevent the development of diabetes.

NHS Health Checks are one way of identifying people at high risk of developing Type 2 diabetes. The programme is commissioned by local authorities, and provides a check to assess risk of heart disease, stroke, kidney disease, and diabetes to people aged between 40 and 74 every five years. It is estimated that, if fully

implemented, this programme could prevent 4,000 people a year from developing diabetes.<sup>10</sup> Since 2013, 62% of people in England who are eligible for these checks have been offered one. However, less than a third (30%) have attended one [FIGURE 1].<sup>11</sup>

In most of the areas we visited, services and commissioners told us they use NHS Health Checks to identify individuals with diabetes or at risk of developing diabetes. However, the Health Check programme does not cover all those at high risk due to the age limits – for example, people from South Asian backgrounds may develop diabetes five to 10 years earlier than White Europeans.<sup>12</sup>

FIGURE 1: UPTAKE OF NHS HEALTH CHECKS 2013 TO 2016



Data Source: NHS Health Check Data as at 30/08/2016

Total eligible population: 15,402,612 people. Each icon represents 1%

In several of the areas we visited, GP practices used their patient lists to identify people with known risk factors for Type 2 diabetes; others used routine blood tests when they registered people at the practice. In five CCGs areas, registers were used to monitor individuals once they were identified as at high risk for developing diabetes. Some CCGs told us that workloads could prevent GP practices from undertaking proactive identification of risk among their patients.

CCGs told us about barriers to identifying people with diabetes or at high risk of developing it. These included a lack of public awareness and understanding about diabetes and its risk factors, and people's reluctance to attend health checks or go to the doctor about symptoms. Several CCGs said they found it difficult to engage with certain groups including young people, transient populations or some BME groups where there may be a stigma attached to diabetes.

Half of the CCG areas we visited commissioned additional activities to help identify people at risk of developing diabetes, such as awareness raising events, with referral to GP for those identified as high risk. A few of the areas we visited told us about the strategies they use to support users of

adult social care to access regular health checks, where risk of diabetes would be picked up. This included working with care home staff to make sure residents received a health check at their GP practice or at the care home.

### COMMUNITY OUTREACH

Slough and South Reading CCGs commissioned Silver Star Diabetes to engage with local communities and identify people at high risk of developing diabetes. The charity runs mobile diabetes units. These travel around to places of work, worship, community events, high streets and retail parks discussing risk of diabetes and offering lifestyle advice. Through working with Silver Star, Slough CCG was also able to identify 1,500 people deemed to be at high risk of diabetes and invited them to join an intervention programme.

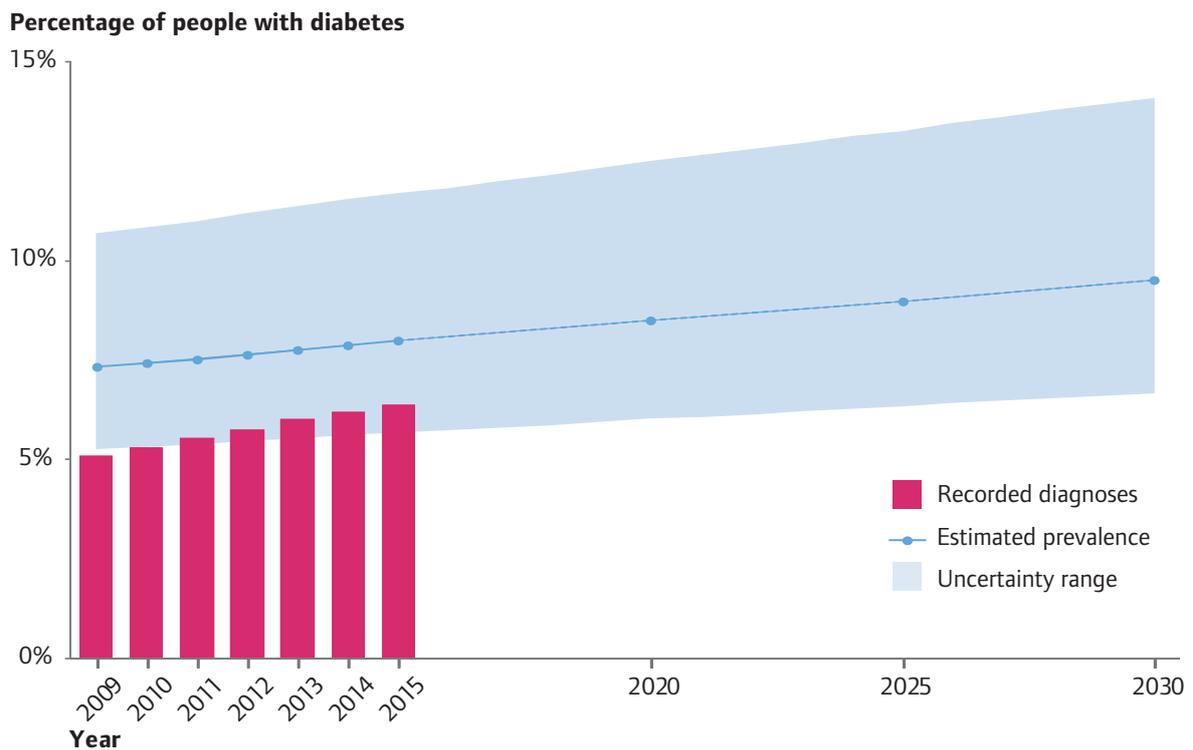
**Slough and South Reading CCGs**

When people are identified as at high risk for developing diabetes it is crucial to take action. Proactive primary care is central to this, as is the more systematic use of evidence-based intervention strategies. The NHS Diabetes Prevention Programme has been set up to refer people at high risk of developing Type 2 diabetes to a behaviour change programme to help reduce their risk. The programme starts in 2016 with a first wave of 27 areas covering 26 million people, and will roll out to the whole of England by 2020 with an expected 100,000 referrals each year thereafter.<sup>13</sup> Those referred will get help to reduce their risk through education on healthy eating and lifestyle, help to lose weight and bespoke physical exercise programmes, all of which together have been proven to reduce the risk of developing diabetes.

## Diagnosis of diabetes

It is estimated that there are over 500,000 people with diabetes in England who have not been diagnosed.<sup>8</sup> Left unmanaged, serious health complications are likely. GP practices register the number of people diagnosed with diabetes and report on this through the Quality and Outcomes Framework (QOF, an incentive scheme for primary care). The gap between estimates of the prevalence of diabetes and the number of diagnoses of diabetes recorded through QOF suggests that some practices may not be diagnosing people with diabetes early enough [FIGURE 2].

**FIGURE 2: PREVALENCE OF DIABETES\*: RECORDED DIGNOSIS VS. ESTIMATED TOTAL PREVALENCE**



Data Sources: Registered prevalence: Quality Outcomes Framework (QOF), 2014-15 estimated GP list size: 45,737,325 people  
 Estimated prevalence Association of Public Health Observatories and Public Health England Diabetes Prevalence Model  
 \*people aged 16+ yrs (APHO) and 17+ yrs (QOF).

The CCGs we visited used a range of methods to identify GP practices with lower than expected recorded prevalence. Most commonly, CCGs told us they used data from QOF to identify practices that appeared to be performing less well. Several CCGs told us that diabetes specialist nurses would support the services to increase identification; such as holding learning events or pairing practices with well performing peers.

Most people we spoke with during our fieldwork reported a positive experience of their diagnosis overall. People told us they received useful information about the condition and how to manage it. However, people who responded to our online feedback form indicated that the quality of support offered at the point of diagnosis was mixed: some received good support while others only received the most basic information without any discussion of their concerns.

The most common approach we found for informing people about their diagnosis was to have an initial appointment with the GP, followed by a longer appointment with a nurse to provide more information about diabetes and its treatment. Health professionals stated the importance of giving people enough time to understand the information they were receiving. One GP practice in Rushcliffe CCG saw people three times within the first six weeks following diagnosis to make sure they had enough time

to understand and come to terms with their diagnosis.

*“The diabetes nurse in my practice is excellent in helping me manage my diabetes. So much so it is fully under control in under six months. She also listens to me which helps very much.”*

**Man with Type 2 diabetes**

A few of the areas we visited noted that they provide information that is suitable and relevant to patients from different BME communities and people with a learning disability. We saw a good example in one area of a consultation with a diabetes specialist nurse and dietician. The patient was supported to understand and manage their condition through interpretation provided by the dietician who was Urdu-speaking, use of diagrams and translated written information. The discussion regarding diet and food choices reflected a South Asian diet.

Some people, for example those with a learning disability, may require additional support to understand and manage their diabetes, including at the time of diagnosis. This support can come from family members, care staff, or others. When this support is lacking it can impact on the person, as illustrated in the example.

One person with a learning disability told us about her shock when she was first told she had to use an insulin pen. She was phoned by her GP and was asked to come in that afternoon to see the nurse, but was unable to organise a support worker to accompany her at short notice. She and her support worker felt the training offered during the meeting was inadequate. The support worker subsequently arranged for a district nurse to come in and explain how to use the pens after talking to the GP surgery. The woman was anxious and distressed while recalling these events.

*“When I was first diagnosed, that was bad care, when they just dumped the insulin on me, that was bad care. They could have at least explained it to me, because I tried to get out of it. I tried to say ‘Well can’t you wait till...’ and I tried to get support but I couldn’t, because it’s such short notice. That was the worst part, they just dumped it on me like that.”*

**Woman with Type 2 diabetes**

### ADDITIONAL SUPPORT WHEN REQUIRED

We heard how multiple professionals and agencies in Liverpool worked together to provide personalised support at the time of diagnosis for people who needed it. This could include community matrons and mental health teams, supported by food workers and health trainers if required. Social care workers were aligned to each neighbourhood area to make sure that no one who needed support was overlooked. Learning disability nurses also helped to support people when diagnosed, sharing information from, and with, diabetes specialist and practice nurses. Staff said they would educate the relatives or carer of the person, and would use communication aids including food pictures for people with a learning disability. Staff in Liverpool gave the example of one person with a learning disability who had been diagnosed with Type 2 diabetes but found it difficult to adapt to the suggested changes in diet and did not follow dietary advice. The person received support from the dietician, and a food worker visited daily for a number of weeks to support the person with shopping and preparing meals, until they were confident enough to manage their new diet.

Liverpool CCG

A common theme in the experience described by people with both Type 1 and Type 2 diabetes was a need for more emotional support, at the time of diagnosis and beyond. This includes emotional support from health professionals (who some people felt prioritised information over emotional well-being) and in some cases a need for access to specialist psychological support. Providing emotional support at diagnosis can contribute to more effective self-management and increase engagement with services and attendance at structured education programmes.<sup>14</sup> The need for emotional support for those with Type 1 diabetes is well established. Our findings suggest that professionals may not always recognise the emotional needs of those with Type 2 diabetes.

Several people told us about the shock of receiving their diagnosis – describing it as a “whole life-changing experience” and a “complete bombshell”, particularly for those who believed they were living a healthy lifestyle.

“Although I was pre-diabetic for a time and knew what was coming in the future, the actual news of becoming a diabetic was shocking. I could have done with some psychological support at this stage.”

Woman with Type 2 diabetes

People felt that it was important to have a health professional who listened to their concerns, rather than just giving them information. Some people suggested that support groups would be helpful. When people do receive emotional support from a health professional after their diagnosis it can have a profound impact.

One person we spoke with said that when she received the diagnosis, “I just wanted to be dead”. She reported not wanting to believe she had diabetes and not wanting to take medications, particularly insulin, as she was aware of the stigma attached to having diabetes by some people in her ethnic group.

She said that her GP was extremely supportive when diabetes was diagnosed and felt her GP was the only one she could talk to. She explained that on one occasion, she was walking to the GP surgery and thinking about suicide because of the diabetes.

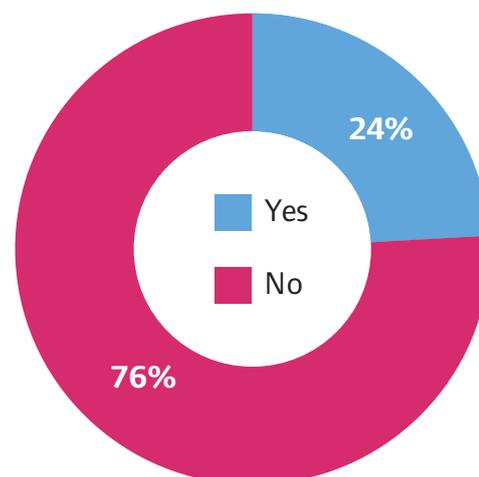
*“The only thing that saved me was the GP. He made me feel like life was worth living, and what would happen to my children and husband if I was not here anymore?”*

**Woman with Type 2 diabetes**

Some people may need additional psychological support after their diabetes diagnosis. Diagnosis is an opportunity to make efforts to minimise the likelihood of a person developing depression – a condition people with diabetes are at higher risk of and one that can impact their ability to manage their diabetes.<sup>15,16</sup> Although not everyone who is diagnosed with diabetes will need specialist psychological support, those who do should be able to access it in a timely way.

People we spoke with who had needed and accessed specialist psychological support found it very helpful. One person told us that the specialist counselling service has “been my rock, given me confidence”. In 2015, Diabetes UK’s care survey found that only 24% of people with diabetes who had needed emotional or psychological support from a specialist healthcare professional or service said they were offered it [FIGURE 3].<sup>17</sup>

**FIGURE 3: PEOPLE OFFERED EMOTIONAL OR PSYCHOLOGICAL SUPPORT**



Data Source: Diabetes UK: Care Survey 2015  
Total respondents: 3,000 people



# Structured education and support for self-management

## KEY FINDINGS

- People who had attended structured education courses felt it improved their ability and confidence to manage their condition. However, the courses were not able to meet everyone's needs and it was not always clear how the education needs of those who had not attended were being met.

## Structured education

People's ability to self-manage is integral to the successful management of diabetes. Self-management reduces the risk of complications and demand on health and care services. Structured education programmes support the person and their family members and carers in developing skills, knowledge, beliefs and attitudes to self-manage diabetes.

NICE recommends that people should be offered a course around the time of diagnosis of Type 2 diabetes, and six to 12 months after diagnosis for people with Type 1 diabetes, with annual reinforcement and review.<sup>18,19</sup>

All the CCGs we visited commissioned structured education programmes, and most offered

courses for people with Type 1 (mostly DAFNE<sup>a</sup>) and Type 2 diabetes (mostly X-PERT Health and DESMOND).<sup>b</sup> However, one CCG only commissioned courses for people with Type 2 diabetes, despite NICE recommending that adults with Type 1 diabetes who have not undertaken a structured education programme should be offered it, regardless of how long they have had Type 1 diabetes. Two areas had additional courses that focused specifically on weight loss.

National Diabetes Audit data for 2014/15 shows that 78% of people with diabetes aged 18 to 64 years have been offered a structured education course. This is mirrored by the responses to our

a. DAFNE: Dose Adjustment For Normal Eating

b. DESMOND: Diabetes Education and Self Management for Ongoing and Newly Diagnosed

online feedback form in which 75% of people said they have been offered a structured education course; 61% had attended one. Both our online feedback form and Diabetes UK's 2015 care survey found that people with Type 1 diabetes were much more likely to have been offered and attended a course than people with Type 2.

In general, people we spoke with who had attended structured education courses were very positive about their experiences. The majority of people (including over 80% of those who responded to our online feedback form) said it was helpful in improving their knowledge and ability to self-manage. People identified benefits including improved understanding and knowledge about their condition (for example insulin and medication); improved self-control

and management (such as diet and exercise); and the opportunity to discuss concerns and share information with other people. However, there was a clear theme of people saying that although the courses were helpful, they wanted more opportunities to attend refresher sessions.

**“I found the course useful and informative. I have a much better understanding now and that has helped me to lose weight, increase exercise and I have been able to reduce the amount of medication I need.”**

**Person with diabetes**

A man told us about the treatment and care he had experienced. He said that training was the most important aspect, and that completing the structured education course enabled him to successfully manage his condition. He spoke highly about the trainers and the support they provided.

His only negative was he had to wait six months to access the training, and was initially anxious about the time he would have to spend on the structured education course. He felt the period before he completed the DAFNE course left him “in the dark”. However, he could not fault the support he received from his GP and practice nurse during this period.

*“I would absolutely recommend it to anyone with diabetes Type 1. For me to manage my diabetes it's been vital, I am able to manage my needs well. The trainers in Worcester were fantastic. Training was pitched to everyone. If someone wanted me to stand up in front of thousands to recommend this course, I definitely would.”*

**Man with Type 1 diabetes**

## A PRACTICE LED APPROACH TO STRUCTURED EDUCATION<sup>c</sup>

The advanced nurse practitioner at the practice ran X-PERT Diabetes, a six-week structured group-based education programme for people with diabetes. At the time of our inspection, this was the only practice in Redditch and Bromsgrove that offered this programme in-house. The GP partners supported the programme as they placed a high value on patient education and self-management of long-term conditions. Between 10 and 18 patients attended each week for two and a half hours.

The service was popular with patients and demonstrated improved outcomes including weight loss, reduction in HbA1c (blood sugar levels) and cholesterol.

**Elgar House Surgery, Worcestershire**

c. This is an example from our comprehensive inspections. CQC has a toolkit that showcases outstanding practice in GP surgeries: [www.cqc.org.uk/content/examples-outstanding-practice-gps](http://www.cqc.org.uk/content/examples-outstanding-practice-gps)

Elgar House Surgery is an example of a GP practice inspected by CQC that demonstrates a successful practice-led approach.

The most common reason people gave us why they had not attended a structured education programme was that the courses clashed with other commitments. Several CCGs told us they had made efforts to improve the choice of times, dates and venues of the courses to try to increase attendance. Four CCGs told us they contacted patients who had not attended to understand their reasons and try to address them.

### IMPROVING ATTENDANCE AT STRUCTURED EDUCATION

People who do not attend session one are contacted to enquire as to the reason and whether they would like to re-book. People who do not attend all four sessions are contacted by letter and asked to give feedback about their non-attendance by an anonymous questionnaire so that the service can address any common issues.

**Rushcliffe CCG**

Three of the CCGs we visited tried to improve attendance at the courses by training primary care staff to engage more effectively with people. This included training practice nurses in motivational interviewing to support people to change behaviour and take up offers of structured education. In some areas, we heard that practice staff are encouraged to attend the structured education courses so that they are better able to advise patients on the course and its contents.

Other areas are developing innovative methods of delivering structured education, such as online education (see case study below).

Using online methods to deliver structured education could be a significant advance in getting information about diabetes to those who may not attend a course in person. Mobile phone and internet-based interventions have been found to support self-management for people living with diabetes. Technology can be used to supplement healthcare provider diabetes care by providing both educational and motivational support. Online learning allows people to work at their own pace wherever they are. Mobile apps have added convenience and can give cues and feedback through the phone.

### IMPROVING ACCESS TO STRUCTURED EDUCATION

In addition to face-to-face educational courses (such as XPERT and DAFNE), the CCG has commissioned a National Institute for Health and Care Excellence (NICE) endorsed online education programme for people with Type 2 diabetes. The successful implementation of Mapmydiabetes was achieved in collaboration with the CCG, Diabetes UK and Mapmyhealth.

The programme supports self-management by providing structured education, information, goal-setting and tools to create meal and exercise plans. Healthcare professionals can use Mapmydiabetes to support collaborative care-planning, communicate with people and monitor progress. Diabetes specialist nurses and community diabetes dieticians have worked to make sure the content of established courses is evidence-based and consistent.

**Mapmydiabetes, South Worcestershire CCG**

Some people told us they did not want to attend a course. In some cases it was because they felt sufficiently supported by their GP or other health professionals. Others in a few CCGs who did want to attend were discouraged by long waiting times due to the limited number of places available. In one area, hospital doctors were unable to refer people directly. In some cases people were told they were only eligible to attend during the first year following diagnosis, but felt they were not ready while adjusting to a different lifestyle and accepting the diagnosis.

Very few of the people (three out of 20) from BME groups that we interviewed in depth had attended a structured education programme. Most were unaware of these programmes and had not spoken with a health professional about them. Six CCGs told us they delivered structured education courses in languages other than English. This included employing specialist diabetes educators who spoke other languages and using interpreters who are trained in the course curriculum. Several CCGs recognised they were not providing courses that were appropriate to their local communities – this was echoed by the people who lived there. Four CCGs told us of the steps they had taken to make sure that courses were culturally relevant.

### IMPROVING CULTURAL RELEVANCE OF STRUCTURED EDUCATION

The South Asian Lifestyle Intervention Programme was put in place to improve access to diet and lifestyle projects for Urdu speaking people. This project won the clinical team of the year award in 2014 for its outcomes and organisation of a non-traditional approach.

**Slough CCG**

On our fieldwork visits we found that structured education was rarely offered to people with a learning disability. It was not always clear whether people's education needs had been met through other channels. Only two of the people with a learning disability who we interviewed in depth said they had been offered access to a course. One did not attend as she did not feel able to go on her own and was unable to arrange for a support worker to go with her. The other person did not feel the course suited her needs. NICE guidance states that for a person unable or unwilling to participate in group education, an alternative of equal standard should be provided.<sup>18,19</sup> In several areas we found that there were no appropriate education programmes for people with a learning disability or cognitive impairment, deaf people or people who are hard of hearing.

We saw several good examples where services had adapted course materials in order to provide structured education content to those for whom the standard courses may not have been suitable. One CCG described specific programmes for people with a learning disability and their carers, which are delivered with learning disabilities health facilitators and community nursing teams at day care services. The programme was also available in different languages, including sign language. In one CCG, people whose first language is not English where group education may not be suitable were offered education on an individual basis with the use of an interpreter, and given bilingual cards to show to the GP so that an interpreter could be arranged. However, these kinds of initiatives and adaptations were not always available in the areas we visited. This means that the people the standard courses are unsuitable for are often not gaining the benefits of increased knowledge and understanding of their condition.

In addition to their efforts to increase attendance and cultural relevance of structured education, commissioners should prioritise evaluation of the courses in their areas. They should be clear on the skills and knowledge they are expecting people to gain from the programmes and assure themselves that the courses are delivering better health outcomes.

## Ongoing support to help people better self-manage

Responses to the July 2016 GP Patient Survey show that 84% of people with diabetes aged 18 to 64 years felt they had received enough support from local services to help manage their health condition.<sup>20</sup> Most of the people we spoke with were very positive about the support they received from their GP practice to manage their diabetes. Particularly important to them was the

feeling they could contact someone, such as the specialist nurse, for advice when they needed it.

People generally reported that their conversations with healthcare professionals included discussions around diet and physical activity. One person told us, “My GP has done research on Asian foods and has helped educate me in healthier cooking techniques and foods to use, specifically for the kinds of food I eat.” Others told us that these conversations did not always take their cultural background into account.

One person we spoke with told us that his experience of diabetes care was good and that local services seemed to be working well together. He felt that his diabetes was well-controlled, and he received check-ups from a specialist nurse every six months at his GP surgery. He said that he had a good understanding of the tests and check-ups he received. He preferred seeing the specialist nurse rather than a GP because of her specialist knowledge and she had more time to explain things to him.

He told us that he had lost 12kg in weight in the last three years through making changes to his diet and lifestyle, which he attributed to a combination of his own determination as well as the input of the specialist nurse. He had not been offered a structured education programme, although he said he would not have attended anyway due to lack of time. He had seen a dietitian when he was first diagnosed, but had not received any dietary advice tailored to a South Asian diet. He said that the information, leaflets and advice he received were all about English food.

*“If they could have an Asian version of foods so that when the Asian community go in, not so much us, because we can eat a bit of that, but there are the elderly Asian communities who may not be able to eat a roast potato or smoked salmon or this or that. I want daals and rotis and stuff like that. So for them to look at that leaflet and to look at all the list that you can eat from ... There’s nothing there.”*

**Man with Type 2 diabetes**

People with a learning disability who we interviewed in depth were often reliant on their support staff to manage their diabetes. This included help with tasks such as monitoring symptoms; buying and preparing food; and arranging visits to services or from healthcare professionals. One person said, “My carer is always getting my shopping for me, with me, make sure I get the right food.”

We found that people with a learning disability living in a residential social care setting had relatively limited self-management. They appeared often to be able to adhere to a controlled diet, although may have less

opportunity to make their own choices. People were often reliant on others for decision-making about their diet, and were encouraged to take physical activity by support staff.

In half of the CCGs visited we were told of the adaptations made to provide information and education on diabetes to people with a learning disability. In one CCG information was provided in an easy read format with one to one support from health and care staff. We spoke with four people with a learning disability and Type 2 diabetes from this CCG area. They felt they had access to education and the support they needed from GPs, community nurses and their own

support staff. One person had been supported to attend appointments by their support workers when community nurses first assisted them with insulin injections to make sure they were comfortable. This support had allowed the person to build a rapport with community nurses.

Almost all of the CCG areas we visited had undertaken work to gather the opinions and care experiences of people with diabetes. A common theme from the feedback was the need for greater ongoing support and education. This included information around healthy lifestyles and available services, emotional support, and support groups with their peers.

Many people with diabetes need, or find it useful to, self-monitor their blood glucose levels. This is usually done with a finger prick blood test using a blood glucose meter that indicates the blood glucose level at the time of the test. For people with Type 1 diabetes and people with Type 2 diabetes using insulin, it is an effective self-management tool. The role of blood glucose self-monitoring for people with Type 2 who are not on insulin is less clear, and NICE recommends that it is not routinely offered.<sup>18</sup>

A Diabetes UK survey found that 27% of 1,000 respondents had been refused a prescription for blood glucose test strips or had the number of test strips on their prescription restricted in the past 12 months. Of these, over half (52%) have Type 1 diabetes.<sup>21</sup> People found these restrictions stressful and had to make difficult decisions about when to test or not.

Healthcare staff from several services described efforts to support specific groups within their local community. This included developing support groups for young people with Type 1 diabetes, the use of health advocates and interpreters for people from BME backgrounds, and increased access to diabetes education during religious festivals which involve fasting. In the example below, lay educators were able to provide culturally relevant information, support and training to people in their local community.

GP practices from two of the CCGs we visited had set up their own education sessions to support patients on an ongoing basis. In one of these areas, GPs felt the success of these were due to them being patient-led.

## USE OF LAY EDUCATORS

City and Hackney CCG use lay educators to run diabetes awareness sessions in the community. They held events in schools, libraries and workplaces where they offered screening and advice on how to reduce the risk of developing diabetes. For those with a specific risk, the lay educators ran group education courses on prevention.

The lay educators delivered structured education to people with Type 2 diabetes. They were trained and quality assured against a national standard and peer-reviewed in their delivery of education. The nationally accredited education programme was delivered in the diabetes centre and in community settings, with courses being run in Turkish and English. Feedback from the education groups was overwhelmingly positive, and people we met who had attended these courses had good knowledge of self-management including diet.

Members of the lay educator team were part of a project to investigate a relatively high non-attendance rate among a group of patients for appointments with diabetes specialist nurses and dietitians.

The lay educators were inducted, trained, reviewed and appraised like other staff and were deemed by the service to be a vital and cost-effective part of the extended diabetes team.

**City and Hackney CCG**

## PATIENT EDUCATION PROGRAMMES

GPs in this area have set up patient-led diabetes education sessions at their practices. This began as a patient group with talks from a clinician. Over time patients led on researching and providing information themselves, with information checked by a nurse for accuracy.

In two practices where we spoke with GPs about the groups, they have become patient-led and attendance has increased. GPs said this format provided people with a greater insight into their condition and was proving more effective in achieving lifestyle changes than clinician-led advice alone. They gave an example of one person who had never complied with statin medication until it was explained by other people at the group how important it was. At the staff focus group we were informed that five out of 16 practices had used similar sessions to educate people with diabetes. The CCG chair told us that the 'model' practices who employed these sessions were the best performers in the CCG in terms of diabetes outcomes and other areas such as cardiovascular disease.

**Slough CCG**



# Care pathway

## KEY FINDINGS

- Most people we spoke with received the checks recommended by the National Institute for Health and Care Excellence (NICE). Generally, people reported they were able to discuss their care with primary care staff and they felt they received good explanations about their care.
- People showed a lack of awareness and understanding of their test results. Very few people had a hand-held care plan they could take with them as they moved between services.

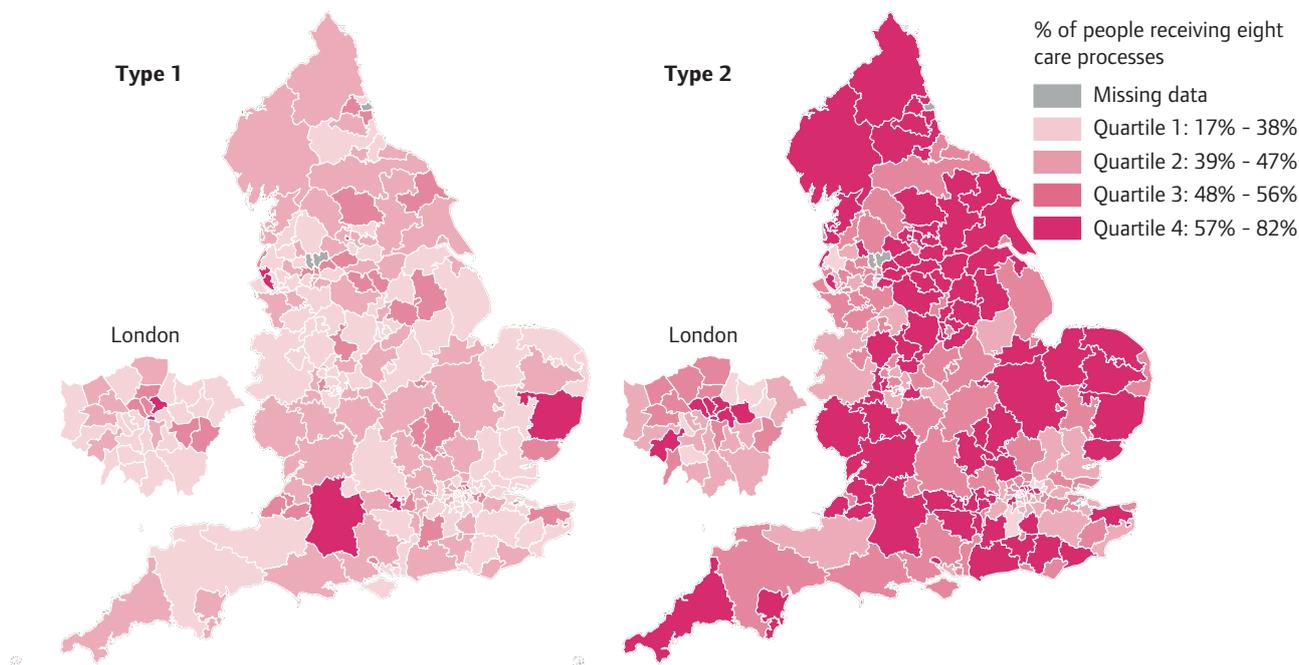
## Care processes

The National Institute for Health and Care Excellence (NICE) outlines the care pathway for management of diabetes, which includes a focus on providing individualised care, education and lifestyle advice, and identifying and managing complications of diabetes through an annual review.<sup>18</sup> The annual review is an important opportunity to monitor a person's health, act on any concerns, understand individual needs and plan future care. Each year, everyone with diabetes should have their blood glucose, blood pressure, cholesterol, eyes, feet, kidney function, weight, and smoking status checked. These 'care processes' are important to identify and act on potential complications.

The majority of people we spoke with on our fieldwork were aware of the tests and checks they should be receiving, and told us they received the checks every six or 12 months. Generally, people reported they were able to discuss their care with primary care staff and felt they received good explanations. People with a learning disability had less awareness and understanding of the care processes and whether they were receiving them. However, national data shows that too many working age people do not receive all of the care processes, with people with Type 1 diabetes less likely to receive them (39%) than those with Type 2 diabetes (54%) [FIGURE 1, page 22].<sup>d</sup>

d. National Diabetes Audit does not include data on uptake of retinopathy screening.

**FIGURE 4: PERCENTAGE OF PEOPLE WITH DIABETES AGED 18 TO 64 YEARS RECEIVED THE EIGHT CARE PROCESSES RECORDED BY THE NATIONAL DIABETES AUDIT, BY CCG**



Data Source: National Diabetes Audit 2014-15  
 Total number aged 18-64 registered with Type 1 diabetes: 98,907 people  
 Total number aged 18-64 registered with Type 2 diabetes: 655,647 people

In several areas, services identified barriers in engaging or reaching some groups of people to make sure they received the checks they need. Groups noted as being more difficult to engage with or monitor included younger people and people who are homeless. In some areas with culturally diverse populations, engagement with services was identified as a barrier.

CCGs told us of methods to increase the number of people attending their checks. They included refining systems for inviting and reminding people of their annual reviews, and offering

extended opening hours including appointments on Saturdays. Several people we interviewed told us they appreciated it when their practice sent them reminders for forthcoming appointments.

A few CCGs had developed electronic pathways or checklists that guided GPs and practice nurses through the care processes and referral on to other services. Elsewhere one CCG incentivised GPs to deliver and record all care checks that would be followed up by specialist nurses if any were missed.

### INCREASING AWARENESS OF KEY TESTS

The retinopathy service in Sandwell and West Birmingham has developed a **comic style leaflet** and a **YouTube video** about the importance of eye screening, available in different languages.

Languages are Sign, Urdu, Somali, Romanian, Punjabi, Polish, Pashto, Hindi, Gujarati, Chinese / Mandarin, Arabic, Bengali / Sylheti.

In most areas referral to other services as a result of checks (for example podiatry and dieticians) seemed to be working effectively. However, a few areas identified that access to these services needed improving. Some services lacked capacity resulting in delays; elsewhere communication breakdowns between services prevented adequate follow-up of patients.

It was common for staff in care homes to support people with diabetes to attend checks. However, in one CCG area we were told this could create resource issues for care homes as they would have to release a member of staff to accompany the individual.

The care homes we visited in two CCG areas were not recording or monitoring whether residents had received the necessary care processes. In another there was a lack of awareness or understanding among care home staff of the care processes. Although staff knew that maintenance of blood glucose levels was important, some care homes had received conflicting information about how frequently this should be monitored for people with Type 2 diabetes.

We were told of several people with a learning disability who were reluctant to attend some of their health checks, in particular, ones that are more intrusive such as eye screening. In one case we heard about a person who, concerned that his levels would be too high at his annual review the following day, deliberately starved himself and overworked at the gym resulting in collapse. These examples highlight the importance of knowledgeable care staff who can support people to undertake all of their checks safely.

## Treatment targets and test results

Three treatment targets – relating to glucose control (HbA1c), blood pressure, and cholesterol – should be monitored and met in all people with diabetes.<sup>e</sup> When these targets are achieved, they reduce the risk of people developing complications. However, in 2014 to 2015, only a third of people with Type 2 diabetes achieved all three, and people with Type 1 were half as likely to do so – only 17% met the three targets.

Services in five CCGs told us that people found it difficult to make the lifestyle changes needed to manage their diabetes effectively. Two people whose care we tracked in detail told us they knew their test results were not in the desired range but had not altered their lifestyle to improve their health. This included continuing to smoke and having a diet they knew to be unhealthy. This demonstrates the importance of an individual approach to supporting people to manage their diabetes, which considers the influences on individual's behaviour and choices. The patient-led education approach in Slough is an example of a supportive approach which helped people to change their behaviour. Elsewhere others told us how they received helpful support from their GP, with comments such as: "My GP explains how to make changes, takes time to talk to me" and "My GP and nurse helped me greatly to achieve my goals."

CCGs told us that a lack of resources, lack of access to support and lifestyle services, and a lack of specialist practitioners were barriers to improving achievement of the treatment targets. Services in a few areas also told us that the existence of comorbidities, including mental illness, and societal factors such as deprivation and homelessness were barriers to people achieving treatment targets.

---

e. HbA1c target should be individualised. This is particularly important for the frail elderly, in whom tight glucose control may be associated with greater risk of hypoglycaemia.

While people were generally aware of the checks they should be receiving, it was less common for them to be aware of and understand their test results, especially their foot risk scores. This raises questions about the effectiveness of the structured education programmes and annual review – a person's ability to self-manage their diabetes will be reduced if they do not have a good grasp of the condition or their current status.

In a few areas we saw that people were provided information booklets that described the care they should expect to receive. This seemed to increase awareness and understanding of their condition. In one area where people seemed to demonstrate better understanding of their test results, we were told that nurses spent time answering their questions and explaining the results in a way they could understand.



# Person-centred care coordination

## KEY FINDINGS

- Knowledge of diabetes was often lacking within some staff groups, particularly in adult social care, and in some areas diabetes training for care workers was absent. This can result in insufficient support for people who rely on others to help manage their diabetes.

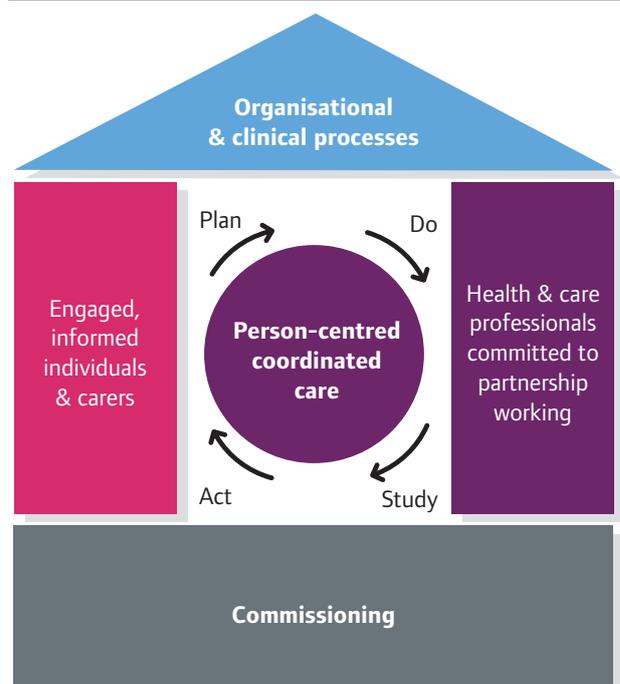
## Care planning

Evidence shows that people who are engaged in their health and care are more likely to receive care and treatment that is appropriate to their needs, to adopt healthier behaviours and are less likely to use emergency care.<sup>22</sup>

NHS England's House of Care model for long term conditions puts person-centred, coordinated care at the centre [FIGURE 5].<sup>23</sup> The model was developed from the Diabetes UK Year of Care, as a framework that enables continuity of care, with care organised around the person and their individual goals, rather than expecting them to fit into the system.<sup>24</sup>

Our report *Better care in my hands* describes how well people are involved in their own care and what good involvement looks like.<sup>25</sup> In this report we found that people with a long-term condition were less likely to feel involved in their care than others.

FIGURE 5: NHS ENGLAND'S HOUSE OF CARE MODEL



Generally, people we spoke with told us they felt involved in decisions relating to their diabetes care. This included decisions around medication, insulin treatment, diet, and type of blood glucose monitor. However, some people wanted more control over their prescriptions, including avoiding the inconvenience of multiple trips for repeat prescriptions.

People from the majority of areas we visited told us they felt supported by healthcare staff in planning their care. People who described the support they had received highlighted the importance of staff providing clear explanations when their treatment changed and spending enough time during appointments to give them confidence in understanding and managing their condition. Some people with Type 1 diabetes told us they would like print outs of test results and copies of letters sent between services such as GPs and hospitals. One person who was sent copies of letters relating to their care told us how much they appreciated it, "This is brilliant for me. I am really interested in the results and it helps me to keep track."

People described their positive experiences of being supported using phrases such as "consistency", "continuity", being "listened to" and "kept informed". However, we were told of a few instances where people felt their GP did not respond to their needs or they felt judged by healthcare staff, leading them to disengage with the service.

In order for care to be person-centred, people should be fully involved in their care planning. This is also important in people's ability to self-manage their condition. However, we found that most people did not have written care plans they could take with them when they moved between services. Only 9% of people who responded to the GP Patient Survey (July 2016) aged 18 to 64 years with diabetes said they had a written care plan. In the 2015 Diabetes UK care survey, 64% of respondents said they were not involved in care planning.

People told us that their carers or family were involved when they wanted them to be. Some people described how it was helpful to involve family who could then help with changes to diet. People with a learning disability told us how their family or support worker assisted them with appointments. However, a few of those with a learning disability told us they experienced a lack of sensitivity during consultations or at their GP practice reception. This included staff talking to the person's mother rather than them or not listening to what they had to say. One person told us about being confused during appointments, and needing the support of a friend afterwards. In contrast, another person told us that their GP was particularly good because he explained things "slowly and politely". In the example below, the person found their GP particularly helpful but identified a lack of support more widely for people with a learning disability.

## WORKING EFFECTIVELY ACROSS SERVICES

In South Reading CCG, a specialist community team including a consultant and diabetes specialist nurses, worked with complex patients and practices in the management of complex diabetes.

The specialist team held a virtual clinic with the practice to discuss patients who were not well managed and advise the GP on the best course of action. When patients had blood tests, results were included in their care plan and sent to the patient before their review meeting. This meant that at the review they were aware of their results and could focus discussions on areas for improvement.

When the diabetes specialist team were involved directly with patients, they worked collaboratively with the GP practice to discuss care planning with the patient and primary care staff so that the same advice and information was given to everyone.

**South Reading CCG**

We spoke with a woman with a learning disability living in Salford. She had been diagnosed with Type 2 diabetes 12 years previously. After her diagnosis she was referred by the adult learning disability team to a dietitian who supported her to change her diet.

*“So she went ‘change your diet’ and I did, I went on diet coke, it was a bit funny at first when you taste diet coke to normal coke but I’ve got used to it now, my diet has changed completely now.”*

She has six-monthly checks with her GP or the practice nurse, and felt that she had good control of her diabetes, although she needed to reduce her sugar levels. She said she had a good understanding of how to manage her diabetes. She told us that she liked her GP, who was a specialist in treating people with a learning disability, and described the good care she received.

*“People understanding me, that they know I have a learning disability, being patient, because [my GP] is really patient with you, she listens to you, so she doesn’t jump in, she gives you time to talk and stuff.”*

She had tried a number of slimming and exercise approaches but felt they did not meet her needs because they were complicated and confusing, or aimed at an older age group.

*“[The GP] recommended this guy, he was useless, I told him about my disability and what I wanted and he said ‘great,’ he said, ‘there’s a diabetes keep-fit class.’ I said ‘forget keep fit’. I have a disability where I can’t do keep fit because I can’t copy the person if they’re facing me, they have to stand beside me then I can copy them.”*

Although she had been offered a structured education programme, she did not want to go because she felt she already understood some of the content, such as how to take medication. She also told us there was a need for more information and support around diet and exercise for people with a learning disability, and that she would value a support group for people with a learning disability who have diabetes.

*“Where I live there’s no clubs or support groups for people with learning disabilities to go and exercise.”*

**Woman with Type 2 diabetes**

Person-centred care for people we spoke with was about ease of making contact with healthcare professionals for advice; being seen by perceived specialists (in particular specialist nurses); being listened to; having some control over aspects of their treatment; and being considered as a whole person (not just as someone with diabetes). It was felt to be absent if consultations lacked compassion or appeared to be only 'tick-box' exercises.

**“I am a whole person, not just a foot, eye or blood sugar level. Clinicians need to think what is best for the whole person”**

**Woman with Type 2 diabetes**

Diabetes specialist nurses and diabetes specialist dietitians in City and Hackney CCG had behaviour change training and used the principles of active care planning from the Year of Care model to deliver coordinated care and promote self-management in those with diabetes. All people we spoke with in this area had care plans and an awareness of their contents.

## Experience of coordination

People reported a mixed experience of care coordination between organisations. They felt staff were well coordinated within general practice, such as diabetes specialist nurses working well with GPs. However, some told us they did not feel their care was as well coordinated between GP and hospital services. Some people told us they had to repeat their information and noted that their test results were often not shared after a hospital appointment to the GPs or vice versa. They frequently mentioned having to repeat information to specialist services.

In most of the CCGs we visited, some people told us they had received conflicting information relating to their diabetes care. In a few instances this related to conflicting dietary advice; others said advice about how to manage their diabetes conflicted with advice they had received on how to manage their other conditions.

People felt their care was well coordinated when they saw the same health professionals at each visit. Some people felt that changes in staff could lead to a lack of consistency in their care. In some areas, care for people who have a learning disability and diabetes was not well coordinated. Elsewhere we saw examples of support staff working well alongside healthcare professionals to coordinate care. One person we interviewed had a team of professionals, including her GP, learning disability nurse, social worker and support worker, visit her home to assess her current condition and review her care plan, including diabetes.

**“Nursing staff provide support and I discuss my diabetes with them in terms of blood sugars, diet and control. I’ve not been referred to a dietician but the cooks are aware of my condition, I am able to make drinks or snacks anytime if I feel unwell. I see the podiatrist every six to eight weeks. I see the GP for annual reviews independently and feel confident and knowledgeable about my condition. The only time I need a carer to accompany me is for retinopathy checks, both to help manoeuvre the wheelchair through narrow parts and once I’ve had the drops put in I find it more difficult to see.”**

**Man with Type 2 diabetes**

Services commonly told us that developing and maintaining good working relationships with other services was key to improving coordination. Efforts from CCGs focused on education and specialist support for primary and community healthcare professionals. Approaches to encourage information-sharing across services included multidisciplinary team meetings; diabetes networks; and making it possible

for primary and secondary care staff to view electronic records.

Information sharing across services is essential for coordinated care. Most CCGs were positive about information sharing where services were using the same IT system. However in four CCG areas staff reported difficulties accessing information. This made it difficult to get a clear and full picture of a person's care needs and could cause

issues like delays if, for example, there were changes to medication. In another area staff reported that there were sometimes difficulties accessing electronic information because they did not have the necessary 'permissions'.

Through community diabetes models, specialists interact with primary care in supportive ways to assist with the care of people with diabetes who may not need to be seen in a hospital clinic.

## INTEGRATION OF SERVICES

Liverpool's new approach to diabetes care is focused on six community-based clinics that promote good self-management, integrated delivery and education. The clinics provide specialist support to people to help them manage their diabetes.

Clinicians from each partner organisation work together to deliver care, with the most specialist care continuing to be delivered in hospital. People with diabetes see consultants, nurses, dietitians and podiatrists closer to home in community-based clinics.

People are given resource packs, agree a care plan tailored to their own individual health and care needs, and are offered the opportunity to attend diabetes education sessions. The service also aims to increase the knowledge base and skill level of primary and community care health professionals who diagnose and treat people with diabetes.

Liverpool Diabetes Partnership (LDP) nurses determine how best to support GP practices and their patients – for example attending diabetes clinics at the practice or spending time with nurses and GPs to discuss patients with complex needs. The introduction of food workers and health trainers enables care to be provided to people based on their needs, such as shopping and cooking support for people with a learning disability.

The LDP holds monthly multidisciplinary meetings to discuss people with particularly complex needs, enabling all relevant professionals to have input into the person's care. Staff told us this was an effective way to share information about people's care and treatment and that working between organisations had improved. All people we spoke with as part of the review felt care for people with diabetes had improved as a result of the LDP.

**Liverpool Diabetes Partnership**

While many people we spoke with were positive about the support they received from their GP practice, not all were confident that their primary care staff had sufficient diabetes knowledge and expertise to be able to support them. Two people told us their GPs did not understand the treatment and prescribing that was being led by hospital doctors. One of these people told us that the lack of understanding at their practice meant that he did not receive all of the recommended checks. Another person told us that their GP “was not knowledgeable enough about treatment options.”

We heard of a range of learning activities available for primary care staff to increase their knowledge of diabetes and its treatment, including courses, seminars and workshops. Across several CCGs diabetes specialist nurses were seen as key in supporting and developing the knowledge and understanding of other healthcare professionals. In one area specialist nurses offer training days every six months to NHS staff and primary care staff, while in another

the specialist nurse designed a competency framework for practice nurses. Staff in one area told us they feel comfortable approaching the specialist nurses at any time for support.

In one CCG we heard how diabetes specialist nurses would support care home staff to increase their awareness and understanding of diabetes. In another area support workers told us they felt confident in their knowledge to support people and had training from their employers and from the local acute trust. However, in a few CCG areas there was little or no training available. A lack of awareness and understanding of diabetes among adult social care staff may mean those they care for who are at risk of diabetes or already living with undiagnosed diabetes are not identified. It can also result in a lack of care for those who have been diagnosed; they may not be supported to self-manage effectively or to attend necessary checks meaning complications may not be identified.



# Conclusions

The scale of the diabetes challenge in England is enormous. There are 3.5 million people with diabetes and diabetes care accounts for 10% of the NHS budget – both of which are rising. Through better supporting people to manage their diabetes, we have an opportunity to delay or avoid a huge amount of complications and over a number of years save the NHS billions of pounds.

CQC supports the strengthened focus on improving diabetes prevention and care as a result of the NHS Five Year Forward View. This includes the introduction of the NHS Diabetes Prevention Programme that will support people who have been identified as at high risk of developing Type 2 diabetes to become healthier.

In addition to a strong public health focus on tackling obesity, and preventing or delaying those at high risk from developing diabetes, we need to ensure that everyone who has diabetes receives the care and support they need.

We have found that most people experience good community diabetes care overall. However care is not always flexible and responsive enough to meet people's individual needs. A stronger focus on personalised care is needed, along with the recognition that people need emotional support at the time of diagnosis and on an ongoing basis. Rather than expecting people to fit in with current arrangements, services need

the flexibility to provide care that fits around people's lives and responds to their priorities.

With the input of specialists when required, health and care services based in the community play a key role in providing people with care and support. It is also vital to emphasise the importance of self-care for long-term conditions, and to make sure people are equipped with the necessary support and knowledge about their condition. Our review found the extent to which people are supported to successfully self-manage their diabetes is limited. When the NHS does not support and empower people to self-manage their long-term condition, it impacts on patient experience and on NHS resources. Better community care leads to better outcomes for people and better use of public money. All parts of the health and care system need to make self-care a real priority, for the benefit of patients and the future of the NHS.

As the number of people with diabetes increases, the challenge for health and care professionals to deliver coordinated care for everyone becomes greater. The current model of care provision will become unsustainable as the prevalence of Type 2 diabetes continues to rise. Responding to these challenges is at the core of improving care quality; improving health and managing resources more effectively.

Community diabetes care can be improved through building on what is good and learning from what is already working well, in particular where commissioners and services are using innovative approaches including technology to engage with and support their communities.

CQC encourages **health and social care commissioners, providers and professionals** to work together to deliver an approach to diabetes care that puts people at the centre of their own care and enables them to improve their health and wellbeing and manage their diabetes effectively.

Key components of this approach are:

- A **local plan** for improved diabetes care through support to self-management.
- Commissioners and providers **engaging** with their whole community to **increase awareness and understanding** of diabetes and **encourage uptake of health checks**.
- Professionals engaging with people to understand their individual needs and developing a **personalised care plan** together.
- **Emotional support** embedded in care for people with diabetes.
- Development of **education approaches** to ensure everyone, including people from BME groups and people with a learning disability, can gain the **knowledge and skills** they need.
- **Evaluation** of the effectiveness of structured education and annual review in giving people the knowledge and ability to self-manage their diabetes.
- Making better use of available **technology** to support self-management through education, motivation, and self-monitoring.
- **Training** in diabetes **for care workers** to enable them to fully support and care for people with diabetes.

CQC is committed to encouraging improvement in diabetes care. CQC will:

- Review our approach to long-term conditions, including diabetes, as part of the development of the next phase of our inspections of primary medical services and community health services.
- Support our inspection teams to develop their understanding of good and outstanding diabetes care.
- Identify and share examples of outstanding diabetes care from our inspections.
- Include data relating to diabetes care in the development of our new insight model for monitoring quality and encouraging improvement.
- Use our inspections to encourage providers of adult social care to ensure their staff have necessary capacity and capability.

# Acknowledgements

We would like to thank Liverpool and Sandwell & West Birmingham Clinical Commissioning Groups, who agreed to be pilot sites for this review and the following Clinical Commissioning Group areas that we visited in the review:

- City and Hackney
- East Lancashire
- Lewisham
- North East Lincolnshire
- Rushcliffe
- Slough
- South Reading
- South Worcestershire

We are grateful for their support particularly in putting us in touch with people and staff, and use of facilities to enable us to hold focus groups.

Thank you to providers of care for enabling staff to speak with us and for helping to organise the logistics of the fieldwork.

We would also like to thank the members of our external advisory group for their support and advice during the review:

## Organisations in the external advisory group

- Association of British Consultant Diabetologists
- Department of Health
- Diabetes and You
- Diabetes UK
- Joint British Diabetes Societies for Inpatient Care
- National Diabetes Audit
- NHS England
- Race Equality Foundation
- Sandwell & West Birmingham NHS Trust
- South Asian Health Foundation
- The Whittington Hospital NHS Trust

We would also like to thank the people who were willing to share their experiences with us during the review.

# References

- 1 Association of Public Health Observatories **Diabetes Prevalence Model**
- 2 Hex N and others, **Estimating the current and future costs of Type 1 and Type 2 diabetes in the United Kingdom, including direct health costs and indirect societal and productivity costs**, 2012
- 3 National Audit Office, **The management of adult diabetes services in the NHS**, 2012
- 4 National Audit Office, **The management of adult diabetes services in the NHS: progress review**, 2015
- 5 Baxter M and others, **Estimating the impact of better management of glycaemic control in adults with Type 1 and Type 2 diabetes on the number of clinical complications and the associated financial benefit**, 2016
- 6 Care Quality Commission, **Diabetes care pathways thematic data review**, 2014
- 7 Health and Social Care Information Centre (Now NHS Digital), **National Diabetes Audit 2014–2015 Report 1: Care Processes and Treatment Targets**, 2016
- 8 Diabetes UK, **Facts and Stats**, 2015
- 9 NHS Diabetes, **Commissioning for people with learning disabilities who have Diabetes**, 2011
- 10 Public Health England, **NHS Health Check: our approach to evidence**, 2013
- 11 **NHS Health Check national data, 2013–2018 5 year cumulative**, 2016
- 12 Diabetes in BME communities working group, **Diabetes in BME communities: raising awareness, improving outcomes and sharing best practice**, 2014
- 13 NHS England, **Public Health England and Diabetes UK, NHS Diabetes Prevention Programme**
- 14 NHS Diabetes and Diabetes UK working group, **Emotional and Psychological Support and Care in Diabetes**, 2010
- 15 National Institute for Health and Care Excellence (NICE), **CG91 Depression in adults with a chronic physical health problem: recognition and management**, 2009
- 16 Public Health England, **Adult obesity and type 2 diabetes**, 2014
- 17 Diabetes UK, **Care Survey Results**, 2015
- 18 NICE, **NG28 Type 2 diabetes in adults: management**, 2015
- 19 NICE, **NG17 Type 1 diabetes in adults: diagnosis and management**, 2015
- 20 NHS England, **GP Patient Survey**, 2016
- 21 Diabetes UK, **Test Strip and Meters Survey**, 2016
- 22 Hibbard JH & Greene J, **What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs**, 2013
- 23 NHS England, **NHS Outcomes Framework, Domain 2: Enhancing quality of life for people with long-term conditions: House of Care**
- 24 Year of Care Partnerships, **Year of Care Thanks for the Petunias – A Guide to Developing and Commissioning Non-Traditional Community Services to Support Self-Management of People with Long Term Conditions**, 2011
- 25 Care Quality Commission, **Better care in my hands: A review of how people are involved in their care**, 2016

# Appendix: How we carried out the review

We worked with an expert advisory group who provided advice and guidance throughout the review and with a range of health and social care providers and commissioners who helped us to understand diabetes care in their areas.

We developed our approach with the help of two Clinical Commissioning Groups (CCGs Liverpool and Sandwell & West Birmingham) areas during the pilot stage. We used findings from the pilot to refine the assessment framework and fieldwork.

We selected CCG areas for the review based on their context (geographical region and demographic characteristics) and performance across a range of available quantitative measures we identified as giving insight in to the quality of community diabetes care in an area.

We carried out the fieldwork for the review between January and March 2016 in the following areas:

- City and Hackney (London)
- East Lancashire (North)
- Lewisham (London)
- Liverpool (North)
- North East Lincolnshire (North)
- Rushcliffe (Midlands and East)
- Sandwell & West Birmingham (Midlands and East)
- Slough (South)
- South Reading (South)
- South Worcestershire (Midlands and East)

## What we did

### Existing evidence and data

We reviewed existing evidence from our comprehensive inspections, information provided by Healthwatch and CCGs, and a range of data sources including the National Diabetes Audit, Quality Outcome Framework and GP Patient Survey.

### Online feedback form

We used an online webform, limited to the areas covered by the field work, to gather the experiences, opinions, and insights of people about their diabetes care. Between mid-November 2015 and early 2016 we gathered 96 responses from individuals who told us about the support and education they are given, how in control of their diabetes they feel and how coordinated their care is across different services.

### Fieldwork by our inspection teams

We held interviews with GPs, lead clinicians and commissioners; multi-professional/multi-agency focus groups with staff; focus groups and one to one interviews with people with diabetes. We also case-tracked people with diabetes.

## Engagement work with people from specific Black and minority ethnic (BME) groups and people with a learning disability

Qualicis Research was commissioned to explore the perceptions and experiences of community diabetes care among individuals from BME groups and also people with a learning disability. Semi-structured in depth interviews were used to capture the lived experiences of individuals with diabetes. 20 people from BME backgrounds (specifically, African, African-Caribbean and South Asian) and 22 people with a mild learning disability (with approximately two thirds living independently and the others in residential care).

## Review framework

Our review and report were structured around four key questions:

### 1. Identification and diagnosis

Do services ensure that all those at high risk of developing type 2 diabetes are identified?

Do people receive their diabetes diagnosis in a clear and effective way?

### 2. Structured education and support for self-management

Are people newly diagnosed with diabetes referred to a structured education programme offering health and wellbeing advice to enable them to better manage their condition?

### 3. Care pathway

Are people with diabetes receiving the care processes recommended by the National Institute for Health and Care Excellence (NICE)?

Is the risk of developing complications associated with diabetes reduced or minimised?

### 4. Person-centred care coordination

Is care planned, co-ordinated, and delivered effectively to ensure that the person is at the centre of their care?

Do people have good experiences of moving between services and providers?

© Care Quality Commission 2016

Published September 2016

This document may be reproduced in whole or in part in any format or medium for non-commercial purposes, provided that it is reproduced accurately and not used in a derogatory manner or in a misleading context. The source should be acknowledged, by showing the document title and © Care Quality Commission 2016.

## How to contact us

Call us on > 03000 616161

Email us at > [enquiries@cqc.org.uk](mailto:enquiries@cqc.org.uk)

Look at our website > [www.cqc.org.uk](http://www.cqc.org.uk)

Write to us at

Care Quality Commission  
Citygate  
Gallowgate  
Newcastle upon Tyne  
NE1 4PA



Follow us on Twitter >  
[@CareQualityComm](https://twitter.com/CareQualityComm)

Please contact us if you would like a summary  
of this report in another language or format.

