



Delivering Better Diabetes Outcomes in the New NHS

Report by the All Party Parliamentary Group for Diabetes



ALL PARTY PARLIAMENTARY GROUP FOR DIABETES

A report by the All Party Parliamentary Group for Diabetes.

The All Party Parliamentary Group for Diabetes works to push diabetes up the parliamentary agenda. The Group brings together MPs, Peers and parliamentary staff from across the political spectrum to discuss key issues for people at risk of and living with diabetes.

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Chair's foreword

2012 may well be remembered as the year the Health and Social Care Bill passed through parliament, ushering in what has been called the biggest reorganisation in the 63-year history of the NHS.

We do not have the foresight to know how history will judge the reforms to our health service, but we can say that there will be no better indicator of how they perform than to look at their effect on diabetes care.

This report looks at the current state of diabetes care and makes recommendations to ensure high quality essential care is available for all people with diabetes, no matter where they live. It is based upon meetings and discussions of the All Party Parliamentary Group for Diabetes over the last year.

We sought to use our position as a cross-party group to facilitate discussion between people with diabetes, clinical staff, charities, policy experts and politicians.

The overall picture that those meetings painted was one of poor, fragmented, expensive and patchy care. I was moved by the powerful testimony of a person with diabetes who had lost part of his foot as a complication of diabetes; but also heard about the valuable role NHS Multidisciplinary Teams have played in preventing such complications elsewhere. This is just one of many examples we have heard of the shocking variations in care throughout the country. In our series of meetings over the last year, the APPG for Diabetes has witnessed both the best and worst of diabetes care.

The challenge now for the NHS is to ensure that everyone with diabetes receives the care they need. The role of the All Party Parliamentary Group for Diabetes is to shine a spotlight on diabetes care, especially in the transition to a new system, raising the issues that affect people with diabetes to the top of the political agenda.

There have been many improvements in diabetes care in recent years and as a person with Type 1 diabetes I have witnessed some of the advancements in knowledge, technology and care processes over the last 20 years from a patient's perspective. However, there is still much to be done to improve diabetes outcomes in this country.

This report does not cover all that needs to be done, nor could it hope to. Addressing the growing diabetes crisis will require the efforts of politicians, healthcare professionals, policy experts, people with diabetes, scientists, teachers, academics and the public at large. The All Party Parliamentary Group for Diabetes is one small piece of this bigger effort, and I hope that the recommendations in this report are constructive and practical steps towards a better future for people with diabetes.

Adrian Sanders MP

Chair, All Party Parliamentary Group for Diabetes

An introduction to diabetes

Diabetes is the fastest growing health threat in the UK.

Diabetes is a condition where there is too much glucose in the blood because the body cannot use it properly. This happens because the pancreas does not produce any insulin, or not enough, or the insulin it does produce is unable to work properly. This is a problem because insulin is the key that unlocks the door to the body's cells so glucose can enter them. So with diabetes, the body is unable to use glucose as fuel and instead glucose builds up in the blood.

There are two main types of diabetes – Type 1 and Type 2. They are different conditions, with different causes. The treatments can be different too. Both types are serious, lifelong conditions that can lead to devastating complications if they are not managed well. But with the right treatment and support, people with diabetes can reduce their risk of developing complications.

People with Type 1 diabetes cannot produce insulin. About 10 per cent of people with diabetes have Type 1. No one knows exactly what causes it, but it's not to do with being overweight and it isn't currently preventable. It usually affects children or young adults, starting suddenly and getting worse quickly.

People with Type 2 diabetes don't produce enough insulin or the insulin they produce doesn't work properly. 85 to 90 per cent of people with diabetes have Type 2. They might get Type 2 diabetes because their family history, age and ethnic background puts them at increased risk. They are also more likely to get Type 2 diabetes if they are overweight. It starts gradually, usually later in life, and it can be years before they realise they have it.

There are 2.9 million people in the UK living with Type 1 and Type 2 diabetes and around 850,000 more who have Type 2 diabetes but don't know they have it because they haven't been diagnosed.

Diabetes costs the NHS over £10 billion a year. That's £1 million an hour. It accounts for 10 per cent of the NHS budget. Eighty per cent of NHS spending on diabetes goes on managing complications, many of which could be prevented.

1 A snapshot of living with diabetes



1.1 Essential checks that everyone with diabetes should receive

Every person with diabetes should receive a planned programme of nationally recommended checks each year to mitigate the devastating complications that can result from their condition.

The National Institute for Clinical Excellence (NICE) set out **9 Key Care Processes** that people with diabetes should receive:

1. Blood glucose level measurement
2. Blood pressure measurement
3. Cholesterol level measurement
4. Retinal screening
5. Foot check
6. Kidney function testing (urine)
7. Kidney function testing (blood)
8. Weight check
9. Smoking status check.

These checks should form part of a programme of personalised care planning, where a person with diabetes and their healthcare professionals jointly agree actions for managing their diabetes.

Over the last year the All Party Parliamentary Group for Diabetes has met people with diabetes from across the country and has heard repeatedly that people were not receiving those checks. Others did not know what checks they had or had not had, or had no record of the results of those checks.

The National Diabetes Audit shows that two-thirds of adults with Type 1 diabetes, and half of people with Type 2 diabetes fail to get the annual tests and investigations that are recommended in the national standards. The number of people receiving all nine recommended tests and investigations ranged from 6 per cent to approximately 69 per cent, depending on the area they lived. For children, the figures are worse. In England, 96 per cent of children don't receive all of the annual routine health checks that they should. Across paediatric specialist units, the percentage of children and young people having episodes of diabetic ketoacidosis (DKA) varies from 0 to 30 per cent.

There is also variability in terms of key outcomes. Over 90 per cent of people with diabetes have their blood glucose measurement (HbA1c), blood pressure measurement and cholesterol measurement checked annually. However, once people with high blood pressure have been identified, not enough is being done to help them bring it under control, increasing their risk of diabetes-related complications such as heart disease, kidney failure and stroke.

The outcome data available shows that people achieving the recommended HbA1c measurement ranges from only 50 per cent to 72 per cent (average for England 63 per cent) and 70 per cent of people with Type 1 diabetes including 85 per cent of children do not achieve their target long-term blood glucose level. 41–61 per cent of people with diabetes do not achieve their target blood pressure (average for England 51 per cent) and for cholesterol this is 31–49 per cent (average for England 40 per cent).

Complications cannot be prevented, identified or managed if they are not even checked. These huge variations in care have to end. If people got the care that standards say they should, their outcomes would be better and less variable.

Our recommendations

- As a minimum, every person with diabetes should receive all nine checks annually.
- Personalised care planning should be in place for everyone with diabetes, and support to self-manage should include providing people with their test results – eg HbA1c, blood pressure and cholesterol results – one to two weeks prior to their annual review in a meaningful form to the person with diabetes.

1.2 Long-term complications

Diabetes is a complex condition that can have devastating effects on the body. These wide-ranging effects were outlined to the All Parliamentary Group for Diabetes by Baroness Young at a meeting of the Group:

“Diabetes is the leading cause of blindness amongst adults in the western world. It is the biggest single cause of amputation, stroke, blindness and end stage kidney failure in British adults.”

In January 2012, Dr Rowan Hillson, National Clinical Director for Diabetes, led a roundtable discussion as part of an All Party Parliamentary Group meeting focussing on complications associated with diabetes in two specific areas – feet and eyes. Those present included parliamentarians, healthcare professionals, diabetes charities and people with diabetes.

The group discussed the different ways in which foot and eye care is organised. They noted that there is a national eye-screening programme which is structured and has national standards. Dr Hillson highlighted that there are some variations in delivery but nonetheless 98% of people with diabetes have been offered retinal screening and take up of screening is in the region of 80%.

The group emphasised that the most prescient issue with diabetic retinopathy is variations in the follow-up and treatment following screening. The point was made that there is great value placed on new appointments in the NHS but what people with diabetes who have eye problems need is regular follow-up to see whether the condition has been satisfactorily treated.

Dr Hillson then reported that there is no single national programme looking at feet. Several members of the group pointed out that best practice in footcare is well known as there are several centres of excellence. Hallmarks of best practice discussed included a foot protection team to which patients whose feet have been detected as at high risk of problems can be referred to stop serious problems developing. It would also include a specialist integrated multidisciplinary diabetic footcare team for people with active foot disease.

The group noted variations in footcare, whereby teams are in place in one location providing a high quality service to treat and manage complications, but just miles down the road there may be no such teams and patients could suffer unnecessarily and be at much greater risk of losing their leg. Dr Hillson summed up the conversation by saying that it is astonishing that commissioners in one area commission excellent footcare whilst those in the next area do not. She said that it doesn't seem fair or logical that we don't share excellence better.

Members of the group spoke of the importance of being able to see a diabetes foot specialist quickly, noting that a weekend can be a long time without access when 'time is tissue'. The group argued that people need to be able to access specialist assessment and treatment within 24 hours at all times.

The group then discussed the Quality Outcomes Framework (QOF). It was noted that the QOF rewards the checking of the foot but GPs are not paid for ensuring people are informed about their risk status and what action they should take.

The group also discussed integration and noted that a patient will have to cross different financial boundaries, making it difficult to integrate care, with potential adverse consequences for people with diabetes.

Dr Hillson concluded the group's discussion by saying that there was shock about both the levels and variations in amputation levels. She added that the majority of amputations are preventable.

Our recommendations

EYECARE

- Retinal screening must be carried out at least once a year as part of a person with diabetes's annual review.
- Screening programmes must track patients' progress to ensure they receive annual screening and access to prompt treatment and follow-up when needed.
- Screening services must have good links with local provider eye departments.

FOOTCARE

- All people with diabetes should have annual foot checks by someone with the necessary training and competence. Patient education is an essential part of the annual review of feet and people should be aware of the reason for the examination, the results, the services to which they should have access if they require specific preventative measures and action to be taken if they develop a foot problem.
- According to their foot risk status, people in all areas should have swift access to a Foot Protection Team or Multidisciplinary Footcare Team, which have been shown to significantly reduce levels of risk.
- People with diabetes who go into hospital, for whatever reason, should have their feet checked on admission and throughout their stay.
- Healthcare professionals need a greater understanding of the importance of diabetes footcare.

1.3 The knowledge gap: raising awareness and diabetes education

Raising awareness

During the year the APPG for Diabetes met to discuss issues concerning children and young people with diabetes. One of the recurring themes of that meeting was the late diagnosis of Type 1 diabetes, which frequently leads to hospitalisation.

Type 1 diabetes cannot be prevented, but awareness of the signs and symptoms and early identification are crucial to ensure that both children and adults who develop it do not become acutely ill with diabetic ketoacidosis (DKA) where abnormally high blood glucose levels lead to coma or death, and a raised blood glucose level can lead to the early stages of organ damage.

A quarter of young people with Type 1 diabetes are diagnosed after requiring emergency treatment, suggesting that awareness of the signs and symptoms of Type 1 diabetes is low and that we are detecting Type 1 diabetes far too late. Diabetes UK's recently launched 4 T's campaign aims to address this and raise awareness of the signs and symptoms of Type 1 diabetes and ensure a swift and accurate referral.

Low awareness of symptoms of Type 2 diabetes has also been a recurring theme of the group's meetings. In January 2012 Professor Sir George Alberti, President of Diabetes UK, led an APPG for Diabetes roundtable discussion on the prevention and early detection of Type 2 diabetes.

Professor Alberti stated that NHS health checks have a small take-up. He added that they need to be encouraged, expanded and used as an educational opportunity.

The group praised the NHS's Change for Life programme, a series of tools to encourage healthy living and reduce the risk of Type 2 diabetes. The group went on to discuss schools education and noted that a number of good programmes do exist.

Lord Collins of Highbury emphasised the importance not only of increasing awareness of diabetes symptoms, but also converting that knowledge into both governmental and societal action.

The group also argued for the need to focus programmes on high risk groups – those with family histories of diabetes, BAME communities and poorer communities.

Finally, the discussion turned to nursing homes and hospitals. It was stated that some 26% of people in care homes have diabetes, but far fewer are diagnosed. Professor Alberti added that a high proportion of people coming into hospital also have diabetes and many are undiagnosed.

Our recommendations

- There needs to be an awareness campaign of the signs and symptoms of diabetes, of the magnitude of that which brought meningitis to the forefront of the public imagination in recent times.
- Particular focus needs to be placed on raising awareness in higher risk groups, such as black and minority ethnic communities and people in hospital and care homes.

Diabetes education

Diabetes is a lifelong condition that requires continual self-management. It is estimated that around 95% of diabetes care is self management, and people with the condition have to manage it every day.

In any given day, a person with Type 1 diabetes is likely to have at least three insulin injections and perform approximately 3–6 fingerprick blood tests. A child diagnosed with Type 1 diabetes aged five faces 19,000 injections by the time they are 18 years old. They also have to count the amount of carbohydrates in any food and drink intake and adjust for exercise when judging insulin intake.

Balancing blood glucose levels is a complex task for a person with diabetes and a steep learning curve for the newly diagnosed. In January 2012, Gillian Thompson, National Director of the Type 1 diabetes education programme Dose Adjustment for Normal Eating (DAFNE) chaired a discussion between policy experts, parliamentarians and people with diabetes as part of the APPG for Diabetes's investigation into variations in care. The discussion centred on the wide disparities across the country in terms of content, duration and access to structured diabetes education.

The group raised questions about the ability to convey comprehensive information in a short course. Members of the group also noted that Type 2 diabetes education can be commissioned locally. This has meant that structured education is sometimes in place for people with Type 2 diabetes but absent for those with Type 1 diabetes.

It was also argued that commissioners responsible for commissioning structured education are often making decisions based on cost rather than quality and that very few courses are commissioned at the scale and pace that is needed.

Gillian Thompson argued that structured education is essential to successful care planning and that good care planning is reliant on engaged and educated patients.

The group agreed that there are plenty of recommendations and guidelines in place about structured education, but that there is no 'stick' to enforce structured education and care planning.

Finally, the group discussed potential barriers to integrated care planning and structured education. The barriers included the current changes to commissioning, which can blur the lines of responsibility in terms of who is responsible for commissioning structured education.

Our recommendations

- Everyone with diabetes should be offered an education course to help them to manage their diabetes.
- The proposed indicator in the Commissioning Outcomes Framework “People with diabetes diagnosed less than a year who are referred to structured education” should be accepted by the NHS Commissioning Board, and more indicators should be developed so that the NHS ensures that people with new and established diabetes are starting and completing structured education and having that education reviewed and reinforced.
- Service developers must ensure that the provision of education is prioritised, planned as a long-term activity and sufficiently resourced to meet the needs of the local population.
- The advantages of peer-involvement and age specific courses should be considered.

2 Research: prevention, treatment and a cure



The quality of life of a person living with diabetes now is much better than it was 10, 20 or 30 years ago.

Technological improvements allow people with diabetes to accurately test their blood glucose level in a matter of seconds. Insulin needles can now be as small as 4mm and hardware such as insulin pumps are shrinking in size each year. Mobile phone ‘apps’ have been developed to help people manage their diabetes. Professor Des Johnston from the National Institute of Health Research Diabetes Research Network told the APPG for Diabetes that more progress has been made on curing diabetes in the last five years than in the last 25.

All of these improvements were possible because of diabetes research. Our understanding of both Type 1 diabetes and Type 2 diabetes is improving, but there are still a lot of unknowns. What causes Type 1 diabetes? Why is incidence of Type 1 diabetes rising by five per cent each year in children under 5? Why does Type 2 diabetes develop earlier in people of South Asian origin?

The APPG for Diabetes met in June 2012 to discuss the current state of diabetes research and to look at some of the programmes currently being funded to promote diabetes prevention, treatment and a potential cure.

Karen Addington, Chief Executive of JDRF discussed some of the charity’s research areas, which include the closed-loop artificial pancreas, novel insulins that are glucose-responsive, faster-acting, easier to use, and more effective and new approaches to assess risk and block complications from developing/progressing.

However, Ms Addington also stated that the UK Government’s investment into Type 1 diabetes research already falls behind countries such as the USA, Canada and Australia. She added that although the Government allocated £51million to the Medical Research Council (MRC) and National Institute of Health Research (NIHR) to tackle the growing problem of diabetes, only £6.6million was ‘applicable’ to Type 1 diabetes.

Our recommendations

- Greater investment in diabetes research to support the prevention, treatment and an eventual cure for diabetes.
- An increase in government funding into Type 1 medical research.

3 Summary recommendations: delivering better diabetes outcomes in the new NHS



Leadership – Diabetes should have a clinical lead and function within the Commissioning Board.

Diabetes Networks – Multidisciplinary networks working across all aspects of diabetes care and local commissioning currently work well for diabetes care. It is essential that Strategic Clinical networks have a separate group and work programme focused on diabetes.

NHS Healthchecks – The NHS Vascular Healthcheck aims to risk assess people between the age of 40 and 75, and could be vital in stemming the rise of diabetes. It is essential that the programme is fully implemented and sustained.

Variations in diabetes care – There is huge variation in delivery of the standards across England. Two thirds of adults with Type 1 diabetes and half of people with Type 2 diabetes fail to get these recommended annual tests and investigations. It is essential that people with diabetes receive their NICE recommended annual care and treatment.

A national implementation plan for diabetes – The result of taking a generic approach is a risk of losing sight of what is needed for people with diabetes. There must be an implementation plan which incorporates prevention, early diagnosis, education for people with diabetes, assurance of the education and training of healthcare professionals, integrated care through local diabetes networks and a reduction in variation in diabetes care.

Unless there is urgent action on diabetes, thousands more people a year will be condemned to debilitating complications and early death.

The time for action is now.

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