

Diabetes education: the big missed opportunity in diabetes care

SUMMARY:

People with diabetes spend only **three hours** a year with a healthcare professional on average. For the remaining **8,757 hours** they manage their diabetes themselves¹.

Diabetes is a complex and challenging condition. People need the skills and confidence to cope with the daily demands of self-management and avoid devastating complications.

Diabetes education is key to successful day-to-day diabetes management and can be life-changing for people with diabetes. Yet few people are offered high quality education courses in a persuasive way due to myths that diabetes education does not really work, is never going to be attended by many people and is expensive.

The current lack of diabetes education is leading to:

- unnecessary and expensive complications such as amputations, strokes and blindness
- fewer people with diabetes being in control of their health – seriously affecting their quality of life and engagement with their care.

A radical improvement in the provision and uptake of diabetes education courses is urgently needed. Evidence shows that this is achievable and would provide very high value healthcare or even save the NHS money.

“Going on the course took the worry away. It reduced my HbA1c. It reduced my cholesterol. I lost three stone in weight. My blood pressure came down and is perfectly normal for my age. Now I understand the condition.”

Malcolm,
living with Type 2 diabetes

“The understanding and education I gained has helped me continuously since completing the course. My HbA1c has dropped from 8.3 to 6.9 and is now within the recommended range. I feel more in control of my own life.”

Charlotte,
living with Type 1 diabetes

WHAT IS DIABETES EDUCATION?

People learn about their condition in different ways. One way of understanding diabetes education, broadly based on a model used in Scotland², is in three levels:

- **Level one:** Information and one-to-one advice.
- **Level two:** Ongoing learning that may be quite informal, perhaps through a peer group.
- **Level three:** Structured education that meets nationally-agreed criteria (defined by

NICE/SIGN³), including an evidence-based curriculum, quality assurance of teaching standards and regular audit.

While all three levels are important for people with diabetes, this briefing focuses on level three education for adults. For more information about other levels of education, including a King's Fund review of approaches to level two education, go to www.diabetes.org.uk/self-management-education

THE CURRENT SITUATION

All four nations of the UK have committed to improve access to diabetes education. Yet recent data suggest that attendance at diabetes education courses remains far too low across the UK.

In Northern Ireland

12 per cent of people with Type 1 and **2 per cent** with Type 2 attended group-based diabetes education in 2013/14⁴.



Commitment: The Diabetes Strategic Framework states that "structured diabetes education to support self-management should be a core element of diabetes care"⁵.

In Wales

3 per cent of people with Type 1 and **1 per cent** with Type 2 attend group-based diabetes education⁷.



Commitment: The Government's Diabetes Delivery Plan makes diabetes education a priority and commits to improve uptake⁸.

In Scotland

No reliable national data on access to diabetes education, but our local intelligence suggests there are considerable gaps in provision.



Commitment: The Diabetes Improvement Plan identifies access to "consistent, high quality education" as a national priority⁶.

In England

2 per cent of people newly diagnosed with Type 1 and **6 per cent** newly diagnosed with Type 2 recorded as attending structured education⁹.



Commitment: Structured diabetes education is a key indicator in the CCG Improvement and Assessment Framework, which sets out clinical priorities for the NHS in England¹⁰.

THE CASE FOR CHANGE

Diabetes costs the NHS £10 billion every year. However, 80 per cent of this is spent on complications, many of which can be prevented through good day-to-day diabetes management¹¹.

Diabetes education equips people with the skills and confidence they need to take control of their condition, live well and avoid costly complications. As such, it is key to successful day-to-day diabetes management.

Delivering a radical improvement in the provision of diabetes education courses will:

- ✓ prevent serious complications
- ✓ be popular with people with diabetes
- ✓ provide very high value healthcare with reasonable upfront costs, or even save money.

PREVENTING COMPLICATIONS

Diabetes education improves health outcomes and reduces the onset of serious complications. As a result, it is recommended by NICE¹² and, in Scotland, SIGN¹³.

A systematic review of group-based education for people with **Type 2** diabetes assessed 21 randomised controlled trials. It concluded that group-based education improves a range of clinical, lifestyle and psychosocial outcomes – including significant improvements in:

- glycaemic control (significantly reduced fasting blood glucose levels and HbA1c, the latter by 0.46 percentage points at one year)
- self-management skills
- diabetes knowledge
- self-efficacy/empowerment
- patient satisfaction
- body weight at 12 months¹⁴.

In the UK, an audit of the X-PERT diabetes programme found that the course increases people's diabetes self-management skills and confidence, improves HbA1c (by 0.5 percentage

points at one year) and reduces cardiovascular risk factors¹⁵. Another UK-based course, the DESMOND programme, has been shown to support weight loss and smoking cessation, improve people's understanding of diabetes and reduce depression at 12 months¹⁶ – although evidence suggests that the programme needs to continue for improvements to be sustained¹⁷.

The evidence base for **Type 1** group-based education is extremely strong. In the UK, the DAFNE programme has been shown to:

- significantly improve long-term glycaemic control – reducing HbA1c by 1.0 percentage point at six months¹⁸, 0.5 at one year¹⁸, and 0.3 at 7 years¹⁹
- reduce the risk of severe hypoglycaemia by 67 per cent and ketoacidosis by 61 per cent²⁰, substantially reducing emergency treatment costs (see page 5)
- restore hypoglycaemia awareness²¹
- improve quality of life^{18,22} and perceived well-being^{18,21}
- reduce anxiety and depression²¹.

"Before the course I was being scraped up literally by paramedics due to hypos at least once a week. One week three times in a week. Since the course I have not needed outside assistance once. Four years now since the course."

Allan,
living with Type 1 diabetes for over 30 years

POPULAR WITH PEOPLE WITH DIABETES

Some areas struggle with low uptake of diabetes education – but evidence suggests that uptake rates can be increased dramatically through targeted interventions.

Problem	Solution
Referrals do not convince people to attend.	Work with healthcare professionals, so that they understand and promote the benefits of diabetes education; encourage healthcare professionals to attend taster sessions of local courses.
Location and timing of courses; long waiting times can deter people.	Consult people with diabetes to identify convenient venues and times; commission courses at the scale required by the local population to create more options; consider using trained lay educators (paired with healthcare professionals) to scale up provision of Type 2 education.
Off-putting terminology – for example, the term ‘structured education’ is widely used, but has negative associations for some people, particularly those who did not enjoy school ²³ .	Develop more compelling marketing and distribute this widely; collect and evaluate patient feedback.
Lack of data on who is and is not attending courses; low uptake from hard to reach groups.	Use an electronic administration system to identify and follow up non-attendees; collect patient feedback; consider targeted courses for specific groups.

In Lambeth and Southwark, for example, the Diabetes Modernisation Initiative increased attendances by some 80 per cent over three years²⁴. As part of this, materials for patients were designed in collaboration with the local Healthwatch and dropped the term ‘education’ altogether, instead using the phrase ‘learn about your diabetes’.

Likewise, in Bexley improving access to diabetes education courses was made a priority during a diabetes service redesign. Local healthcare professionals were engaged and people with diabetes consulted to identify convenient venues.

As a result, the CCG achieved its target of reaching 50% of people with Type 2 diabetes who were in the first year of diagnosis. Attendance at X-PERT increased from only 40 people in 2009 to over 1,000 in 2010, on average reducing attendees’ HbA1c level by 1.3 percentage points²⁵.

For more information about how other areas across the UK are improving diabetes education, go to www.diabetes.org.uk/shared-practice

“With any patient education programme it must be promoted by primary care professionals as well as hospitals. It must become the norm for newly diagnosed patients to be made fully aware of what opportunities exist to help them understand, come to terms with and manage their condition.”

Chris,
living with Type 2 diabetes

PROVIDING HIGH VALUE HEALTHCARE

Evidence shows that diabetes education is cost effective – and can save the NHS money in the medium to long term.

The cost of a five-day DAFNE course for people with Type 1 diabetes is around £308 per person (based on educating 120 people per area per year)²⁶. An economic evaluation of the DAFNE programme showed that, by reducing the onset of costly complications such as blindness, end-stage renal disease and foot ulceration/amputation, DAFNE would pay for itself within 4.5 years and save the NHS £2,237 per patient over 10 years²⁷.

In the long run, the Department of Health has estimated that the DAFNE programme could save the NHS £48 million per year nationally, or £93,133 per 100,000 of the population, if it is made available to everyone in the UK with Type 1 diabetes²⁸.

A subsequent evaluation, based on more conservative assumptions about reductions in HbA1c, concluded that DAFNE is a cost-effective intervention, but would not result in cost savings over a lifetime horizon²⁹. However, this may underestimate potential savings. A more recent study found that DAFNE reduced emergency treatment costs for ketoacidosis and severe hypoglycaemia by 64 per cent, or £81 per patient, over a year²⁰ – suggesting that course costs would be recouped in under four years.

Analysis of two of the most prominent education programmes for people with Type 2 diabetes, X-PERT and DESMOND, concludes that both are likely to be cost effective compared with usual care^{30,31}. One evaluation suggests that, if rolled out to everyone with Type 2 diabetes, X-PERT could save £367 million per year as a result of reduced medication costs³².

The cost of delivering X-PERT and DESMOND courses has been estimated at £65³³ and £76³⁴ per person respectively (based on educating around 500 people per area per year).

This means that diabetes education could be delivered to everyone in the UK diagnosed with Type 2 diabetes – over 3.1 million people – for £40 million per year over five years³⁵. This is just under 0.6 per cent of the £7 billion that the NHS spends every year on Type 2-related complications³⁶. Moreover, this is likely to overestimate the investment required, as economies of scale mean that course costs would fall with high levels of provision.

In addition, there is good evidence that trained lay educators can deliver Type 2 diabetes education courses effectively when they are teamed with a healthcare professional^{37,38}. There is therefore considerable potential to use lay educators both to increase educator capacity and improve the cost effectiveness of courses.

CALLS TO ACTION

✓ **Healthcare professionals should:**

- Promote the benefits of diabetes education courses to their patients.
- Find out what courses are available locally, be familiar with referral pathways and consider attending a taster session.

✓ **Local decision makers should:**

- Put plans in place to ensure that all people with diabetes have the skills and confidence to manage their condition by 2020.
- Commission or provide a menu of education options for people with diabetes, including:
 - accessible structured education courses, meeting NICE/SIGN criteria³, for all adults with Type 1 and Type 2 diabetes
 - other learning options appropriate for the local population.
- Ensure that at least half of all people newly diagnosed with diabetes attend a structured education course within a year.
- Reach those who have missed out in the past – so that at least half of people with diabetes receive structured education over the next five years.

✓ **National decision makers should** work with local areas to drive delivery of these calls to action, in order to achieve a radical improvement in diabetes education and self-management.

REFERENCES

- 1 Department of Health (2007). *Working together for better diabetes care. Clinical case for change: Report by Sue Roberts, National Director for Diabetes*
- 2 Diabetes Education Scotland (2013). www.diabeteseducationscotland.org.uk/Patient.aspx
- 3 NICE (2011). QS6: *Diabetes in adults quality standard. Quality statement 1 – structured education*. In Scotland: SIGN (2010). 116: *Management of diabetes. A national clinical guideline*
- 4 Department of Health, Social Services and Public Safety (2015). *Patient Education/Self Management Programmes for People with Long Term Conditions (2013/14)*
- 5 Department of Health, Social Services and Public Safety (2016). *Diabetes Strategic Framework*
- 6 Scottish Government (2014). *The Diabetes Improvement Plan*
- 7 Nicholls H (2014). *Structured Diabetes Education in Wales. All Wales Diabetes Implementation Group*
- 8 Welsh Government (2013). *Together for Health – A Diabetes Delivery Plan*
- 9 HSCIC (2016). *National Diabetes Audit 2013-2014 and 2014-2015. Report 1: Care Processes and Treatment Targets*
- 10 NHS England (2016). *CCG improvement and assessment framework 2016/17*
- 11 Diabetes UK (2014). *The cost of diabetes*
- 12 NICE (2015). NG17: *Type 1 diabetes in adults: diagnosis and management*; NICE (2015). NG28: *Type 2 diabetes in adults: management*
- 13 SIGN (2010). 116: *Management of diabetes. A national clinical guideline*
- 14 Steinsbekk A, Rygg LO, Lisulo M et al (2012). Group based diabetes self-management education compared to routine treatment for people with Type 2 diabetes mellitus. A systematic review with meta-analysis. *BMC Health Services Research* 12; 213
- 15 Deakin T (2011). The diabetes pandemic: is structured education the solution or an unnecessary expense? *Practical Diabetes* 28 (8); 1–14
- 16 Davies MJ, Heller S, Skinner TC et al (2008). Effectiveness of the diabetes education and self management for ongoing and newly diagnosed (DESMOND) programme for people with newly diagnosed Type 2 diabetes: cluster randomised controlled trial. *British Medical Journal* 336; 491–95
- 17 Khunti K, Gray LJ, Skinner TC et al (2012). Effectiveness of a diabetes education and self management programme (DESMOND) for people with newly diagnosed Type 2 diabetes mellitus: three year follow-up of a cluster randomised controlled trial in primary care. *British Medical Journal* 344; e2333
- 18 DAFNE Study Group (2002). Training in flexible, intensive insulin management to enable dietary freedom in people with Type 1 diabetes: dose adjustment for normal eating (DAFNE) randomised controlled trial. *British Medical Journal* 325; 746
- 19 Gunn D, Mansell P (2012). Glycaemic control and weight 7 years after Dose Adjustment For Normal Eating (DAFNE) structured education in Type 1 diabetes. *Diabetes Medicine* 29 (6); 807–12
- 20 Elliot J, Jacques RM, Kruger J et al (2014). Substantial reductions in the number of diabetic ketoacidosis and severe hypoglycaemia episodes requiring emergency treatment lead to reduced costs after structured education in adults with Type 1 diabetes. *Diabetic Medicine* 31 (7); 847–53
- 21 Hopkins D, Lawrence I, Mansell P et al (2012). Improved biomedical and psychological outcomes 1 year after structured education in flexible insulin therapy for people with Type 1 diabetes. *Diabetes Care* 35 (8); 1638–42
- 22 Speight J, Amiel SA, Bradley C et al (2010). Long-term biomedical and psychosocial outcomes following DAFNE (Dose Adjustment For Normal Eating) structured education to promote intensive insulin therapy in adults with sub-optimally controlled Type 1 diabetes. *Diabetes Research and Clinical Practice* 89 (1); 22–29
- 23 All-Party Parliamentary Group for Diabetes (2015). *Taking Control: Supporting people to self-manage their diabetes*
- 24 Diabetes Modernisation Initiative (2014). *Living well with diabetes: Learnings report from the Diabetes Modernisation Initiative*
- 25 Cotter B, Grumitt J (2011). GP commissioning: Shaping diabetes care in Bexley. *Diabetes & Primary Care* 13 (6); 375–80
- 26 DAFNE Fact Sheet Six (2012). *Cost per patient 2012/13*
- 27 Shearer A, Bagust A, Sanderson D et al (2004). Cost-effectiveness of flexible intensive insulin management to enable dietary freedom in people with Type 1 diabetes in the UK. *Diabetic Medicine* 21 (5); 460–67
- 28 Department of Health (2009, updated 2013). *Quality and Productivity: Proven Case Study. Improving the quality of care for people with Type 1 diabetes: dose adjustment for normal eating (DAFNE)*
- 29 Kruger J, Brennan A, Thokala P et al (2013). The cost-effectiveness of the Dose Adjustment for Normal Eating (DAFNE) structured education programme: An update using the Sheffield Type 1 Diabetes Policy Model. *Diabetic Medicine* 30 (10); 1236–1244
- 30 Gillet M, Dallosso HM, Dixon S (2010). Delivering the diabetes education and self management for ongoing and newly diagnosed (DESMOND) programme for people with newly diagnosed Type 2 diabetes: cost effectiveness analysis. *British Medical Journal* 341; c4093
- 31 Jacobs-van der Bruggen MA, van Baal PH, Hoogenveen RT et al (2009). Cost effectiveness of lifestyle modification in diabetic patients. *Diabetes Care* 32 (8); 1453–58
- 32 Deakin T (2011). The diabetes pandemic: is structured education the solution or an unnecessary expense? *Practical Diabetes* 28 (8); 1–14
- 33 As above. Costs based on groups of 15–18 people with diabetes plus carers.
- 34 Gillet M, Dallosso HM, Dixon S (2010). Delivering the diabetes education and self management for ongoing and newly diagnosed (DESMOND) programme for people with newly diagnosed Type 2 diabetes: cost effectiveness analysis. *British Medical Journal* 341; c4093. Costs based on an average of 10 people per course.
- 35 UK-wide costs are based on providing the X-PERT programme, at a cost of £65 per person, to 3,107,731 people in the UK diagnosed with Type 2 diabetes. The total cost of the intervention would therefore be £202,002,489, or £40,400,498 per year over five years. Diabetes prevalence figures are sourced from: *Quality and outcomes framework (QOF) 2014/5*
- 36 For the cost of diabetes-related complications see: Hex N, Bartlett C, Wright D et al (2012). Estimating the current and future costs of Type 1 and Type 2 diabetes in the United Kingdom. *Diabetic Medicine* 29 (7); 855–62
- 37 Carey MC, Mandalia P, Daly H et al (2014). Increasing capacity to deliver diabetes self-management education: results of the DESMOND lay educator non-randomised controlled equivalence trial. *Diabetic Medicine* 31 (11); 1431–8
- 38 Mandalia P, Stone M, Davies MJ et al (2014). Diabetes self-management education: acceptability of using trained lay educators. *Postgraduate Medical Journal* 90; 638–642



FURTHER INFORMATION

For more information on diabetes education, including resources for healthcare professionals, commissioners and providers, go to:

www.diabetes.org.uk/self-management-education

For more information about Diabetes UK's Taking Control campaign to increase the provision and uptake of education for people with diabetes, go to:

www.diabetes.org.uk/taking-control

GET IN TOUCH

ENGLAND

CALL 0345 123 2399*
EMAIL info@diabetes.org.uk
GO TO www.diabetes.org.uk

DiABETES UK

NORTHERN IRELAND

CALL 028 9066 6646
EMAIL n.ireland@diabetes.org.uk
GO TO www.diabetes.org.uk/northernireland

DiABETES UK
NORTHERN IRELAND

SCOTLAND

CALL 0141 245 6380
EMAIL scotland@diabetes.org.uk
GO TO www.diabetes.org.uk/scotland

DiABETES
SCOTLAND

WALES

CALL 029 2066 8276
EMAIL wales@diabetes.org.uk
GO TO www.diabetes.org.uk/wales

DiABETES UK
CYMRU