



Taking Control: Supporting people to self-manage their diabetes



ALL-PARTY PARLIAMENTARY GROUP FOR DIABETES

The All-Party Parliamentary Group for Diabetes (APPG Diabetes) is a nonpartisan cross-party interest group of UK parliamentarians who have a shared interest in raising the profile of diabetes, its prevention and improving the quality of treatment and care for people living with diabetes.

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Foreword

Diabetes, whether it is Type 1 or Type 2, is not easy to live with. It is a balancing act that, for the vast majority of the time, the person living with diabetes has to perform away from doctors and nurses. Many people manage the challenges of diabetes remarkably well – the UK has the lowest rates of early death due to diabetes of the 19 wealthy countries included in 2013's Global Burden of Disease Study, and when it comes to most of the complications of diabetes, the chance of any individual with diabetes developing such a problem has decreased in recent years.

Yet despite this, still too many people living with diabetes are going on to develop serious and debilitating complications. Losing your sight, coping with loss of a limb, and having to deal with kidney or heart disease are difficult and life-changing experiences. They are also costly to the NHS, yet we know many of these complications can be avoided.

The NHS Five Year Forward View sets out the need for a fundamental shift towards prevention if the NHS is to remain sustainable. It describes our intentions to implement, at scale, a national evidence-based diabetes prevention programme to prevent Type 2 diabetes. But we must also focus intentions on ensuring everyone living with diabetes – whether Type 1 or Type 2 – has the necessary skills and support to manage their own health and reduce the risk of both devastating and costly long-term complications.

NHS England's Action for Diabetes made clear that if we are to improve the health outcomes of people living with diabetes, we must improve individuals' personal management of their condition and empower them to take charge of their own care. To do this, people living with the condition need to be able to understand their diabetes and how it affects them.

The All-Party Parliamentary Group (APPG) for Diabetes investigation is therefore timely in that it has examined in detail why many individuals are not getting the support they need to self-manage their diabetes and what the NHS, clinical commissioning groups, healthcare professionals and providers can do to address this. Having attended each of the APPG's evidence sessions, it is clear to me there is a need for a wider range of education, learning and support options that better meet the needs of individuals.

Empowering individuals living with diabetes to better manage their own care also has wider implications. While more and more people are living with diabetes, many more are living with other long-term conditions, and some are living with multiple long-term conditions. This report offers us important lessons that we can apply to all people living with long-term conditions.

The NHS is committed to empowering people to manage their own health – both through traditional models of patient education and through other interventions where appropriate to an individual's health and support needs.

I welcome the findings of this report as an important step towards improving the health burden on people affected by diabetes, the NHS and the wider UK economy.

Professor Jonathan Valabhji
National Clinical Director for Obesity
and Diabetes, NHS England
Consultant Diabetologist, Imperial College
Healthcare NHS Trust
Adjunct Professor, Imperial College London



Chair's Introduction

When the All-Party Parliamentary Group (APPG) for Diabetes embarked on its investigation into the state of diabetes education and support, little did we suspect just how much it would capture the hearts and minds of the diabetes community.

We received a mountain of evidence from experts including clinical staff, academics, academic health science networks, and strategic clinical networks, calling for a way to break the ongoing deadlock in the provision and uptake of diabetes education.

We also heard from hundreds of people and families affected by diabetes calling for an end to the postcode lottery that determines whether they will receive the essential skills and support that are needed to self-manage their condition effectively. The strength of this response shows just how important an issue this is.

Over the course of the year, we heard wonderful accounts of how education has transformed the lives of those who have been lucky enough to receive it, improving blood glucose control, reducing the risk and fear of debilitating hypoglycaemia, cutting emergency hospital admissions, and empowering people to take control of their own health.

'Taking the decision to attend the course was the best thing I ever did. It was the first time I really got my head straight on looking after myself'

Pete Ellis

But we also heard about major gaps in the training and support that is available. Emotional and psychological support is almost non-existent; support for children and families with diabetes is inconsistent; and advice on identifying and using new diabetes technologies effectively is patchy at best. Moreover, far too many people receive no diabetes education whatsoever.

If we are really serious about supporting people with long-term conditions and providing holistic person-centred care, what could be more important than empowering people to have the confidence and skills to manage their own condition?

In this report, we have not tried to reinvent the wheel, recognising the wealth of expertise and the many pockets of excellence that exist at this time and the many voices that have been calling for change over the last 10–15 years.

Instead, we have brought together current evidence on the barriers to the provision and uptake of diabetes education together with proposed solutions from the examples and ideas we have heard.

The role of the APPG is to shine a spotlight on the most pressing issues facing people with diabetes. I would therefore echo the recent National Diabetes Audit in calling for diabetes education – and the wider options for support recommended in this report – to 'set the agenda for diabetes care improvement by every diabetes care provider, by every clinical lead for diabetes services and by every diabetes care commissioner'. But I would also call for national leadership in driving this forward and in making effective diabetes education and support a reality for everyone affected by diabetes.

Adrian Sanders MP
Chair of the All-Party Parliamentary Group for Diabetes



The case for change

There are currently 3.2 million people who have been diagnosed with diabetes in the UK, and this figure is increasing by approximately five per cent each year. The direct cost to the NHS is £9.8 billion a year, or approximately 10 per cent of the health system's expenditure.

The need to do better

Although health and care outcomes have improved in recent years,¹ approximately 80 per cent of these costs are incurred by treating largely avoidable diabetes-related complications. Up to 100 people a week have an amputation as a result of the condition. Diabetes is the most common cause of end stage kidney disease, it doubles the risk of cardiovascular disease, and it is one of the most common causes of preventable blindness in people of working age. On top of this, the rate of depression is twice as high in people with diabetes, which is linked to an increase in healthcare costs of around 50 per cent. This demonstrates that significant improvements can still be made, particularly for those of younger and working age where health outcomes are worse than those who are older.

Education and support is essential for diabetes management

Managing diabetes well – achieving good glycaemic control and reducing the risk of long-term complications – requires considerable expertise and time. Although people affected by diabetes will interact with a range of healthcare professionals over the course of each year, 99 per cent of diabetes care falls to self-management.²

Evidence shows that structured patient education can stabilise blood glucose levels, reduce the risk of diabetes-related complications, improve quality of life for patients and their families, and reduce the burden of healthcare costs on the NHS.³ However, according to the National Diabetes Audit 2012–2013: Report 1: Care Processes and Treatment Targets, only 15.9 per cent of newly diagnosed people with diabetes were offered access to a structured education course in that audit year and just 3.4 per cent actually attended one.

The definition of diabetes education needs to change

Evidence gathered by the APPG makes clear that a more holistic set of interventions is required if the House of Care model – the NHS's framework to enhance the quality of life for people with long-term conditions – is to be realised.⁴ Ensuring that people have the necessary skills and confidence to manage their condition is vital. Consequently, education and support may be seen as the cornerstone of diabetes care.

Throughout the APPG's year-long investigation, the group received clear evidence underscoring the need for a broader and more flexible range of options for diabetes support, including topic-specific modules to tailor learning to a person's needs, and a choice of other forms of support from, for example, peers and online resources. However, health policy to date has focused predominantly on quality assured structured education courses as the gold standard of diabetes care. For example, National Institute for Health and Care Excellence (NICE) guidelines 10, 15 and 87 all set out the importance of patient education, both for adults and children, and for people affected by Type 1 or Type 2 diabetes.

NICE Technology Appraisal 60 – which is legally enforceable under the NHS Constitution – states that: 'It is recommended that structured patient education is made available to all people with diabetes at the time of initial diagnosis and then as required on an ongoing basis, based on a formal, regular assessment of need.'³ The NICE Quality Standard for Diabetes in Adults defines clinical best practice for the provision of structured education, which is based on the five key criteria set by the 2005 report on Structured Patient Education in Diabetes by the joint Department of Health and Diabetes UK Patient Education Working Group. These criteria define the gold standard for developing and delivering quality assured structured education programmes.

1 Health & Social Care Information Centre, National Paediatric Diabetes Audit Report 2012-2013: Part 1: Care Processes and Outcomes (2014). Available from: <http://www.hscic.gov.uk/nda>.

2 The amount of time a person living with diabetes spends on their annual GP visit and care processes makes up less than 1% of the round the clock hours spent self-managing their condition on a daily basis.

3 See, for example, The ExPand Policy Toolkit on Diabetes (2014). Available from: http://www.idf.org/sites/default/files/ExPandPolicyToolkitonDiabetes_0.pdf

4 NHS England, Domain 2: Enhancing quality of life for people with long-term conditions – The House of Care. Available from: <http://www.england.nhs.uk/house-of-care/>

In addition to NICE guidelines, in 2013 a new indicator was added to the Clinical Commissioning Group Outcomes Indicator Set which measures the number of 'people with diabetes diagnosed less than one year referred to structured education' (C2.5).

Children and young people

With regards to children and young people, International Society for Pediatric and Adolescent Diabetes guidelines provide detailed recommendations on the provision of paediatric diabetes education, and the paediatric Best Practice Tariff now clearly states that structured education should be tailored to the needs of children and their family, from the point of diagnosis through transition to adult diabetes services.

Now is the time

Despite these guidelines and indicators, there has been little improvement so far in increasing the proportion of people receiving structured education. JDRF's Type 1 Diabetes Research Roadmap (2013) emphasises the need to identify more effective ways of engaging people in diabetes self-care for the longer term.⁵ This may be through the development of more flexible programmes to cater for diversity of need and local populations and by reducing reliance on a drop in HbA1c as the endpoint of diabetes education. More recently, Diabetes UK's State of the Nation: Challenges for 2015 and beyond called for a different approach to education and learning which includes 'the delivery and funding of appropriate learning initiatives designed to meet the needs of a wide range of people with diabetes – including peer support and online learning'.⁶

Strategic clinical networks and academic health science networks are developing these ideas further to produce local toolkits and examples of best practice which can be replicated across the country. Some of these examples are included in more detail in the report. Yet despite these pockets of good practice, we are still not seeing wide-scale provision of diabetes education and support by local clinical commissioning groups or the translation of this into wider uptake by people affected by diabetes.

With diabetes costing the NHS nearly £10 billion each year, we need to transform this wealth of healthcare policy into tangible healthcare practice. Indeed, we cannot afford not to.

5 JDRF, Type 1 Diabetes Research Roadmap: Identifying the strengths and weaknesses, gaps and opportunities of UK Type 1 diabetes research; clearing a path to the cure (2013). Available from: <https://www.jdrf.org.uk/research/type-1-diabetes-research-roadmap>.

6 Diabetes UK, State of the Nation: Challenges for 2015 and beyond (2015). Available from: http://www.diabetes.org.uk/About_us/What-we-say/Improving-services--standards/State-of-the-nation-challenges-for-2015-and-beyond/



Barriers

Barriers

Barriers to the uptake of diabetes education and support

Adults

Over the course of its investigation, the APPG received evidence from a range of experts, including nearly 170 people living with, or affected by, diabetes. Although nearly all respondents strongly welcomed any opportunity to build skills and confidence to manage their condition, a number of factors were identified as potential barriers to the uptake of structured education:

- The vast majority of people with diabetes have not been offered the chance to participate in diabetes education or do not recognise that it has been offered to them. For example, research done by the Cheshire and Merseyside Strategic Clinical Network found that, of those who had not attended an education course, 70 per cent said they had not been offered access to a programme.

This is largely due to the postcode lottery that exists in whether courses are available locally, but there is also evidence to suggest that healthcare professionals are not referring people to the education available (see next section).

'I've been Type 1 for 12 years and don't know what DAFNE or DESMOND are. They've never been mentioned to me'

@mosleyowl

- Where diabetes education is signposted, people affected by the condition are often given little information or explanation about the aims and benefits of attending and consequently many people reported doubts about the usefulness of the programmes available. The X-PERT Diabetes programme found that when people are offered education in a positive manner, up to 75 per cent choose to attend.
- Where patients did seek referral to a course, waiting times can be extensive, with 12 to 18 month delays not unusual. A number of people also reported that places were only available to those newly diagnosed with the condition and that there was nothing available for people who had been living with diabetes for a number of years.

'If I had had the opportunity to have some training at the beginning I think that I might have managed my diabetes more effectively than I have done'

Claire Senior

June Williams was diagnosed with Type 2 diabetes in 2010. At the time, she knew very little about the condition and felt completely out of her depth in knowing how to deal with it. Instead of information and support, she was sent away with a prescription for medication and a lot of unanswered questions.

Eventually, she heard about a local diabetes education course. She asked her GP for a referral but was told she did not need it and advised just to keep on taking the medication. Eventually, after much persistence over 10 months, her

GP relented and June was able to join the local programme. Having the opportunity to talk about diabetes with other people on the course helped boost her confidence and stabilise her blood glucose levels.

However, no further support has been offered and June still worries that she is not managing her diabetes as well as she might. She strongly feels that diabetes education should be made available to people much sooner after diagnosis and should be ongoing as required to support people through their diabetes journey.

- A major barrier concerned practical difficulties around the location and timing of courses available. If courses were not available locally people often struggled to travel long distances to alternative programmes. Similarly, many courses require substantial time off work during the week which was a major disincentive to attendance as people did not wish to use up annual leave to attend, had caring responsibilities during this time, or could not secure time off from employers.

‘I did not want to draw attention to my medical condition and make myself look different to other employees’

Charlotte Lightman

- Patient preferences are not considered in terms of the design, content and delivery of education courses, resulting in programmes that only partially meet people’s needs. A more holistic approach is needed that incorporates, among other things, emotional and mental well-being, support for family and carers, and information about new diabetes technologies. Different learning styles must also be taken into account to ensure that information and skills training reaches as many people as possible.
- Online resources and support are rarely signposted to families newly affected by diabetes. These can be useful in explaining what training and assistance is available at a time when it is most needed.

However, even where courses were provided at suitable times and locations a number of cultural and psychological disincentives were reported:

- There is a major lack of understanding about the seriousness of diabetes so some people feel no incentive to develop skills to manage the condition better. For example, we heard of people being told by healthcare professionals that they ‘have a touch of diabetes’ and so they were neither concerned nor aware of the potential consequences of the condition.
- Diabetes ‘burn out’ can be a big factor in the uptake of education. The psychological toll of managing the condition for a long time can lead to disengagement and a lack of motivation to self-manage well. Peer support or buddying with patients who have undergone education and can explain the benefits could be useful in re-engaging people who have become hard to reach.

‘I had been suffering from ‘diabetes burnout’ and this course helped me to understand why good control was so important and helped me to see that it was manageable’

Charlotte Lightman

- The phrase ‘structured education’ itself can have negative associations for some people, particularly for those who did not have the best experience of school. New, more user-friendly terminology is needed to explain that diabetes education is interactive, group, skills-based learning that helps people to manage their condition.
- Finally, for some the shame and stigma associated with the condition was too much to overcome. This was particularly found to be the case in some black, Asian and minority ethnic communities where there is a belief that diabetes does not exist or that, if it does, there is nothing that can be done to manage it. Consequently, many people did not want others to know they have diabetes.

Children

Of the 29,000 children with diabetes in the UK, 97 per cent are diagnosed with Type 1 diabetes, 1.5 per cent have Type 2 diabetes and a further 1.5 per cent are recorded as 'other'. Currently, less than 16 per cent of children and young people achieve the recommended target HbA1c level of less than 58 mmol/mol.⁷

With the prevalence of Type 1 increasing by 4 per cent each year, particularly in the under five-year-olds, and with Type 2 diabetes becoming increasingly common in children and young people of all ethnicities, high-quality education is essential to ensure children have the best possible life chances.

Many of the barriers preventing children from accessing quality education will be similar to those set out above but there are a number of challenges that are specific to children and young people:

- One of the major barriers to education for children affected by diabetes is that recognised structured education programmes such as DAFNE, DESMOND, and X-PERT are all designed for adults. It is widely accepted that diabetes education for children needs to be age-appropriate and tailored to the developmental and psychosocial needs of the individual with ongoing regular needs assessment as the child develops. Currently, there is no nationally evaluated and accredited programme or 'off the shelf' model for paediatric teams to use.
- Similarly, as many of the parents contributing to this investigation highlighted, there is little in the way of family focused models of education to help parents, siblings, grandparents and other carers in supporting children with diabetes. Parents frequently reported high levels of anxiety and guilt as they learn to manage glucose levels through a process of 'trial and error experimentation' with their children.
- The impact of a diagnosis of diabetes can take a psychological toll on people at any time in life but among children and young people the impact can be particularly pronounced. Therefore, a multidisciplinary healthcare team with paediatric diabetes experience and psychological expertise is essential to ensure that coping skills are developed so that children and young people remain motivated and engaged in their self-management. This is particularly important during adolescence and through transition to adulthood. Since building trusting relationships is vital to this process, it is widely felt that education should be embedded within the child's routine healthcare team, yet there is limited time, funding, training, and few quality-assured programmes to enable this.

A practical example provided of this is that there are rarely any suitable rooms or areas available for paediatric education to take place.

- Families with diabetes also noted the importance of peer support from other families affected by the condition. Many online resources and support groups were very highly rated but few of these are signposted by healthcare professionals – leaving children and parents feeling isolated and unsupported, especially in the early years of managing the condition.

'The support offered to my parents was close to zero'

@le3ky

⁷ Health & Social Care Information Centre, National Paediatric Diabetes Audit Report 2012-2013: Part 1: Care Processes and Outcomes (2014). Available from: <http://www.hscic.gov.uk/nda>

Barriers to the provision of diabetes education

During the course of the investigation, APPG members wrote to their local clinical commissioning groups to seek information on the challenges and opportunities faced in providing diabetes education and to find examples of best practice. We also received evidence from a range of education providers, healthcare professionals, academics, and other experts alongside academic health science networks and strategic clinical networks to identify the following obstacles to the provision of diabetes education:

Commissioning

- Although many commissioners reported increasing demand for diabetes education courses, low attendance rates and pressure on commissioning budgets can make expansion of existing courses harder to justify.

Low attendance levels may reflect the fact that what is sometimes commissioned is not always fitted to the needs of the local population. Clinical Commissioning Groups can cover diverse areas with high social, cultural and economic variation and a 'one size fits all' model will not necessarily benefit all sections of a population.

- There are almost no national, quality-assured, standardised, ongoing patient education programmes – combining a range of learning formats and approaches – to provide choice for local commissioners to choose the most suitable options for their local populations.
- Service level agreements for diabetes education are often vague and do not ensure that every section of the population has access to the education required by NICE guidance and NICE Technology Appraisal 60.

- There is a need for greater collection of data on the provision and uptake of diabetes education to ensure that the service commissioned is fit for purpose and is delivering what it is intended to deliver.

For example, the APPG heard of examples where GPs had been encouraged to send out large numbers of referral letters – with little information about the purpose or benefits of the education course – to meet the Quality and Outcomes Framework indicator for the number of referrals to structured education within nine months of entry onto the diabetes register. However, this did not translate into more people attending diabetes education courses.

Better data collection would also enable healthcare professionals to target harder to reach individuals.

Referral and delivery

- Perhaps the biggest obstacle to ensuring people living with diabetes have access to diabetes education and learning is that many healthcare professionals do not value, or are unaware of, the benefits of education programmes. One study found that over half of general practitioners do not believe that diabetes education can change the behaviour, or improve the self-management skills, of patients, while other evidence found that the majority of healthcare professionals felt it was a ‘tick box exercise’ or an ‘optional extra’ rather than an integral part of diabetes care.⁸

This leads to a lack of referrals or, where referrals are made, they are poorly explained and the negative attitude of the referrer is passed to the patient. It is therefore vital that healthcare professionals fully understand the benefits of education and are able to promote it to people affected by diabetes. The APPG heard that where healthcare professionals have been encouraged to attend ‘taster sessions’ results have been extremely positive.

- A related barrier focused on staff training. Although there are a number of training courses available to improve knowledge and skill sets for healthcare professionals working in diabetes, the APPG heard that nurses and dieticians in particular have very limited access to study leave or training budgets and service requirements are always greater than the need for ongoing training.

Furthermore, staff delivering education programmes may require training in educational techniques and key skills such as motivational interviewing, problem solving and conflict resolution. This has been identified as particularly important for paediatric teams delivering education programmes for children and young people. In Germany, teaching skills are embedded in the training of all healthcare professionals caring for children and families with diabetes.⁹

More generally, all staff must have the knowledge to raise awareness of the benefits of diabetes education and reinforce key messaging through routine clinic appointments, even if they do not provide education directly. Without this, evidence suggests education is much less effective and has shorter impact.

- The APPG heard that GPs are often too busy to refer people to education and there are very few incentives to encourage healthcare professionals to develop services in this way.
- There is a need for better joined-up working between commissioners, referrers and education providers, delivering effective communication with the service user and ensuring that people who do not attend can be identified, supported and signposted to other learning opportunities.
- Healthcare professionals delivering education also need access to a range of educational materials and teaching methods to offer a range of ways to reach different subsets of the local population.

8 Winkley, K., A study to determine health professionals’ views of structured education for people with newly diagnosed type 2 diabetes, preliminary results. In preparation.

9 Fiona Campbell & Sheridan Waldron, Structured patient education to improve self-management: A vision for the future, Diabetes Care for Children and Young People, Vol.3, No.1 (2014).



Solutions

Solutions

Better commissioning

One of the key barriers identified by the APPG was the sheer scale of the need for education and learning and the subsequent lack of provision. There are many accounts of long waiting times or courses not being available. This is despite evidence that structured education courses are cost-effective – or even cost saving-interventions.¹⁰

Clinical commissioning groups (CCGs) are not commissioning education courses at the scale required by their populations. Evidence presented to the APPG shows that courses can be reasonably priced when delivered at a level to create economies of scale. Evidence provided by the South London Health Innovation Network found that for courses delivered at larger scale, the costs per person were:

- **DESMOND – Newly Diagnosed: £76**
- **X-PERT Diabetes Programme: £65**

DAFNE, a more intensive course for people with Type 1 diabetes, is more expensive per patient. However, the improvements to glycaemic control are long-lasting, meaning that savings build up over time and become cost-saving after four years. There are also numerous short-term benefits to providing the DAFNE course for people with Type 1 diabetes. For individuals who attended the DAFNE course, their risk of developing hypoglycaemia or ketoacidosis (where blood glucose levels go very low or high) falls by more than 60 per cent. This reduction of risk in developing these serious short-term complications results in savings of about £80 per year.¹¹

People living with diabetes told the inquiry about how much structured education courses improved their own management of their condition:

‘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 Rutland

‘Since completing the course, my HbA1c has dropped from 8.3 to 6.9 and is now within the recommended range for a diabetic’

Charlotte Lightman

‘I feel confident now that I will be able to keep as near to the ideal levels as necessary to manage my own disease’

Dorothy Trow

Commissioners may need to consider the need to commission wider forms of training and support to ensure people are offered more holistic models of care. Examples of these are discussed in more detail later in this section.

¹⁰ Diabetes UK, The Cost of Diabetes (2014). Available from: <http://www.diabetes.org.uk/Documents/Diabetes%20UK%20Cost%20of%20Diabetes%20Report.pdf>

¹¹ Elliott J et al, ‘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*, Jul;31(7):847-53 (2014).

Data collection and evaluation

A further issue for commissioners is poor data collection and a subsequent lack of understanding as to who is going on courses and who is not. User feedback is not being measured and therefore not being used to make adjustments. However, evidence to the APPG highlights that data collection and evaluation are essential for being able to provide services that meet the needs of the population.

A patient feedback system where providers routinely collect course satisfaction questionnaires from all attendees and report the findings would provide commissioners with a systematic way to identify problems and address barriers to uptake. More proactively involving people with diabetes in co-designing courses will help to ensure that people's needs are being met.

An electronic administration system would mean:

- Referrals can to be managed in a timely manner and people can self-refer
- A straightforward mechanism to provide venue details and times of available courses
- Patients who are not attending can be identified and followed up
- Service performance is much easier to measure and track, e.g. if there are 'black spots' where people are not being referred or not attending.

Service specifications

Another problem identified in the evidence is that service specifications can be vague. Commissioners should ensure that their specifications are clear and consistent with the NICE guidelines and that quality assurance is part of the specification. While different locations have different needs, there is ample opportunity for areas to borrow and learn from one another and share best practices. Croydon CCG has shared their service specifications for adult diabetes education for others to use.¹²

¹² Croydon CCG, Service specification: Diabetes Education (Adults – 18 years+) (2013). Available from: http://www.hin-southlondon.org/system/resources/resources/000/000/036/original/page_15_Croydon_-_Diabetes_education_spec_25.6.13v1_1_.pdf?1410971983

Improving uptake of education and support

As outlined earlier, the APPG received evidence that although not enough opportunities for diabetes learning and support are being commissioned, many individuals are simultaneously not taking up opportunities when they are offered. Evidence collected outlined a series of practical steps to address this problem:

- Improving the quality of the referral from healthcare professionals
- Improving location and timings of existing courses
- Reducing stigma
- Using more compelling marketing to attract more users.

Raising the quality of the referral

Evidence received by the X-PERT programme suggests that a 75 per cent rate in uptake has been achieved in some areas. A key factor in reaching this level is to persuade healthcare professionals of the benefits of education so they are able to talk about the course in a positive manner, outline what the course involves, and how it can benefit the individual living with diabetes. Healthcare professionals must see education and learning as an essential part of empowering individuals to self-manage their diabetes.

One example of making the case for education to healthcare professionals was demonstrated to the group by the South London Health Innovation Network. The organisation has created an education toolkit for referrers that explains the benefits of the course as well as the practical details of the referral pathway. They also provide patient-focused information and make available patient champions who can provide a first-hand account testifying to the benefits of the course. Finally, healthcare professionals can themselves attend courses so they gain further insight into what is being provided to the individual they are referring.

Another example received was that of an earlier project in Bexley which telephoned people who had been referred to understand patients' expectations of the course. In doing so, the project was able to close the gap between what patients believed they would be offered and the reality. This was a very low cost piece of administration that successfully minimised 'did not attend' rates.

Evidence provided by the DAFNE programme argues for making it compulsory for any healthcare professionals dealing with diabetes education to attend training so that they provide clear and consistent messages about the benefits of education. In Lambeth and Southwark, healthcare professional training was a part of the Diabetes Modernisation Initiative and increased the number of people referred who actually go on to attend the course from 74 per cent to 90 per cent.

Research into practice nurses' views makes the case for holding education in GP surgeries to increase engagement of healthcare professionals and to ensure a familiar environment for people with diabetes.¹³

Given how important education and learning is to enabling individuals to self-manage their diabetes, it is vital that healthcare professionals are aware of – and committed to – the benefits of education for people with diabetes. This could be facilitated through standalone courses or as part of wider training.

Many people living with diabetes made similar points in their evidence to the APPG:

'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 Gillette

'I know about national programmes because I've researched them. Sheffield are good at saying what's available, especially refresher courses'

@davidcragg

¹³ Winkley, K. A study to determine health professionals' views of structured education for people with newly diagnosed type 2 diabetes', preliminary results. In preparation.

Improving location and timings

There was a clear consensus that courses need to be convenient for people to attend – and that many of them currently are not. This reflects a more general issue in diabetes care where people of working age or who have Type 1 are less likely to receive the key NICE recommended checks than older people.

Factors such as school holidays, parking availability, bus routes, and time of day can significantly affect attendance rates and need to be taken into consideration when offering education and learning opportunities. These factors can be addressed when delivering diabetes education at scale, as outlined above, in that it makes it more practicable to hold courses in more venues at a wider range of times. Good data collection and evaluation can guide these very local decisions.

‘Just joined a new clinic, they actually offer Saturday courses for those of us who work!’

@Le3ky

Evidence from people living with diabetes demonstrates how important it is to offer courses that fit people’s lives:

Reducing stigma

Diabetes-related stigma was identified as a barrier preventing people from attending education courses. However, it is difficult for local commissioners to fully address a societal level issue such as this. This problem underscores the importance of encouraging individuals living with diabetes to attend courses as an opportunity to meet other people with the condition and as a possible way of breaking down stigma. Furthermore, when other steps to raise attendance are taken it is likely to encourage greater understanding of the condition, suggesting that addressing stigma is not an insurmountable barrier.

More compelling marketing

The inquiry specifically asked whether we should move away from the term ‘structured education’. Some argued that a discussion around terminology detracts from the real issue around improving quality of referrals from healthcare professionals that do not explain the benefits of educational opportunities. However, a number of people did feel that the wording ‘structured education for self-management’ does not reflect what these courses are about and suggested ‘learning’ or ‘training’ as alternative possibilities.

As part of the Diabetes Modernisation Initiative in Lambeth and Southwark, materials for patients were designed in collaboration with the local HealthWatch which dropped the term ‘education’ altogether and instead use the phrase ‘Learn about your diabetes’.

Wider marketing can also be beneficial. As part of his oral evidence to the group, Dr Charles Gostling of the South London Health Innovation Network described the benefit of distributing leaflets in pharmacies and libraries in order to broaden reach and to enable people to self-refer to education courses.

Flexibility of content and delivery – the need for a more holistic approach

A common theme that emerged from the evidence was that people wanted more flexible approaches to learning that better fitted into their lives and would allow for education and learning opportunities to reach more people living with diabetes.

Structured education

A call for more variety in the types of education and learning being offered is not uncontested. The DAFNE programme argued in their evidence that only education courses that meet all five NICE criteria should be commissioned. Similarly, the X-PERT programme claims that while people may say that they do not want to attend a course, the very positive feedback of those who have gone on a course demonstrates that pushing people towards attending is the best approach.

Lifelong learning

Nevertheless, in order to provide learning over the course of someone's diabetes 'career' – and to reach people who are not willing or able to go on a full course – some degree of flexibility is needed, especially if we want to reach the more than 3 million people currently living with diabetes. For example, the model suggested in oral evidence provided by Dr Aftab Ahmad of the Strategic Clinical Network for Merseyside and Cheshire recommends taking a lifelong learning approach. Dr Ahmad's vision is for a clear curriculum that lays out what skills and knowledge people need to have at what time. There are then tailored learning modules and formats for specific complications, such as neuropathy or topics such as medications.

The need for varying types of learning and support provided through a variety of channels was repeatedly stressed by people living with diabetes. Many described the need for ongoing learning:

'So easy to sit back after decades with T1 and not realise things are moving on v fast. VITAL that older T1Ds are educated'

@LisWarren

'Although I control my diabetes well, a brief refresher on some of the more subtle points discussed in the DAFNE course could help me to do it even better'

John Driver

Peer support and online resources

Many people described a range of website, social media, network and peer support groups they use to keep up-to-date:

'I read publications such as the Balance magazine and use a lot of online sources, such as the diabetes.co.uk forums where I can speak to other diabetics. I also use Facebook pages such as those run by JDRF and Diabetes UK. It is very useful to be able to share experiences and knowledge with other diabetics'

Charlotte Lightman

John Grumitt, Vice President of the International Diabetes Federation and Diabetes UK, used his experience of diabetes education in Bexley to argue that a key aim is for people with diabetes to give each other ongoing peer support so they gain skills and knowledge from each other after a particular course has finished. In Bexley, a community of over 1,000 people are currently signed up to the local patient support group.

'For younger people it might be good to promote it as a more social thing as well as education'

@_charlottela_

'Training from others with T1D who know what it's like to live with it. Peer to peer education'

@diabeticbanana

'The best part for me was meeting my peers'

Anna Dallaway

The value of peer support also came through strongly in evidence submitted by people living with diabetes:

Evidence from the Association of British Clinical Diabetologists agreed that virtual and online learning can be a valuable way for people to learn more about their condition. However, it is difficult to distinguish quality and healthcare professionals do not always know which is best. This mirrors evidence from patients who have said they were not made aware by healthcare professionals of the variety and quality of services or products.

Time off work

Ability to get time off work, especially to do a week long course like DAFNE, presents a serious barrier to uptake of education courses. Many people suggested that it should be a legal requirement to give people time off work for diabetes education. This is common practice in Germany where the social insurance model means there is a closer relationship between employers and their employees' health.

Another proposed solution is to adequately communicate the benefits of diabetes education to employers. DAFNE produces specific materials for employers explaining why they should give staff time off to go on the course.

Hard to reach groups

Having an electronic administration system makes it possible to follow up with those who have been referred and to make contact if they have not booked a course. Collecting and evaluating course feedback can also suggest ways in which courses need to be better tailored to meet the needs of specific groups. This approach was used in Bexley and resulted in dramatic increases in numbers of people attending diabetes education courses.

There are also targeted courses available for people from specific ethnic groups, such as DESMOND BME or DIMPLE – a peer-led prevention and self-management programme in West London.

Specific ways to address issues with children's education

A clear gap identified by the Association of British Clinical Diabetologists and by leaders in paediatric diabetes is that there is no national programme for paediatric diabetes education.

There is an urgent need for a central organisational structure with funding to support the amalgamation of existing resources into a national package. There would then be the need to develop a system for ensuring educational packages are up to date and establish monitoring and quality assurance to assess the effectiveness of these programmes.

Evidence submitted by individuals living with diabetes demonstrates the need for a holistic approach to children's education that involves the whole family:

'Feel that we could be getting much better education on supporting our T1 daughter and that direct education for her is dangerously piecemeal'

@32flavours

'Nothing around for parents or CYP'

@colonelblighty

The German model

An ambitious vision of the future is provided by the German model of diabetes support. Intensive education programmes provided for the whole family are the norm. The success in Germany's approach is demonstrated through their health outcomes – the average HbA1c values in adults and children are lower than other countries in Europe, including the UK, and there are fewer incidents of complications.

The APPG heard from Lara Brockmann, an individual living with Type 1 diabetes, who told the APPG about her experience of being diagnosed 10 years ago at the age of 13. Upon diagnosis, Lara and her mother were given three consecutive days of training that included all the immediate things they needed to know from a dietitian and diabetes specialist nurse (DSN). This included injecting, carbohydrate counting, how to cope with Type 1 at school, exercise and going on holiday.

Following the initial induction, Lara attended a further 10-day-long overnight residential course that offered more detailed information on living with Type 1. How to deal with more specific issues in the future, such as driving and drinking, were also covered. The course also gave Lara an immediate chance to meet other people with Type 1 and to share experiences. Lara has since been on courses to go on an insulin pump and to use a continuous blood glucose monitor. Adults in Germany are entitled to a course each year to refresh and learn new skills, and training and support is available for partners covering areas like work and pregnancy.

Recommendations

People living with diabetes and their families need to learn about their condition in the best way for them to meet their circumstances and preferences. They need education at the right time, in the right place and in the right way.

The Five Year Forward View reflects this, saying that “we will invest significantly in evidence-based approaches such as group-based education for people with specific conditions and self-management educational courses, as well as encouraging independent peer-to-peer communities to emerge.”

However, the APPG has found wide variation in the provision of educational opportunities available and makes the following recommendations:

- 1.** The 2015–16 NHS England Planning Guidance should ensure that all areas have plans in place to ensure that all people with diabetes have the skills and confidence to manage their diabetes by 2020. By copying best practice it is realistic for every area to:
 - a.** Commission convenient and high quality structured education courses and top-up modules for all who wish to go on one when the benefits of a course have been clearly explained to them.
 - b.** Offer other learning opportunities about diabetes and support through peers, groups, taster sessions and online courses and communities. These need to be made available and clearly communicated to people.
- To make this happen, the following steps need to be taken:**
 - 2.** IT systems need to be integrated to enable better data collection, electronic referrals and provision of patient feedback. These make it possible to ensure wide coverage, increase uptake, and drive service improvement. An electronic administration system can also inform commissioning decisions about location, timings and marketing that are determining factors for driving attendance.
 - 3.** Commissioners and healthcare professionals should understand and promote the benefits of education for people with diabetes. This requires healthcare professionals to be better trained in the advantages and objectives of diabetes education and have current knowledge of the programmes available locally.
 - 4.** National partners should work together to develop a shared approach to paediatric diabetes education for children, young people and families and throughout transition to adult services. This has the potential to reduce duplication and make it more straightforward for clinical teams to deliver high quality education.
 - 5.** The clear benefits to people’s health of attending education courses mean that the Government should give people a legal right to time off work to attend education courses about their diabetes that their healthcare team believe are appropriate to their needs.

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