

Implementing structured patient education

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Article points

1. Standardised, high-quality structured education should be provided for all people with diabetes.
2. There may be successful home-grown courses that satisfy the needs of local populations.
3. However, there are standards that all education programmes should meet to ensure that everybody with diabetes can access the tools and support they require to manage their condition.
4. In addition, adapting or developing a local programme to meet these standards may not be cost-effective.

Key words

- Structured education
- Quality assurance
- DAFNE
- DESMOND

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In 2005, the Patient Education Working Group published a report on structured patient education in diabetes (Department of Health, 2005b). The aims of this article are to summarise the main point of the working group report, to discuss the implications for practice and to make some suggestions on how to begin to address structured patient education delivery to meet the required standards.

In July 2005, guidance on structured patient education was published (Department of Health [DoH], 2005b). Its aim was to provide clear direction regarding the expected delivery of structured education in all primary care trusts (PCTs) across England from January 2006. The need to deliver structured education for diabetes comes as no surprise. The increasing focus on people's ability to self-care commenced with the publication of *The NHS Plan* (DoH, 2000), and structured education was an integral component of the National Service Framework [NSF] for diabetes (DoH, 2001a; DoH, 2003). There is a question that needs to be asked: does this document provide us with the guidance we need to deliver effective structured education or potentially generate more questions than it answers?

The majority of people with diabetes have contact with healthcare professionals (HCPs) for approximately 3 hours per year, leaving 8757 hours in which they need to be able to self-manage their condition (DoH, 2005a). *Self care – A real choice* (DoH, 2005a) and *Supporting People with long term conditions* (DoH, 2005c) expand on the importance of individuals having the knowledge, skills and confidence to support self-care. Evidence suggests that people with the

appropriate skills to self-manage their condition have improved quality of life, well-being and satisfaction with their care (DoH, 2005a). In addition, many require reduced medication or have enhanced medication concordance (DoH, 2005a). The aim (DoH, 2005c) is for 70–80% of people with diabetes to be able to manage their care at level 1 (supported care), with minimal support from HCPs.

The purpose of patient education is clear. Empowered people will engage in care decisions more effectively, facilitating delivery of patient-centred care (DoH, 2001a). People are more likely to make changes in lifestyle and treatment if they are facilitated through patient-centred care rather than imposed by care based on the medical model of care delivery (DoH, 2001a).

The Expert Patients Programme (DoH, 2001b) has been strongly advocated for all people with long-term conditions (DoH, 2001a; DoH, 2005a; DoH, 2005c). As a programme for people with any long-term condition, the Expert Patients Programme is aimed at developing generic skills in individuals to enable them to participate more actively in their care and care decisions. What the programme does not do is develop diabetes-specific skills.

How diabetes HCPs can support people with diabetes in achieving self-care has been less clear. The guidance of the National Institute for Health and Clinical Excellence (NICE; formerly the National Institute for Clinical Excellence) on patient education models (NICE, 2003) actually stated:

'There is insufficient evidence available to recommend a specific type of education or provide guidance on the setting for, or frequency of, sessions.'

This document did provide guidance on some good principles of practice, which have been expanded further in the report from the Patient Education Working Group (DoH, 2005b).

What should structured education include?

The aim of structured education should be to empower and inform people, and to support self-management of their diabetes by building up sufficient knowledge and skills to do so. Although many existing programmes would have these objectives, NICE (2003) noted that there is inconsistency in how effectively these programmes deliver their aims; there is also great variation in the length, content and style of programmes. The NICE guidance addresses this variation, in order to standardise education for people with diabetes, so that no matter where the person with diabetes lives, he or she will receive a consistently high quality of service that meets his or her needs and can demonstrate effectiveness. There is also a change in emphasis, with structured education being viewed as an essential part of diabetes management, not as an optional extra.

Diabetes UK (2005) provides guidance on the subjects to be included in structured education programmes for people with diabetes in its report *Recommendations for the provision of services in primary care for people with diabetes*. They are as follows.

Nature of diabetes:

- significance and implications of a diagnosis of diabetes
- aims and different types of treatment

- relationship between blood glucose, dietary intake and physical activity
- short- and long-term consequences of poorly controlled diabetes
- nature and prevention of long-term complications
- importance of annual surveillance, including annual ophthalmoscopy through dilated pupils and retinal photography.

Day-to-day management of diabetes:

- importance of a healthy lifestyle, especially physical activity and smoking cessation
- importance of self-management
- diet and diabetes
- self-monitoring – home glucose monitoring or urine testing
- interpreting the results of self-monitoring and tests of long-term glycaemic control
- adjusting insulin dosage and the importance of the systematic use of different injection sites
- importance of regular foot care, choice of footwear, foot hygiene and the role of podiatry.

Special problems:

- hypoglycaemia (for people on insulin or sulphonylureas) – warning signs, likely causes, role of alcohol, the need to have rapidly absorbed carbohydrate available and the particular care required if undertaking high-risk activities, such as driving or working with dangerous machinery
- intercurrent illness and diabetes – illness rules that must be given to every person with diabetes
- preconception advice – the importance of excellent control at the time of conception as well as during pregnancy.

Living with diabetes:

- the importance of carrying personal identification, such as MedicAlert, and a warning card including the name, contact address and telephone number of a person who can help
- driving – notifying the Driver and Vehicle Licensing Agency and insurance company, and the importance of avoiding hypoglycaemia while driving

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1. The aim of structured education should be to empower and inform people, and to support self-management of their diabetes.
2. There is great variation in the length, content and style of structured education programmes, which National Institute for Health and Clinical Excellence guidance addresses.

Table 1. Main elements of the quality assurance process (taken from DoH, 2005b).

<p>1 Development of a defined programme, with a clear content, structure, curriculum and underlying philosophy which educators are given the necessary training to deliver. The training programme itself is tested and informed by the quality assurance process.</p>
<p>2 Defined quality assurance 'tool(s)' based on the set curriculum, philosophy and process that identifies a core set of observable behaviours required to deliver the programme. These could be described as standards and a benchmarking process could inform the standards set and review on a periodic basis.</p>
<p>3 Internal and external process in place to assess the delivery and organisation of the programme itself.</p>

- implications of diabetes for employment, life insurance and travel insurance
- making the best use of healthcare services – people with diabetes are entitled to receive an annual free eye examination by an optometrist or ophthalmic medical practitioner (those receiving treatment with either tablets or insulin are exempt from paying prescription charges).

Sick day rules:

- managing medication during illness
- increasing the frequency of blood glucose monitoring, and adjusting insulin doses as necessary according to results
- appropriate fluid replacement
- ensuring carbohydrate intake if normal food intake is reduced
- testing for ketones
- who to contact and at what point in the illness.

Assuring quality

In December 1997, the Government published a White Paper (DoH, 1997) that was to herald significant changes within the NHS. Although only quietly alluded to at the time, clinical governance was to become the Government's main vehicle for continuously improving the quality of patient care (Miller, 2001). Clinical governance encompasses various concepts that have long been familiar in healthcare delivery, including clinical audit, evidence-based practice and continuing professional development. The use of quality assurance tools with which to monitor and improve standards in health care is now long established, particularly within the context of clinical management. It was thus only a matter of time before the tentacles of clinical governance enveloped our educational practices.

A plethora of literature now supports education as a fundamental component of diabetes care (Lucas et al, 2004) and key government documents highlight this as a priority in the management of people with diabetes (DoH, 2001a; DoH, 2001b; DoH, 2003, NICE, 2003). As yet, however, there are no formal systems within the UK that address the issues of quality assurance with respect to this. Although the report from the Patient Education Working Group identifies these anomalies

and gives guidance for addressing them, the recommendations require clarity.

Of particular concern is that some practitioners perceive the report to infer that only two diabetes education models – Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) and Dose Adjustment For Normal Eating (DAFNE) – will fulfil the quality criteria. Other practitioners have been left wondering if home-grown programmes, which have had much time and effort invested in them, will now be considered inferior.

Quality assurance process

The Patient Education Working Group report states that the key criteria a structured education programme should meet, in line with NICE guidance, are:

- having a structured curriculum
- having trained educators
- being quality assured
- being audited.

What do these recommendations mean for those involved in the education of people with diabetes? How might the report from the Working Group be interpreted to ensure that it is used (as is its intention) as a guide to best practice, rather than being pilloried as an unhelpful or threatening dictate?

The report outlines three main elements of the quality assurance process (Table 1). Meeting the first element of the quality assurance process will involve:

- identifying the target group for educational intervention and outlining the rationale for choosing that group
- setting clear aims and objectives for the course
- collating records of collaborative work undertaken by all personnel involved in the planning and implementation of the course
- formulating coherent lesson plans
- providing transparent course materials
- training educators to deliver the programme.

The second and third elements of the quality assurance process involve the use of audit tools to validate the efficacy of the educational initiative. For this process to be as robust as possible, both internal and external methods of measuring the quality of the educational programme need to be

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incorporated, as described in the report. But what does this mean in practical terms?

Internal and external quality assurance

Internal quality assurance should involve the collection of clinical and psychological data on individuals before and after the educational intervention in order to fully assess its overall impact. This may involve measuring certain clinical parameters, such as HbA_{1c}, lipids and weight (quantitative data collection), and the employment of questionnaires, interviews or other user-involvement methods, in order to assess quality-of-life issues (qualitative data collection).

Within this internal quality assurance process, it is also essential to ensure that the skills of the educator are sufficient and that there is a developmental framework in place to support those skills being maintained and updated. A simple method of achieving this is through experiential learning: regular involvement in educational programmes, which will nurture professional development (that is, progress from novice to expert); the use of reflective diaries; and peer review and discussion with co-educators.

It has been recognised by the Patient Education Working Group, in its report (DoH, 2005b), that it may not be feasible to externally validate the skills of every educator within a service. It will thus be fundamental to the quality assurance process to ensure that the internal quality assurance is robust, thereby ensuring the reliability and validity of the intervention. However, practical examples of participation in external quality control could include the provision of audit data to local or national networks as well as educators from neighbouring health organisations observing each other's educational programmes and giving feedback (external peer review). Although this external process may at first appear daunting, it is designed to inform and enhance best practice.

So is quality assurance necessary? It is clear that any intervention for people with diabetes should have a robust mechanism by which to measure the efficacy of its outcome. Otherwise how will people with diabetes, HCPs and commissioners know if high-quality care is being provided? It is also clear that the report from the Patient

Education Working Group indicates that all educational programmes should aim to fulfil the key criteria. It does recognise, however, that many organisations will need time to review, refine and develop their quality assurance frameworks within this area of care.

The concept of clinical governance in health care arose in order to address the serious issues in inequality, variations in practice and lack of public confidence in the NHS (DoH, 2000). Key areas for action include setting standards, delivering standards at a local and national level and monitoring standards. The recommendations from the Patient Education Working Group's report should be seen for what they are: guidance to help all stakeholders involved achieve that quality goal so that educational interventions of the future can prove unequivocally successful.

What's available already?

Type 1 diabetes

DAFNE (Table 2) is a recognised example of structured education for type 1 diabetes that meets the key criteria for a structured education programme (DoH, 2005b). The course is based on the intensive treatment and teaching programmes established in Germany and evaluated there for more than 20 years (Muhlhauser and Berger, 2002). This model aims to maximise the benefit of experiential learning. Active participation on behalf of the person with diabetes relies on the provision of appropriate information training, and his or her personal motivation and acceptance of the condition, which are closely related to health beliefs (Assal et al, 1985). The long-term evidence from Germany shows improved outcomes maintained for up to 6 years following the intervention (Muhlhauser and Berger, 2002). The experiences from developing these programmes, however, show that it is not easy to evaluate such complex interventions.

An economic evaluation published in 2004 aimed to evaluate the long-term cost-effectiveness of structured treatment and teaching programmes in the UK by projecting the benefits based on the evidence from Europe and comparing them with current practice (Shearer et al, 2004). This evaluation suggests that this approach to the management of type 1 diabetes could save

Table 2. DAFNE: A recognised example of structured education.

DAFNE is a 5-day, skills-based intensive education programme enabling diabetes education and practical skills to be delivered in a group setting. The initial trial of this model (DAFNE Study Group, 2002) showed a reduction in HbA_{1c} and improved well-being and treatment satisfaction. Ongoing research into the DAFNE approach will be important to evaluate the maintenance of self-management skills and improved outcomes over the longer term. The DAFNE initiative continues to develop: there are currently 39 fully-trained DAFNE centres, across England, Northern Ireland, the Republic of Ireland, Scotland and Wales (DAFNE, 2006).

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1. Both the DAFNE and DESMOND programmes are run via a national collaboration of centres that are able to contribute to their ongoing development and research and that have put in place robust quality assurance systems.
2. Using a patient-centred approach encourages patient participation, autonomy, independence and empowerment, where the patient defines his or her needs and sets the agenda.

valuable resources for the NHS by reducing the morbidity and mortality which are a consequence of diabetes complications.

Recommendations for structured education to be available for all has opened up a debate regarding the criteria necessary for an education programme to be quality assured. The Type 1 Network aims to share ideas and explore all models of patient education for people with type 1 diabetes.

Type 2 diabetes

DESMOND is a structured group education programme for people with type 2 diabetes and their carers, and it was piloted in 17 PCTs during 2004. The initial DESMOND programme provides 6 hours of structured education, ideally within 2 weeks of diagnosis, and is currently being formally evaluated in a randomised controlled trial, with the final outcomes due to be reported in 2006 (Carey and Daly, 2004). An additional education programme for the ongoing management of type 2 diabetes is currently being developed.

Meeting good practice criteria

Both the DAFNE and DESMOND programmes are run via a national collaboration of centres that are able to contribute to their ongoing development and research and that have put in place robust quality assurance systems. These models meet the good practice criteria set out by the Medical Research Council for the evaluation of complex interventions (NICE, 2003). Nationally, there are a number of education models available for people with type 1 and type 2 diabetes and there needs to be a strategy to evaluate and validate these interventions and share good practice. The DoH and Diabetes UK are currently developing an assessment tool in the form of a questionnaire to enable PCTs to evaluate their current patient education programmes against the key criteria a structured education programme should meet, in line with NICE guidance (DoH, 2005b).

Implications for practice

Although there can be little argument against the provision of standardised, high-quality

structured education for all, delivered by appropriately trained personnel, the challenges in delivering this can be daunting. From January 2006, it has been necessary to have funding available to fulfil the requirements of NICE Technology Appraisal 60 (NICE, 2003), which include ensuring that there are enough trained people to cover the huge numbers of people with diabetes involved and providing local venues to facilitate easy access to education. Apart from concerns about the availability of funding, there are a number of questions about the implementation of the NICE guidance.

The cost of training staff and delivering programmes may be a barrier, especially in the current climate, with PCTs and hospital trusts struggling financially. Given the increasing numbers of people being diagnosed with diabetes each year, it is likely that these costs will continue to grow, requiring more and more staff to cope with the increasing demand. Costs will have to cover a number of other things: administrative staff to send out appointments and chase up people who did not attend; the collection and recording of data; the provision of 'backfill' when staff are being trained or delivering education; and postage for letters.

The purpose of staff training is obvious, but what will it consist of? The deliverers of patient education need to move away from the traditional medical-centred model, which tends to include didactic lectures, focusing on the patient as a 'problem' and a passive participant, with the HCP defining the patient's needs. Using a patient-centred approach encourages patient participation, autonomy, independence and empowerment, where the patient defines his or her needs and sets the agenda.

Facilitating this change requires specific skills, which include adult education principles and models of behaviour change. However, many HCPs will also need to learn how to give feedback to other educators as part of internal quality assurance, and possibly external quality assurance for other centres. Furthermore, they will need to work out how to use the learning needs assessment tool required by the NICE guidance (NICE, 2003).

DAFNE, DESMOND and the Diabetes XPERT Programme include training for educators delivering those programmes. However, if HCPs are delivering a locally developed programme, they will need to ensure that appropriate adult education training has been undertaken. No particular training programme is recommended by NICE, but diabetes team managers will need to identify funding for the training and ensure that staff involved with delivering structured education have included it in their personal development plans.

Patient education may not be seen as a priority in primary care, as there is an emphasis on the achievement of the targets set by the new General Medical Services contract (DoH, 2004). As education is not a direct target, there may be little incentive for practice staff to encourage people with diabetes to attend structured education programmes. With the development of practice-based commissioning, groups of practices will work together to deliver services to their local population and share resources. Ideally, practices in a particular locality could share the costs of the venue and education programme, but whether this will happen without incentives is not known.

Unfortunately, there is still relatively little evidence that structured education works, yet HCPs are being asked to implement some national programmes that have not reported results from randomised controlled trials (for instance, DESMOND has been recommended [DoH, 2005b], but results from the randomised control trial of its Newly Diagnosed Programme are not expected until later this year [<http://www.desmond-project.org.uk> (accessed 06.02.2006)]). This may make it more difficult to convince budget holders or primary care commissioners to fund patient education programmes without the evidence to show that they are cost-effective.

There may be concern in primary care that education delivered elsewhere may de-skill practice nurses, particularly in smaller practices. Education may eventually be seen as the role of others (as in the US, where the diabetes educator has a role separate from the diabetes team). Practice nurses are a key component in the long-term ongoing education of most people with diabetes, linking learning with the annual diabetes review, and so

it is essential that they are involved in any local diabetes education programme.

The concept of introducing an internal and external quality assurance process to patient education may be disconcerting to some HCPs. It will involve a change in culture, having others 'checking their competence' in delivering a course that they may have been running for years, and some people may find it quite threatening. However, quality assurance is accepted as the norm outside the NHS, particularly in industry, and it is standard practice in some aspects of diabetes work (such as blood glucose monitoring in hospitals). The elements of the quality assurance process defined to meet NICE guidelines (DoH, 2005b) are comprehensive. They cover the development of a defined programme, tools to benchmark the achievement of standards, and internal and external quality assurance, where the service is reviewed to ensure that the programme is meeting the criteria set. Although some aspects of this can be achieved by individual reflection and periodic peer review, it is the review by an external source that may be difficult. Review by HCPs from another diabetes team nearby may be a solution, but will it be acceptable?

What about patient choice? The Choose and Book process is now actively being promoted (<http://www.chooseandbook.nhs.uk> [accessed 06.02.2006]), and the amount of choice for people with diabetes on how their condition is managed will increase. Some people may not wish to attend a structured education programme. One-to-one sessions will still be important, and they may be the only option for some (such as those with learning difficulties, hearing deficits or psychiatric disorders, for whom a group setting may not be suitable). DAFNE appears to be popular now as participants are self-selected, but what if patients are 'pushed' into attending structured programmes? It is essential to avoid a 'one size fits all' approach and to provide a variety of choices to meet the needs of people with poor literacy skills or from ethnic minorities, for instance. Many people will not be able to get time out of work for group education sessions if they are held in working hours, especially if they take place over several weeks. Provision of out-of-hours

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sessions may be an answer, but there could be extra staff costs as well as possible safety issues if staff are delivering sessions alone in the evenings.

The Expert Patients Programme (DoH, 2001b) is a generic programme for empowering people living with a long-term condition (not just diabetes) to improve their quality of life and develop self-management skills. Where this programme fits in with structured diabetes education is debatable. It may be seen as an essential preparation for diabetes-specific education, with individuals needing to develop core empowerment skills before specialising in diabetes skills.

The promotion of DAFNE and DESMOND by NICE may cause some concern for HCPs who are already running home-grown education programmes. They may feel quite strongly about keeping a format that they are familiar with and that suits the needs of their population. There may be no need to discard an established programme. However, HCPs need to ensure that the programme meets the criteria set out by NICE.

Developing a local programme or adapting one that is currently in place may not be cost-effective. It has been estimated that it takes 3 years to develop a high-quality local course, and if the time taken for staff to develop it and the cost of writing materials and printing, among other things, are taken into account, it may not be a cheaper option to DESMOND, which it is sometimes perceived as.

Summary

The NICE Technology Appraisal on the use of patient education models for diabetes was published in 2003, but the funding direction was delayed until January 2006. Standardised, high-quality structured diabetes education should be provided for all people with diabetes. Meeting the criteria for achieving this, as well as allocating funding to provide the ever-increasing numbers of people developing the condition, will be a challenge.

The national programmes recommended by NICE may not be appropriate for some populations, and there may be successful home-

grown courses that satisfy the needs of local populations. There is no need for a 'one size fits all' solution, or to discard successful local programmes. However, NICE has set standards that all education programmes should meet, to ensure that everybody with diabetes, no matter where they live, can access the tools and support they require to manage their condition. In addition, adapting or developing a local programme to meet these requirements may not be cost-effective, and the use of nationally recognised and evidence-based programmes is encouraged by NICE. ■

Assal JP, Muhlhauser I, Pernet A, Gfeller R, Jorgens V, Berger M (1985) Patient education as the basis for diabetes care in clinical practice. *Diabetologia* **28**(8): 602–13

Carey M, Daly H (2004) Developing and piloting a structured, stepped approach to patient education. *Professional Nurse* **20**(2): 37–9

DAFNE (2006) *DAFNE Today*. Available at <http://www.dafne.uk.com/scripts/professionalhealthcare/dafnetoday.html> (accessed 06.02.2006)

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**(7367): 746–9

Department of Health (DoH; 1997) *The New NHS: modern, dependable*. Cm 3807. The Stationery Office, London

DoH (2000). *The NHS Plan: a plan for investment, a plan for reform*. DoH, London

DoH (2001a) *National Service Framework for diabetes: Standards*. DoH, London

DoH (2001b). *The expert patient: a new approach to chronic disease management for the 21st century*. DoH, London.

DoH (2003) *National Service Framework for diabetes: Delivery strategy*. DoH, London

DoH (2004) *QOF guidance*. DoH, London. Available at <http://www.dh.gov.uk/assetRoot/04/08/86/93/04088693.pdf> (accessed 06.02.2006)

DoH (2005a) *Self care – A real choice*. DoH, London

DoH (2005b) *Structured Patient Education in Diabetes: Report from the Patient Education Working Group*. DoH, London

DoH (2005c) *Supporting People with long term conditions*. DoH, London

Diabetes UK (2005) *Recommendations for the provision of services in primary care for people with diabetes*. Diabetes UK, London

Lucas S, Walker R (2004) An overview of diabetes education in the United Kingdom: past, present and future. *Practical Diabetes International* **21**(2): 61–4

Miller J (2001) *Clinical Governance. Nursing Times Monograph No. 56*. Emap Healthcare, London

Muhlhauser I, Berger M (2002) Patient education – evaluation of a complex intervention. *Diabetologia* **45**(12): 1723–33

National Institute for Clinical Excellence (NICE; 2003) *Guidance on the use of patient-education models for diabetes*. Technology Appraisal 60. NICE, London

Shearer A, Bagust A, Sanderson D, Heller S, Roberts S (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): 460–7