



# Structured Patient Education in Diabetes

*Report from the Patient Education Working Group*



## DH INFORMATION READER BOX

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<b>Contact Details</b>	Dr Sue Roberts' Office Diabetes Team 35-155 Waterloo Road London SE1 8UG 0207 972 4771
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Patient-centred care is one of the central pillars of the Diabetes National Service Framework (NSF). People living with diabetes have a crucial role in managing their condition on a day-to-day basis, so supporting self care should be central to any local diabetes service.

Patient education is a vital part of this support package. There is a considerable amount of excellent work already being done to ensure that quality assured training and education is available to all those who need it. The DAFNE and DESMOND education programmes provide a nationally-led, evidence-based approach for type 1 and type 2 diabetes. Local teams are working hard to develop their own education programmes that match the needs of their local population.



One of the explicit aims of the Diabetes NSF is to ‘make best practice the norm’ and reduce variation between services. Apart from the clinical improvements that this requires, there is also a need to ensure that all patient education is based on sound educational principles and is quality assured.

This report, produced by the joint Department of Health and Diabetes UK Patient Education Working Group, lays out in detail the necessary ingredients for developing a high-quality patient education programme. It highlights best practice to enable local services to meet the recommendations outlined in the NICE guidance and Diabetes NSF, and provides a much needed framework that will help diabetes teams develop and evaluate local programmes.

I would like to thank the Patient Education Working Group for developing this excellent resource. I am confident that the report will help diabetes teams to provide high quality information and education, enabling people to “live with diabetes not suffer from it”.

A handwritten signature in black ink that reads "Rosie Winterton". The signature is written in a cursive, flowing style.

Rosie Winterton MP  
Minister of State for Health Services



## Introduction

Diabetes is a chronic and progressive disorder that impacts upon almost every aspect of life. It can affect children, young people and adults of all ages, and is becoming more common. The number of people with diabetes continues to grow, with an estimated 1.8 million people in the UK diagnosed and a further 1 million undiagnosed.

Supporting self-care is a crucial aspect of any high-quality diabetes service, and the Diabetes NSF recommends structured education as an important part of this.

The NICE Health Technology Appraisal on patient-education models for diabetes defines structured education as “a planned and graded programme that is comprehensive in scope, flexible in content, responsive to an individual’s clinical and psychological needs, and adaptable to his or her educational and cultural background.”

The aim of patient education is for people with diabetes to improve their knowledge, skills and confidence, enabling them to take increasing control of their own condition and integrate effective self-management into their daily lives. High-quality structured education can have a profound effect on biomedical outcomes, and can significantly improve quality of life and satisfaction.

### Structured education – comments from patients

- My bottom line in life is to function and DAFNE gives me that ability. For me, it is not a diabetic treatment initiative, it is my life. It informs my hourly, daily, weekly, monthly, yearly decisions; continually improving my health and my contribution to life. I have lost weight and vastly improved my blood glucose control. Together, DAFNE and I are delivering the best results in diabetic care I’ve experienced in 25 years.
- I did not realise how serious diabetes was at first. Perhaps I might have taken it more seriously if I knew then what I know now.
- My attitude has always been ‘it ain’t going to beat me’ and I believe that the most important care is education in all aspects of the disease...I have been insulin dependent for 43 years and can still do 10 press-ups...It is not all doom and gloom!
- I am now doing a new job which... I could never have managed before the DAFNE Trial.
- Spread the word. It really can make a difference! Thanks! Why didn’t someone think of this earlier!

The need for high-quality structured patient education was one of the key themes of the recent Diabetes Dialogue, an online consultation sponsored by the Hansard Society. The consultation report is available at <http://www.tellparliament.net/diabetes/>

The Patient Education Working Group for diabetes was set up in May 2004, with the aim of supporting the development of structured education for people with diabetes. The Working Group was jointly chaired by Suzanne Lucas, Consultant, Diabetes UK and Dr Sue Roberts, National Clinical Director for Diabetes. The full membership of the group is attached at Appendix A.

The group recognised the need for quality standards for education programmes in order to achieve the maximum benefit for people attending the courses. Key criteria have been developed that local diabetes teams should work towards, in order to ensure that the programmes delivered are effectively supporting self management.

This report aims to be a useful reference point for all those involved in the provision of care for people with diabetes. The report outlines the current education programmes that are available, and provides up-to-date advice on key areas such as health professional training and quality assurance. The report also highlights gaps in education provision; local services will need to consider how these gaps can be met in order to ensure that all people with diabetes have access to high-quality education to support self management.

# The national perspective

Standard 3 of the Diabetes NSF aims to ensure that people with diabetes are empowered to enhance their personal control over the day-to-day management of their diabetes in a way that enables them to experience the best possible quality of life.

Patient-centred care is key for people with diabetes. Self-care can be a complex issue, and it is vital that people with diabetes have the skills they need to manage their condition effectively.

This section focuses on the national context for disease-specific group education.

## 2.1 Policy background

The role of disease-specific education to support self-management is outlined in a wide range of national policy documents, highlighting the need for patient education to be a key part of any local diabetes service.

Disease-specific patient education forms one part of a broad spectrum of different programmes that are available to support people with long term conditions such as diabetes. Patient education should link in with other programmes designed to support self-care, such as the Expert Patient Programme (EPP), and health literacy programmes.

### National Service Framework for Diabetes

The importance of improving the care of people with diabetes is highlighted in the *National Service Framework for Diabetes: Standards*, published in 2001<sup>1</sup>.

Standard 3 of the NSF states that: “all children, young people and adults with diabetes will receive a service which encourages partnership and decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle”.

Structured education is one of the key interventions needed to achieve Standard 3.

The *National Service Framework for Diabetes: Delivery Strategy*<sup>2</sup> includes the following commitment:

“In primary care, update practice-based-registers so that patients with CHD and diabetes continue to receive **appropriate advice and treatment in line with NSF standards** and by March 2006, ensure practice-based registers and systematic treatment regimes, including appropriate advice on diet, physical activity and smoking, also cover the majority of patients at high risk of CHD, particularly those with hypertension, diabetes and a BMI greater than 30.”

The Delivery Strategy clarifies that “treatment in line with NSF standards” should include referral to structured education.

### NICE Technology Appraisal

NICE Health Technology Appraisal #60 – *Guidance on the use of patient-education models for diabetes*<sup>3</sup> recommends 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”.

The usual 3-month funding direction that accompanies NICE Technology Appraisals was waived when the guidance on patient-education models was published in April 2003. However, Ministers have agreed to its reinstatement from January 2006, at which point the NHS will need to make funds available for patients to be treated in line with this guidance.

## Children's services

Standard 6 of the Children's NSF<sup>4</sup> states that: "All children and young people who are ill, or thought to be ill, or injured will have timely access to appropriate advice and to effective services which address their health, social, educational and emotional needs throughout the period of their illness." Children, young people and their families should have the opportunity to become 'expert patients', developing effective self management skills.

The NICE guidance *Diagnosis and management of type 1 diabetes in children and young people*<sup>5</sup> recommends that: "Children and young people with type 1 diabetes and their families should be offered timely and ongoing opportunities to access information about the development, management and effects of type 1 diabetes." The guidance adds that "the method of delivering education and content will depend on the individual and should be appropriate for the child's or young person's age, maturity, culture, wishes and existing knowledge within the family".

## Health improvement

*Choosing Health – Making healthy choices easier*<sup>6</sup> set out a range of commitments designed to support people to reduce risk factors such as obesity and smoking. The White Paper aims to develop health as a way of life for the general population, where people are supported to make the right decisions about their health, and then carry them out in practice.

There are already a wide range of local health improvement programmes that support access for groups and individuals to healthier lifestyles, such as health visitors working with disadvantaged groups and providing information about a wide range of health issues. This is not an alternative to structured patient education; health improvement programmes can support the ethos of self care, as part of a range of educational interventions that includes structured education.

## Supporting people with long term conditions

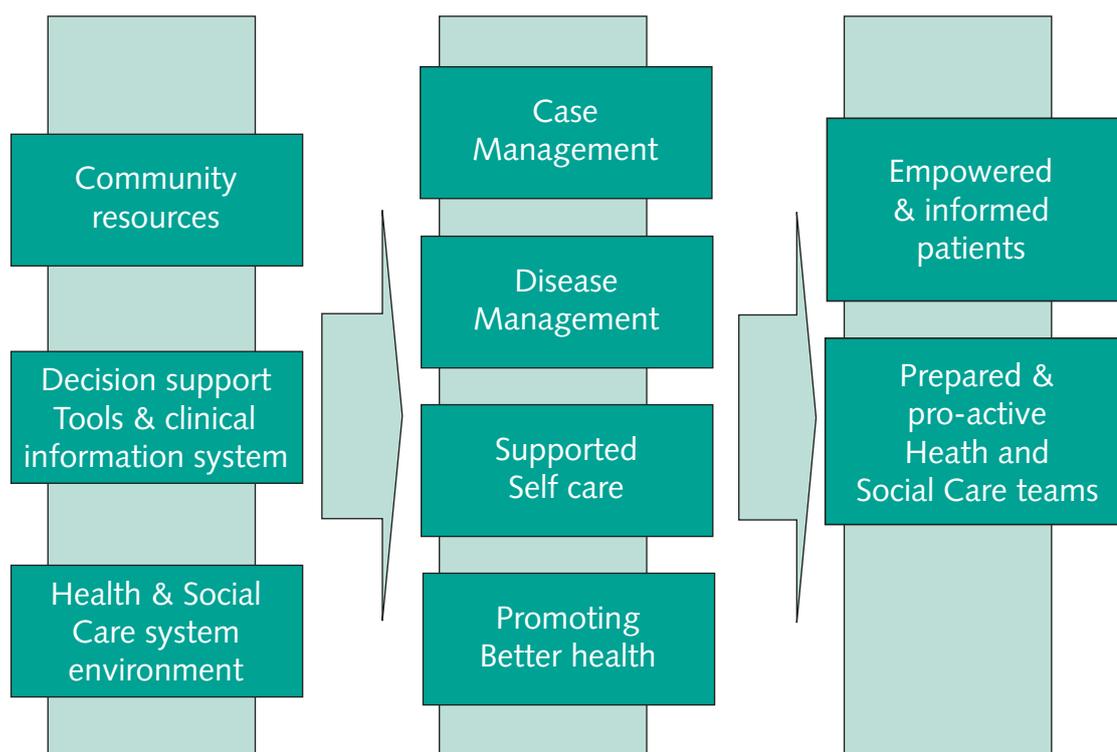
*Self care – A real choice: Self care support – A practical option*<sup>7</sup> was published in January 2005, and is aimed at PCT, NHS Trust, SHA and social care management teams as well as health and social care professionals and practitioners. Its purpose is to:

- provide information on the developing policy on support for self care and the reasons why it is important (the why);
- suggest what practical action can be taken by those delivering health and social care (the what);
- provide some ideas on how to support self care (the how).

*Supporting People with Long Term Conditions*<sup>8</sup> aims to embed into local health and social care communities an effective, systematic approach to the care and management of patients with a long term condition.

The NHS and Social Care Long Term Conditions Model involves matching care with need, and patient education will run through all levels of care. The model highlights the need for supported self care in order to ensure that patients are empowered and informed. Education will have an important role in delivering these objectives.

## The NHS and Social Care Long Term Conditions Model



## National Standards, Local Action

*National Standards, Local Action*<sup>9</sup> sets out a standard-based planning and assessment framework for health and social care and standards for NHS health care to be used in planning, commissioning and delivering services. It outlines the core and development standards covering NHS health care and the health and social care planning framework and targets for 2005–2008 against which services can be assessed.

The document states that NSFs and NICE guidance are integral to a standards-based system. They have a key role in supporting local improvements in service quality. Organisations' performance will be assessed not just on how they do on national targets but increasingly on whether they are delivering high quality standards across a range of areas, including NSFs and NICE guidance.

## References

- <sup>1</sup> Department of Health (2001) *National Service Framework for Diabetes: Standards*
- <sup>2</sup> Department of Health (2003) *National Service Framework for Diabetes: Delivery Strategy*
- <sup>3</sup> National Institute of Clinical Excellence (2004) *Guidance on the use of patient-education models for diabetes: Technology Appraisal 60*
- <sup>4</sup> Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services*
- <sup>5</sup> National Institute of Clinical Excellence (2003) *Type 1 diabetes: diagnosis and management of type 1 diabetes in children and young people*
- <sup>6</sup> Department of Health (2004) *Choosing Health – Making healthy choices easier*
- <sup>7</sup> Department of Health (2005) *Self care – A real choice: Self care support – A practical option*
- <sup>8</sup> Department of Health (2005) *Supporting People with Long Term Conditions*
- <sup>9</sup> Department of Health (2004) *National Standards, Local Action*

## 2.2 Quality standards

The NICE Health Technology Appraisal on patient-education models noted that most people with diabetes in England and Wales are offered education, at least at the time of their diagnosis. However, the guidance also stated that “the length, content and style of educational options varies greatly between services; some of the educational programmes offered are unstructured, very few have been formally evaluated, and few individuals who deliver education have been formally trained for this purpose”.

### Key criteria for structured education

For this reason, the first priority of the Patient Education Working Group was to agree a set of quality standards for education programmes. These criteria set out the characteristics of a high-quality structured education programme that would fulfil the NICE requirements.

The key criteria agreed by the group are underpinned by the philosophy that the programme will be evidence based, dynamic, flexible to the needs of the individual and users should be involved in its on-going development. The programme should have a specific aim and learning objectives which are shared with patients, carers and family. The programme should support self management attitudes, beliefs, knowledge and skills for the learner, their family and their carers.

There are four key criteria headings, which state that education programmes should:

- have a structured, written curriculum
- have trained educators
- be quality assured
- be audited

Local diabetes teams should work towards these criteria, and aim to ensure that any local education programmes meet these standards.

The full criteria are outlined at Appendix C and are available on the National Diabetes Support Team website at

[http://www.cgsupport.nhs.uk/downloads/NDST/Edu\\_prog\\_key\\_criteria.pdf](http://www.cgsupport.nhs.uk/downloads/NDST/Edu_prog_key_criteria.pdf)

### Measuring progress

The Diabetes Continuing Care Reference Dataset (DCCR) brings together into one dataset the combined clinical data requirements of the National Diabetes Audit (NCASP), the Diabetes chapter of new GMS Quality and Outcomes Framework, the DiabetesE performance management tool, and the diabetes indicators for Better Metrics Performance Indicator Project.

The dataset was approved as a national standard by the Information Standards Board (ISB) in March 2005, and includes the following three data items on patient education:

- The date on which a review of the patient's diabetes education requirements took place
- The date on which a Diabetes Structured Education Programme was offered to the patient
- The date it was recorded that a patient has completed/attended a patient structured education programme

### Course content

Diabetes UK have provided guidance on the topics that should be covered by education programmes for people with diabetes. These topics come under the following headings:

- Nature of diabetes
- Day-to-day management of diabetes
- Specific issues
- Living with diabetes
- 'Sick day' rules

The sub-topics for each of these headings are given in the Diabetes UK report – *Recommendations for the provision of services in primary care for people with diabetes*<sup>1</sup>.

### References

<sup>1</sup> Diabetes UK (2005) Recommendations for the provision of services in primary care for people with diabetes

## 2.3 Current education programmes

### National programmes

There are two national group education programmes for adults with diabetes that meet the key criteria for structured education. They are:

- DAFNE for type 1
- DESMOND for type 2

### Dose Adjustment for Normal Eating – DAFNE

DAFNE is a skills-based education programme in which adults with type 1 diabetes learn how to adjust insulin to suit their free choice of food, rather than having to work their life around their insulin doses. The programme has been developed over 20 years of rigorous research including a Randomised Control Trial (RCT) in Northern Europe and a feasibility trial and economic analysis in the UK. DAFNE pays for itself in around 4 years<sup>1</sup> (for more information on the research evidence for DAFNE see Section 3.5).

More information about DAFNE can be found at  
[http://www.cgsupport.nhs.uk/diabetes/Structured\\_education.asp](http://www.cgsupport.nhs.uk/diabetes/Structured_education.asp) or  
<http://www.dafne.uk.com/>

### Diabetes Education and Self-Management for Ongoing and Newly Diagnosed – DESMOND

Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) is a new structured group education programme for adults with type 2 diabetes. DESMOND has a theoretical and philosophical base; the programme supports people in identifying their own health risks and responding to them by setting their own specific behavioural goals. The DESMOND approach was piloted in early 2004 and the preliminary pilot information was presented at the Diabetes UK Annual Professional Conference in April 2005<sup>2,3,4</sup>. Phase one of national roll-out is now underway.

More information about DESMOND, can be found at  
[http://www.cgsupport.nhs.uk/diabetes/Structured\\_education.asp](http://www.cgsupport.nhs.uk/diabetes/Structured_education.asp) or on the project website at [www.desmond-project.org.uk](http://www.desmond-project.org.uk)

### Local programmes

There are a number of local adult education programmes, many of which are working towards the criteria for structured education.

The Diabetes X-PERT Programme is a structured group education programme based on the theories of empowerment and discovery learning. It won the HSJ patient-centred care award in 2004, and the overall Secretary for State's 2004 award for excellence in healthcare management. The programme was systematically developed over 5 years, and evaluated with a randomised controlled trial which showed it to positively impact on clinical, lifestyle and psychosocial outcomes. It also has linked training and quality assurance modules.

Further details are available from Trudi Deakin at [xpert.diabetes@nhs.net](mailto:xpert.diabetes@nhs.net) or [www.xpert-diabetes.org.uk](http://www.xpert-diabetes.org.uk)

Local diabetes teams may already have or be planning to develop local education programmes. Local programmes should meet the key criteria for structured education and experience shows that setting up a high-quality programme may take 3 years or more.

### Type 1 Education Network

A number of adult programmes for type 1 diabetes have been set up in recent years. All such programmes are encouraged to participate in the Type 1 Education Network. This group has agreed to benchmark their educational activity against common core elements including core content and audit methodology.

Programmes involved in the Type 1 Network include the Bournemouth programme (which has become known as Bertie) and INSIGHT, based in Oxford. The Bertie curriculum, like DAFNE, is based on the Düsseldorf model. Adaptations include delivery over a 4-week period. The programme has undergone an initial peer review, and audit of clinical and psychological outcomes show significant improvement.

Further details on the Type 1 Network are available from Joan Everett at [joan.everett@rbch.nhs.uk](mailto:joan.everett@rbch.nhs.uk)

### References

- <sup>1</sup> Shearer A, Bagust A, Sanderson D, Heller S, Roberts S. Cost-effectiveness of flexible intensive insulin management to enable dietary freedom in people with Type 1 diabetes in the UK. *Diabetic Medicine* 2004; 21 (5): 460 – 467.
- <sup>2</sup> Davies MJ, Heller S, Khunti K, Skinner TC (2005) The DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) programme: from pilot phase to randomised control trial in a study of structured group education for people newly diagnosed with Type 2 diabetes mellitus *Diabetic Medicine*, 22 (Supp 2) 104.
- <sup>3</sup> James P, Davies MJ, Heller S, Khunti K, Skinner TC (2005) The illness beliefs of people newly diagnosed with Type 2 diabetes and their relationship to depressive symptomology: results from the DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) pilot study. *Diabetic Medicine*, 22 (Supp 2) 110.
- <sup>4</sup> Skinner TC, Davies MJ, Heller S, Khunti (2005) To determine the effects of a structured education programme on illness beliefs, quality of life and physical activity in individuals newly diagnosed with Type 2 diabetes: results from the DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) pilot study. *Diabetic Medicine*, 22 (Supp 2) 15.



# Meeting the criteria

The Patient Education Working Group has agreed key criteria for structured education programmes. Local teams should work towards these standards in order to ensure that the programmes they offer effectively support self management.

Local diabetes teams will need to consider a range of issues in order to ensure that their education programmes meet the criteria. This will include areas such as health professional training, quality assurance and learning needs assessment.

This section provides a summary of the current situation and theoretical base for these key areas, and advice on how best to integrate this into daily practice.

### 3.1 Learning needs assessment

The NICE guidance on patient education 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**”.

However, learning needs assessment for people with diabetes is currently not delivered in a formal, comprehensive and standardised way.

A comprehensive needs assessment forms an essential part of the wider educational framework. It can provide the base from which the interprofessional team develops its working plan, allowing goals to be linked with hard data. It incorporates data and opinions from a variety of sources in order to create, install and evaluate patient education services. In effect, it is concerned with looking at the difference between “what is” and “what should be” for a particular situation. Needs assessment is therefore the vehicle for clarifying the direction to be taken for educational planning, be it for an individual or for a community of people. Like the audit cycle, it provides a means of describing quality in patient education and it can also be used to assess it.

Learning needs assessment should have a defined purpose and clearly outlined methods, and should be based on evidence collected from a variety of sources. Published classifications include *felt* needs (what people say they need), *expressed* needs (expressed in action), *normative* needs (defined by experts) and *comparative* needs (group comparison). Other distinctions include individual versus organisation or group needs, clinical versus administrative needs, and subjective versus objectively measured needs<sup>1</sup>. For education purposes, priority should be given to what people say they need because learning is most likely to be achieved when new information has meaning to people. Individuals themselves are best placed to decide what is right for them in the context in which they live their lives.

The Patient Education Working Group developed four themes around which patients’ educational needs might be assessed. As such, they are based on normative needs, i.e. defined by experts.

Each theme has a set of variables attached, which can be measured using either/both formal methods e.g. validated questionnaires<sup>2</sup>, and informal methods e.g. semi-structured patient interviews.

Theme	Variables
1. Contextual data	<ul style="list-style-type: none"> <li>■ Age</li> <li>■ Gender</li> <li>■ Ethnicity/cultural background</li> <li>■ Type/duration/stage of condition</li> <li>■ Disease management (primary/secondary care/other)/uptake of screening &amp; clinical appointments</li> <li>■ Relationship with health professionals</li> <li>■ Psychosocial support</li> <li>■ Effect on significant others</li> <li>■ Socioeconomic barriers, e.g. employment status, level of education attained</li> </ul>
2. Previous diabetes education	<ul style="list-style-type: none"> <li>■ Sources of information used to guide self-management</li> <li>■ Preferred learning style – group/1:1/self-directed, e.g. books, internet</li> </ul>
3. Personal models of illness	<ul style="list-style-type: none"> <li>■ Attitudes to diabetes and personal care plan</li> <li>■ Readiness to change</li> <li>■ Perceptions of their illness, e.g. beliefs about treatment effectiveness, seriousness of condition, and personal control</li> <li>■ Personal experiences of diabetes, e.g. at diagnosis/of severe hypoglycaemia/ketoacidosis</li> </ul>
4. Self-empowered behaviour	<ul style="list-style-type: none"> <li>■ Quality of life/well-being</li> <li>■ Self-management skills</li> <li>■ Self confidence/self esteem</li> <li>■ Degree of self efficacy</li> </ul>

These examples provide a long list of variables. However, when developing a needs assessment tool, it is important to be selective about the type and amount of data collected. The following therefore provides a checklist that could be considered before needs assessment is undertaken:

1. What needs to be measured?
2. How will it be measured?
3. Do data collection tools need to be newly developed or 'piloted' before they can be used?
4. Do the tools gather data in a format that is easy to summarise and analyse?
5. Who will collect, analyse and summarise the data?
6. How will the findings be translated into action?

### References

- <sup>1</sup> Lockyer J. (1998) Needs assessment: lessons learned. *J. Contin Educ Health Prof*, 18: 190-192.
- <sup>2</sup> For a review of validated measures for patients with diabetes go to:  
[http://www.measurementexperts.org/learn/practice/tf-diabetes\\_pf.asp](http://www.measurementexperts.org/learn/practice/tf-diabetes_pf.asp)

## 3.2 Health professional training

### Philosophy of Practice

There are two principal models of patient education: the traditional medical-centred model and a patient-centred approach<sup>1</sup>. The two models are distinct with respect to their underlying assumptions and concerns. Patient education within the traditional medical model<sup>2</sup> focuses on ‘the problem’ of patient control or non-compliance. The patient-centred model seeks to elicit and satisfy those needs that patients express themselves, and views that as the first step towards supporting patients to take greater control over their own health. Health professionals plan ‘for’ patients in the first model; they plan ‘with’ patients in the second.

**Table 1: Comparison of traditional medical-centred and patient-centred approaches<sup>3</sup>**

Medical-centred model	Patient-centred model
Compliance	Autonomy
Adherence	Patient participation
Planning for patients	Planning with patients
Behaviour change	Empowerment
Passive patient	Active patient
Dependence	Independence
Professional determines needs	Patients define needs

The rationale for the patient-centred model suggests that during the routine conduct of their lives, patients make a series of lifestyle choices regarding eating, physical activity, stress management and so on. Those choices combined have a far greater impact on patients’ overall health and quality of life than the decisions made by the health professionals providing their care. Health professionals may plead, persuade, cajole, threaten or advise patients regarding their health care, but once the patient leaves the clinic, that professional has no control over the patient’s self-management choices. The patient can ignore any recommendation no matter how important the educator believes that recommendation to be<sup>4</sup>.

It is not always the case that people are unwilling to change but they may be unwilling to be changed<sup>4</sup>. If advice is framed from the health professional’s perspective and not the patient’s, the patient may perceive the recommendation to be inappropriate for incorporation into their life<sup>5</sup>. Lack of change is often attributed to poor compliance, but blaming or labelling a patient as “non-compliant” may damage self-esteem and create a barrier to future behaviour change<sup>6</sup>. Non-compliance could be described as two people working towards different goals<sup>7</sup>. When patients do make changes using the compliance

approach, the change is often externally motivated, i.e. carried out solely to please the health professional, and the effect may not be long-lasting.

In contrast, quite strong evidence exists to suggest that some interventions promoting patient-centred care may lead to significant improvements in patient self-management<sup>8</sup>. There is currently, however, no gold standard measure for patient centeredness, and this area needs further work if the patient-centred approach is to be properly assessed<sup>9</sup>.

Another area of neglect in the patient centeredness approach is the development of patient information materials. Currently much material fails to give a balanced view of the effectiveness of different treatments, ignores uncertainties, adopts a patronising tone, and does not promote a participative approach to decision making. Appropriate training will be needed in order for the patient-centred approach, and its centrality to structured patient education, to be universally accepted. This training will be relevant to all health care providers involved in the management of long term conditions and provision of structured patient education.

### Training for health professionals

The move towards greater patient self-management proposed in the Diabetes NSF requires health professionals to work interprofessionally with patients in ways that promote the skills of self-management and the ability to adapt treatment to their condition. The aim of professional training should therefore be to explore the fields of knowledge on which patient education is based, including models of behaviour change. Learners need to be provided with opportunities to integrate and apply these principles to their own patient education context. Interprofessional education is important, as it enables students from different professional groups to learn with and from each other with a view to increasing collaborative practice and improving the effectiveness of care delivery<sup>10</sup>. In this context, difference is valued and is seen as the vehicle through which practice can be transformed<sup>11</sup>.

Structured patient education is only one part of a patient-centred approach. Internationally, educators are seen as the custodians of this philosophy and a comprehensive training programme for educators has been drawn up by the International Diabetes Federation (IDF). In England, educators are seen as part of a patient-centred team, and the title is being applied to those providing courses. The aims for these are outlined in the American Diabetes Association (ADA) standards for instructors, and the DAFNE and DESMOND programmes have identified specific learning objectives for 'training the educators' courses which match to these. Further discussion about these differences and the IDF and ADA standards are provided in Appendix D.

### Current 'Train the Trainers' Programmes

The two national education programmes – DAFNE and DESMOND – and some locally developed and tested education programmes such as the Diabetes X-PERT Programme provide structured training for diabetes health professionals. These courses address the

theoretical base and underlying philosophy of structured diabetes education, include observation of a full education programme and quality assurance to ensure continued quality in the delivery of the patient education.

Warwick Diabetes Care provides a Trainers Education Programme that includes learning about different educational methods in order to deliver workshops for people with type 2 diabetes. The Bournemouth team run a training programme linked to the BERTIE programme for type 1.

The development of patient-centred educational approaches requires the expertise of Higher Education Institutions. Integration of theory and practice should be central to the syllabus, and the delivery of the programme should support autonomous and reflective thinking, and evidence-based practice.

Programme development will require a planning group consisting of patient, academic, education, and clinical experts. Programmes need to connect with the Quality Assurance Agency's Benchmark Statements<sup>12</sup> National Occupational Standards<sup>13</sup> and the key skills framework<sup>14</sup>. Each of these defines standards for the education and training of health care professions at both pre- and post-registration. They should merge with current credit systems to around 'step on, step off' principles promoted by government policies for widening participation in higher education<sup>15</sup>. They also need to link into the concept of personal development planning for educational and career development.

The current Skills for Health Diabetes Competency framework<sup>16</sup> covers the diagnosis and the initial management of diabetes, and further work has been commissioned to develop competences for other areas of the diabetes service including structured patient education. These will fall under the "HB" competence category "Enable self management through structured education".

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### 3.3 Assuring Quality

Quality assurance (QA) is essential to ensuring the quality and validity of any education programme.

If a defined education programme is being delivered within a service (defined by its theoretical base, content structure, philosophy and processes), it will be important to monitor whether the programme continues to be delivered to a high standard. QA should have clear, written, monitorable standards that are regularly reviewed and updated. This is important for any evidence-based programme to show that the ‘intervention’ with demonstrated efficacy is the intervention that is actually being delivered.

Quality assurance also allows for the exploration of variation between services/treatment programmes particularly if differences in outcomes are noted. This process should allow the development (improvement) of the intervention over time.

There are three main elements to the quality assurance process:

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.
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.
3. Internal and external process in place to assess the delivery and organisation of the programme itself.

#### Internal Quality Assurance

This is a process that occurs within a service to ensure that the service is maintaining its standards, practitioners are reflecting on their delivery of the programme and there is ongoing review of the outcomes of the programme not only in terms of biometric indicators, but also reviewing patient satisfaction and experience. These standards may be set within a service or externally, and may include:

- ensuring that an educator delivers an education programme sufficiently often to maintain their skills
- reflective practice by the educator on an ongoing basis, via reflective diaries, peer discussions with co-educator
- periodic peer review of the delivery of a colleague trained in this process using the appropriate QA tools. The ‘reviewer’ needs to be trained in using the QA tools and in the giving of feedback in a constructive and helpful manner. The practitioner’s performance is reviewed in partnership, and learning needs are identified and recorded. A date is set for follow up to ensure the educator has had the opportunity to address their learning/development needs.

- periodic or ongoing reviews of the patient's experience via questionnaires, interviews or other user involvement processes
- maintenance of a database of the outcomes both medical and non-medical such as mood, quality of life, satisfaction etc

### External Quality Assurance

An external review process can have two functions. Firstly, it can be about reviewing the skills of the educators and the 'observation' of courses at that centre to ensure that the intervention is being delivered according to the set quality standards. Secondly, reviewing the processes the service has in place to ensure that they are delivering the programme according to the philosophy, and set standards, ensuring the centre is delivering enough programmes to maintain educator skills, checking organisational processes are in place to guarantee that the programme can be delivered and finally that the service has implemented a robust internal QA system.

In some instances, it may not be feasible to externally validate the skills of each educator within a service and the external QA process will be about ensuring a robust internal QA process to review skills and ensure the validity of an intervention.

If an external process is in place to review skills, it would look much the same as the internal process, but could employ video or audio tape to assess skills. Tools to assess the knowledge and skill acquisition of patients can be used as well as reviewing the practitioner's reflective diaries and personal development plans. In terms of appraising the overall service, the QA process may include the centre providing data or evidence of the number of courses, audit data, patient responses, a review of the internal QA system and possibly the observation of part of a course or the skills of one or more of the educators. Resources used, the referral processes and invitation process may also form part of the review.

### Development of Quality Assurance tools

Any QA process is dependent upon its tools and the skills of the reviewer at using the tools and giving constructive feedback. Tools that assess the delivery of the course by an educator should be based on the course manual or handbook, be linked to the core standards set which will cover the content process and philosophy/style of the programme. The observation and the feedback should be based on identifiable behaviours and feedback needs to be specific and concrete. Ideally, the tools used in any QA process need to be agreed by the educators. Ongoing educator training needs to be adapted in line with the findings of the QA process.

The frequency and maintenance of any QA process should to be agreed by those involved. If action plans have been set based on developmental needs, there needs to be a system for updating or checking that the educator has been able to put these in place. Ideally, QA should be viewed as a space or opportunity to review practice rather than a critical or intrusive experience.

The following provides a checklist of the key questions that need to be asked when initiating quality assurance:

**Purpose** – Why is the evaluation being done?

**Focus** – What aspects of the programme are to be evaluated?

**Method** – What information is to be collected and how?

**Judgements** – Who will make judgements about the worth and effectiveness of the programme? What criteria will be used?

**Organisation** – Who initiates the evaluation? Who collects the data? What resources are available for this process? How and when will the evaluation be carried out?

**Dissemination** – To whom will the findings of the evaluation be reported and how?

**Application** – To what use will the evaluation findings be put? How will they feed into decision making at local and national levels?

## 3.4 Accreditation

### What is meant by accreditation?

Accreditation in relation to patient education falls into two categories:

- Accreditation for patient education programmes
- Accreditation for diabetes educators and trainers

For healthcare professionals training as diabetes educators, the term accreditation refers to a process whereby individuals participating in a particular professional activity are deemed competent to undertake that activity. There are similarities between the terms accreditation, certification and licensure. Certification requires an individual to meet certain eligibility criteria (frequently through an examination) and is delivered by a professional (non-governmental) organisation. Licensure involves a governmental organisation deeming an individual fit to practice their profession.

### Accrediting programmes

It is important that people with diabetes know that the educational programmes they attend are of a high quality. There is currently no formal accreditation body in England to accredit national or local patient education programmes. However, the criteria developed by the Patient Education Working Group (see Section 2.2) can be used by PCTs as a means of ensuring that education programmes are high-quality. The development of a formal accreditation scheme is an area that could benefit from further policy direction from the Department of Health.

### Accrediting educators

There is a clear need for structured training of educators and trainers involved in delivering patient education programmes (see Section 3.2). The skills of healthcare professionals who are trained as educators or trainers should be recognised through formal qualifications, in order to support their career development.

Many healthcare professionals would consider themselves to be already delivering diabetes education. However, in most cases this education is not part of a structured education programme and there is considerable variation in the professional qualifications of the educators.

This report outlines the key components of a structured education programme for people with diabetes. In order to embed structured education in the health service it will also be necessary to reach a consensus on what constitutes a diabetes educator. No such consensus currently exists in the NHS. The UK has not mirrored some international trends for developing a new professional of 'patient educators'. Instead, patient education is seen as core to the whole diabetes team. Further discussion of the different international approaches is included at Appendix D.

Skills for Health are leading two important pieces of work that will support formal recognition of the skills of diabetes educators and trainers. Phase II of the Diabetes Competence framework is out to tender and this will develop those competences around patient education that are unique to diabetes. A further piece of work is also out to tender to develop either National Workforce Competences or National Occupational Standards covering Patient Education/service facilitation. These two pieces of work taken together will ensure, when delivered in 12 to 18 months time, that all the competences needed to deliver a high quality diabetes patient education service are in place.

The two national patient education programmes – DAFNE and DESMOND – already have training programmes in place with defined learning outcomes and behaviours. These will need to cross-reference with the nationally developed competencies. In the process of developing the DAFNE and DESMOND models of diabetes education, it was necessary to establish a “Training the Trainers” programme. A diabetes nurse or dietitian will, in the process of becoming a DAFNE or DESMOND educator, go through a process of training and peer review of their delivery of the structured education. Although the term accreditation is not used, the process would fulfil the requirements for accreditation. In both cases, the accreditation is very programme specific. The challenge is to agree a more generic set of competencies that every healthcare professional involved in diabetes education should meet.

## 3.5 Research and development

### Summary

The NICE Health Technology Appraisal concluded that research in the area of patient education in diabetes is relatively limited both in quality and quantity. The HTA noted that there was evidence that structured education within intensification of treatment in type 1 diabetes produced worthwhile improvements in HbA1c, contributed to a reduction in microvascular complications and was likely to be cost effective. There were no available models in type 2 diabetes that could be identified as effective. In type 1 diabetes, future work should concentrate on developing interventions which can sustain effective self management and others which can engage individuals who do not respond positively to standard approaches.

Developing effective educational models is challenging, and requires multi-centre collaborative working involving the full range of disciplines delivering diabetes care. Patient education is a complex intervention and, as with all complex interventions, will need a new approach to evaluation involving five separate stages<sup>1</sup>.

### Current evidence base

#### Type 1

A Health Technology Assessment review commissioned by NICE and published in 2003<sup>2</sup>, concluded that although reporting and methodology were generally poor, there was evidence demonstrating that when delivered as part of treatment intensification, education delivered to people with type 1 diabetes resulted in both improvement in glycaemic control and reduced diabetic complications. The authors reviewed the publications indicating the benefit of the educational intervention developed in Düsseldorf,<sup>3,4</sup> based on the Assal model of therapeutic education<sup>5</sup>. They also highlighted an additional longer term study suggesting that long-lasting improvement in glycaemic control was associated with continuing professional input and support.<sup>6</sup>

In the UK, the one RCT in this area was published by the DAFNE group in 2002, to test the feasibility of conducting a 5 day out-patient intervention in a British healthcare setting<sup>7</sup>. This programme was also based on the Assal model and follows closely the 5 day inpatient course pioneered at the WHO diabetes centre in Düsseldorf. The DAFNE study reported short-term improvements in glycaemic control (1-0.7% at 6 months) which were comparable to the German data. The Patient Education Working Group is aware of only one other recent RCT conducted among people with type 1 diabetes, although some small-scale work is ongoing in the UK. An economic evaluation modeling UK and German data suggested that DAFNE would pay for itself in 4 years<sup>8</sup>, provided improvements in HbA1c were sustained to the same degree as those in German data.

BITES is a fairly short (total 2.5 days) intervention delivering ‘an imaginative use of insulin’ and CHO counting skills to groups of adults with type 1 diabetes over 6 weeks emphasizing an empowerment model. Those undertaking the course were compared to a control group who had ‘usual treatment’. Both groups experienced an improvement in HbA1c of 0.4% but measures of patient satisfaction and empowerment improved in the intervention group compared to controls. It is not clear whether the reasons for a lack of benefit in glycaemic control compared to other interventions related to the shorter duration of the course or other factors such as a different approach to insulin adjustment. However, the results are important (currently only published in abstract form<sup>9</sup>) since they do suggest that not all adult educational interventions in type 1 diabetes are the same. This emphasizes the need for continual evaluation. People with diabetes will want to be sure that the programme they are receiving has been fully evaluated to assure the maximum benefit.

## Type 2

The development of structured education programmes in the UK for people with type 2 diabetes has drawn from the experiences of chronic disease management programmes in North America<sup>10, 11</sup>, and of those European programmes displaying positive outcomes in which structured education is a key component<sup>12-15</sup>. However, major systematic reviews of such programmes, such as that by Norris et al<sup>16-17</sup>, indicate that the majority of studies with positive outcomes attributable to the education intervention had not been designed to sufficiently separate the effect of the intervention itself with that of other factors, e.g. medical optimisation. In addition, of the international models available, none were readily transferable to a UK primary care setting.

With this in mind, in the UK prior to 2003, a number of programmes had been developed independently, most notably in Northumbria, Leicester, Bournemouth and Portsmouth, with some evaluation conducted by the Bournemouth and Portsmouth teams. However, as NICE discovered in its own review of the area of structured education in April 2003, insufficient data existed to recommend any one programme be adopted as a model of good practice<sup>18</sup>.

This state of affairs was the catalyst for the formation of the DESMOND Collaborative in 2002-03, which subsequently devised, developed and is currently testing the first module of the DESMOND structured education programme (Newly Diagnosed) using the Medical Research Council (MRC) framework for evaluating complex interventions<sup>19</sup>. DESMOND was designed to draw on the best of international and UK practice in order to meet NICE criteria. Preliminary pilot information from this study was presented at the Diabetes UK Annual Professional Conference in April 2005, and is available in abstract form<sup>20-22</sup>.

The Cochrane review on *Group based training for self-management strategies in people with type 2 diabetes mellitus*<sup>23</sup> was published in April 2005. The report states that group-based training for self-management strategies in people with type 2 diabetes is effective by improving fasting blood glucose levels, glycated haemoglobin and diabetes

knowledge and reducing systolic blood pressure levels, body weight and the requirement for diabetes medication.

The Diabetes X-PERT Programme has been evaluated by means of a randomised controlled trial involving 314 people and has shown benefits in clinical, lifestyle and psychosocial outcomes<sup>24-26</sup>.

## On-going work

### Type 1

In September 2003, Diabetes UK funded a number of programmes, which are on-going. These consist of:

#### **Oxford Diabetes Centre, Jan 2004 – Dec 2006, Evaluation of INSIGHT programme**

This is an observational evaluation with case controls of a 16-hour programme over a 4-week period. It incorporates experiential learning and utilises the empowerment approach to education, including the basic skills of insulin dose adjustment and carbohydrate counting. The study is based in Oxford and includes two other centres in Banbury and High Wycombe.

#### **Kings, Jan 2004 – Dec 2005, DAFNE hub and spoke evaluation**

King's College Hospital was one of the original DAFNE centres and its local DAFNE programme has generated considerable local interest. KCH has received a large number of requests from local hospitals to undertake DAFNE training on behalf of their patients. In response, the Kings team have devised a 'hub and spoke' model. In this model, the Hub provides DAFNE training for healthcare professionals at the Spoke centres to enable them to recruit, collect audit data, and provide follow-up support for DAFNE trained patients within their service. The Hub also provides DAFNE training for patients referred from the Spoke. The financial support will fund an observational evaluation of this model.

#### **Sheffield, May 2004 – June 2005, Pilot of DAFNE children's course**

The Sheffield team, based at Sheffield Children's Hospital, has received local funding to develop a curriculum, based on the adult DAFNE course but adapted by the Diabetes paediatric team with help from local comprehensive schoolteachers. This funding will support 6 pilot courses for children with type 1 diabetes aged between 11 and 16. Courses are age banded (11-13, 14-16) with 2 courses run in Sheffield, Derby and Manchester. The experience and effect size will be used to develop a full RCT to be run nationally.

#### **Ipswich, Jan 2004 – Dec 2005, FACTS, RCT of family centred educational intervention in children and adolescents**

This intervention is a short intervention teaching the elements of insulin dose adjustment and carbohydrate counting in a large number of families with a child with type 1 diabetes. Evaluation consists of a comparison with 'controls' who receive usual care at 12 months and a within group comparison at 2 years.

In addition, the DAFNE programme is currently conducting a 12-month study that will be completed in July 2005. This study has used a qualitative design to identify and explore the possible factors that may affect the improvement of an individual's glycaemic control following completion of a DAFNE course.

## Type 2

RCTs of structured education in type 2 diabetes in the UK continue to be the exception rather than the norm.

Diabetes UK funded a number of research studies in 2003 relating to structured education in type 2 diabetes.

The pilot phase and subsequent RCT of the DESMOND Newly Diagnosed Programme is currently ongoing. Involving 15 PCTs in England, the pilot phase was carried out between January and April 2004, with data collection now approaching completion. The full RCT, in which 1000 patients will be recruited from 12 PCTs in England and 2 Community Health Partnerships (CHPs) in Scotland, is due to make its final report in late 2006.

A randomised controlled trial of a structured education programme (University of Warwick) is a two year study researching the effectiveness of a self-management programme. The core of the intervention is a diabetes manual given to patients in their GP practice, with the self-management programme based around the one-to-one consultation between patient and health care professional.

The provision of structured education to black and minority ethnic (BME) communities is an area of particular interest for many primary care organisations and specialist services. Two Diabetes UK-funded projects are ongoing at the present time. The first, a three year study from the Royal London, is an initiative with the Bangladeshi community (BIPOD) to determine knowledge of risk in that community, to develop a greater understanding of factors influencing eating and activity to inform the development of culturally relevant diabetes prevention strategies and to identify training needs in health professionals.

The second project, the DESMOND BME study, aims to build on the DESMOND newly diagnosed programme to devise a methodology by which an English language structured education programme can be developed for use with an ethnic and/or cultural minority. As part of the project, appropriate programmes will be developed for South Asian patients and for those from the Afro-Caribbean community.

## Future developments

### Type 1

Structured education within the context of intensified insulin treatment leads to improved glycaemic control and reduces complications and is probably cost effective. However, what remains unclear is the level and type of support necessary to maintain early improvements. There is an urgent need to develop and compare interventions which provide ongoing support. We need to know whether this is best delivered individually or in groups, and at what intensity and frequency it should be provided. Perhaps only 50-

60% of those undertaking conventional structured education programmes go on to actively manage their own diabetes. Approaches need to be developed which can engage the remaining 40% in self-management and establish whether assessment of individuals at an early stage can predict who will and will not respond positively to standard courses. The development and evaluation of complex interventions is challenging, requiring considerable funding to sustain the different phases leading up to a definitive RCT and beyond. Such work will require the collaborative efforts of large multidisciplinary teams in different centres.

The development and evaluation of proposed models for structured follow-up and ongoing support to sustain self management skills acquired via DAFNE are seen as priorities for the newly formed DAFNE research group.

One DAFNE centre has already conducted a qualitative study into the identification of potential factors that affect an individual's ability to effectively self manage and maintain their skills. Interviews were conducted with individuals that had completed a DAFNE course and maintained the initial improvement in HbA1c and those that had not maintained their initial improvement. The outcomes from this study are expected towards the end of June 2005.

Another priority for the DAFNE research group is to develop an evaluation for an alternative delivery model for the 5-day DAFNE course. It is acknowledged that the evaluated five consecutive day model excludes groups of individuals and diabetes services (e.g. rural communities and smaller District General Hospitals). The DAFNE Hub and Spoke model, if successful, could help some DGHs provide a DAFNE service. However, the DAFNE research group are also keen to evaluate alternative delivery formats such as 5 x 1 day sessions delivered over a period of 5 weeks.

The Bournemouth team have recently reported their work on exploring the reasons why some patients did not improve their glycaemic control following participation in the BERTIE programme. It is anticipated that ongoing work will inform the development of interventions which may benefit such patients<sup>27</sup>.

### Type 2

There continues to be a lack of high-quality RCTs evaluating structured education offered in primary care, due mainly to the challenges and cost of conducting research in this setting. However, considering the numbers of people with type 2 diabetes involved and the high cost of service provision falling on both primary and specialist care services, there continues to be an increasing need for this type of evaluation.

The DESMOND Collaborative has already established a research base in primary care, through partnership with PCTs and CHPs participating in the current RCT. The Collaborative is continually channelling the professional interests, expertise and commitment of its ever-growing membership into further research projects related to structured education for people with type 2 diabetes. In addition to the current RCT and the DESMOND BME module, the Collaborative is progressing proposals around

the development of lay educators, and a comparison of blood glucose monitoring and urine monitoring.

Biomedical data have long been paramount as primary outcomes, and remain the main markers in diabetes research. However, these are not necessarily the most helpful means of opening up the patient experience to general understanding. More qualitative studies are needed alongside the traditional scientific trials to explore areas critical for the development of structured education, for example, patient motivation and attitudes to monitoring and the dynamics of group work.

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# Education gaps

The Patient Education Working Group has identified a number of gaps in provision that need to be filled in order to ensure that all people with diabetes have access to high-quality structured education.

Education programmes such as DAFNE or DESMOND have already made an impressive impact. However, they may not be appropriate for some groups such as people with poor basic skills, or those who experience language or cultural barriers.

Specific areas identified as gaps by the Patient Education Working Group and addressed in this section include:

- One-to-one
- Ongoing support
- Children and adolescents
- Insulin pump therapy
- BME groups
- Impaired glucose tolerance
- Carers
- Pregnancy

However, local diabetes services will need to consider the needs of other potentially vulnerable groups in their area such as:

- people with poor basic skills, such as language and literacy
- people (both patients and carers) with learning difficulties
- difficult-to-reach groups such as travellers, refugees and asylum seekers

Innovative approaches may be needed in order to access and support these groups. It may be that these approaches will need to be more direct or didactic. A variety of techniques can be used, such as picture charts, video techniques, cartoon-based learning, text messaging and the use of e-mail tailored to the group or individual.

## 4.1 One-to-one

The Patient Education Working Group focused on the standards and structure needed to ensure high-quality group education for people with diabetes. However, the Group recognised that one-to-one support will still be an important part of diabetes education.

### Current programmes

The Diabetes NSF Additional Material<sup>1</sup>, produced with the *Diabetes NSF Standards*, highlights a number of key features of effective educational interventions, which can be used by local teams to support one-to-one education:

- extensive use of techniques that aim to promote and sustain changes in health-related behaviour, such as goal setting, problem solving, procedures for modifying environmental cues and reinforcers that control behaviour
- communication styles that encourage and support people with diabetes to participate in setting their own treatment goals
- regular follow-up, either in person or by telephone, which includes the monitoring of the achievement of treatment goals and the provision of continuing education
- hands-on demonstrations and the opportunity to practice the skills required for self-care
- provision of practical aids to support behaviour change, such as charts and reminders to take medication
- simplification of self-care and medication regimens
- use of computer packages to augment the diabetes education provided by health professionals
- involvement of family and significant others
- peer support for goal achievement

The newly formed DAFNE research group will also be progressing proposals for different delivery models of the 5-day DAFNE course. It is recognised that the evaluated 5-day course is restrictive not only to certain groups of individuals but also to some healthcare settings (i.e. rural communities and small District general Hospitals).

### References

- <sup>1</sup> The Diabetes NSF Additional Material is available on the Department of Health website at [http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPAmpGBrowsableDocument/fs/en?CONTENT\\_ID=4096591&MULTIPAGE\\_ID=4901731&chk=H1zSRS](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPAmpGBrowsableDocument/fs/en?CONTENT_ID=4096591&MULTIPAGE_ID=4901731&chk=H1zSRS)

## 4.2 Ongoing support

### Current situation

The development of structured self management education programmes is aimed at bringing about a change in those who attend such programmes: the attendees will recognise their role as being the main deliverer of care and decision making as well as being the key decider about what is best for themselves (or those they care for). This change will also require a change in approach in those health care professionals involved in ongoing clinical care. It is now well known that improved consultation skills are required for improved patient centredness<sup>1</sup>.

The inclusion of structured self management education programmes into the care pathway of someone with diabetes will require a consideration of the effect on the whole pathway<sup>2</sup>. Indeed, some centres are modelling a new care pathway based on routine group follow up care rather than a model based on one-to-one care<sup>3</sup> – such models are also used in Kaiser Permanente primary care sites.

Both DESMOND and DAFNE are considering further developments in relation to ongoing care developments.

### Development of Ongoing Models

There are no developed and tested models of ongoing integrated educational care in the UK. In addition to the national DAFNE and DESMOND programmes, there are a number of local sites that are starting to develop models, including Portsmouth, Sheffield, Bournemouth and Worthing. The Diabetes X-PERT Programme is developing an on-going module that will be available in 2006.

### DAFNE

The DAFNE Collaborative currently employ structured follow-up within 8 weeks of the completion of a DAFNE course and then recurrent reviews (12 – 18 monthly). Both the initial and recurrent follow-up includes group education and the opportunity for one-to-one consultation with a DAFNE educator or doctor.

However, it is recognised that the effectiveness of this and other potential models will need to be firmly established before they can be offered as models for on-going care.

The newly formed DAFNE research group will begin to look at developing and evaluating models for skills maintenance and also attempt to identify factors which may affect an individual's success with self management and develop models for effective support to help patients maintain their newly acquired skills and the benefits these skills bring.

Some qualitative work (interviews using the grounded theory approach) has already commenced in one DAFNE centre, looking at potential factors that may help or hinder the individuals maintain improved glycaemic control following a DAFNE course.

Progress of any research by the DAFNE Collaborative will be posted on the DAFNE website ([www.dafne.uk.com](http://www.dafne.uk.com)) and results disseminated as and when available.

### DESMOND

Concurrent with the RCT of the DESMOND Newly Diagnosed Programme, development is progressing on the next stage of the DESMOND pathway, the Ongoing Model for people with established diabetes. This second stage of DESMOND will be designed to follow on from the newly diagnosed module.

A multidisciplinary group of healthcare professionals (many drawn from primary care), academics, local DESMOND team members and people with diabetes, have revisited the evidence on structured education (see Section 3.5) including the early results of the DESMOND newly diagnosed pilot phase. They are currently exploring various options for creating an integrated pathway of ongoing care and structured self-management education for people with diabetes. A key factor of any Ongoing Model will be the feasibility and cost effectiveness of its provision in primary care.

It is hoped that the DESMOND Ongoing Model will be ready to be tested in primary care in 2006, prior to being made widely available in the UK.

### Training

In order to ensure effective ongoing self management, the inclusion of consultation skills training as part of health care professional training needs to be considered further. At present, there are few dedicated training programmes for consultation skills in the care of those with long term conditions. Consultation skills training has been a significant part of general practitioner training but the philosophical underpinning of these programmes may need adapting to meet the needs of those who are working in a self management domain of care.

### References

- <sup>1</sup> Parkin T., Skinner TC. Discrepancies between patient and professionals recall and perception of an outpatient consultation. *Diabetic Medicine*. 1920;909-14.
- <sup>2</sup> Porta M, Trento M, ROMEO Writing Committee. ROMEO: rethink organization to improve education and outcomes. *Diabetic Medicine*.21(6):644-5, 2004.
- <sup>3</sup> Trento M, Passera P, Bajardi M, Tomalino M, Grassi G, Borgo E *et al*. Lifestyle intervention by group care prevents deterioration of Type II diabetes: a 4-year randomized controlled clinical trial.[see comment]. *Diabetologia*.45(9):1231-9, 2002.

### 4.3 Children and Adolescents

The needs of children and adolescents alter over the years, and therefore their educational needs assessment should reflect these changes. Major factors that will affect the content of an educational package include: age, sex and ethnic/cultural background of the child and family; the psychosocial infrastructure/support available; and their level of educational attainment and ability.

#### Current situation

To the group's knowledge, there is currently no evaluated paediatric or adolescent structured education being delivered systematically in the UK. Although many centres have educational programmes, few if any are structured, use formal curricula or provide training for educators in paediatric diabetes. The value of these programmes is uncertain. Some probably do provide useful information for both parents and children, but the extent to which they enable families and children to manage their own diabetes successfully is unclear. Other work suggests that overall glycaemic control in children and young people is worse in the UK compared to other countries<sup>1</sup>.

#### Training

There are no recognised 'train the trainers' programmes for delivering paediatric and adolescent diabetes education packages. Members of paediatric and adolescent diabetes teams have a varying amount of relevant input within their initial professional training in relation to age-specific and developmental milestones for children and adolescents.

Not all paediatric and adolescent diabetes team members have the same level of academic attainment. There is no current consensus across the UK to allow uniformity for roles and qualifications for different members of these teams to deliver structured patient education for children and adolescents.

There are two paediatric and adolescent diabetes training courses available for members of a paediatric and adolescent diabetes teams in England. The Birmingham Children's Hospital at Home course, which is predominately for children's diabetes nurses and paediatric dietitians, has learning aims and objectives covering the educational needs of children and adolescents<sup>2</sup>.

The Warwick Diabetes Care course is a multi-disciplinary and modular programme with four core modules leading to a Masters in Paediatric and Adolescent Diabetes. This also has learning aims and objectives looking specifically at the learning needs of children, adolescents and their families<sup>3</sup>.

#### Quality assurance

There is generally ad hoc audit rather than QA data depending on the local initiatives currently being delivered. Many local packages have a quiz-based assessment at the end

of a taught package or module, and these are often used to assess patient knowledge following the intervention. There is no standard template that can be used by local paediatric and adolescent teams to assist assessment of patient knowledge and skills.

### Research and development

There is a need for further research and development of educational packages of care for paediatric and adolescent diabetes. Any future work in this area would need input from paediatric educationalists, play specialists and other specialist disciplines to assist in the development of appropriate programmes.

At diagnosis, many children and adolescents follow an Integrated Care Pathway which already includes a check-list of initial knowledge and skills required prior to or soon after discharge.

In many teams, the majority of education provided for newly diagnosed children and adolescents with diabetes is delivered within the home or out-patient environment, and not within the acute hospital setting.

### Educational needs assessment

The baseline assessment changes with age, circumstances, and events and with continual growth and development. This is not only true for children and adolescents, but their families, carers and peers, as the role, importance and influence of these groups alters with increasing age and independence.

### Current programmes

The DAFNE programme initially produced for adults with type 1 diabetes is currently being piloted for children and adolescents. The curriculum has been developed by a group of paediatric nurses and dietitians and has been adapted from the adult DAFNE course in work supported by teachers from a local comprehensive school in Sheffield. The course, delivered over 5 days, is also known as KICK OFF (“Kids in control of food”). The course includes a healthcare professional training package on ‘How to teach children and adolescents’ and learning theory, as this is seen as important for success.

There are many local diabetes education initiatives for children and adolescents with diabetes across the UK.

### References

- <sup>1</sup> Danne T, Mortensen HB, Hougaard P, Lynggaard H, Aanstoot HJ, Chiarelli F, et al. Persistent differences among centers over 3 years in glycemic control and hypoglycemia in a study of 3,805 children and adolescents with type 1 diabetes from the Hvidore Study Group. *Diabetes Care* 2001;24:1342-1347
- <sup>2</sup> Further information is available at <http://www.bch.org.uk/departments/diabetes.htm>
- <sup>3</sup> Further information is available at <http://www2.warwick.ac.uk/fac/med/healthcom/diabetes/courses/masters/paediatrics/>

## 4.4 Insulin Pump Therapy (CSII)

### Current situation

NICE Health Technology Appraisal 57, published in February 2003, recommended that pump therapy was an option for people (including children, adolescents, pre-pregnant and pregnant women) with type 1 diabetes in which multiple dose insulin injection therapy had failed<sup>1</sup>. The guidance stated that pump therapy should be commenced by a specialist trained team including a physician, diabetes specialist nurse and dietitian.

Pump therapy may be suitable for patients who meet NICE guidance criteria and for whom all other methods to control their diabetes (including appropriate education) have been unsuccessful. The NICE HTA on patient-education models should be seen as complementary to the NICE guidance on insulin pump therapy, and the same educational principles should apply.

In order for insulin pump therapy to be successful, people with diabetes and their healthcare professionals need to understand:

- how to use the technology
- how to use the insulin management skills of structured self testing, carbohydrate counting and dose adjustment
- how to integrate pump therapy into day-to-day life

### Training

To date there is no standardised training in pump therapy for healthcare professionals. Health professionals trained in the use of pump therapy may still be reluctant or not have the opportunity to initiate pump therapy in patients<sup>2</sup>.

Necessary areas of training in the use of pump therapy for both health professionals and patients include:

- Necessity for regular self-monitoring of blood glucose
- Changing from injections or pen to pump use
- Setting up the pump consumables to correctly administer insulin
- Setting of varying basal rates in accordance with patient needs
- Delivery of bolus insulin for meals
- Insertion of cannula to deposit needle under the skin
- Calculation of the glycaemic index for carbohydrate values and necessary insulin
- Awareness of gastroparesis where patients will need insulin dosage spread over a number of hours
- The indications for early removal of the infusion site, ketosis, absorption rates and infection risk
- Appropriate infusion sites
- Basal rate increases in accordance with blood glucose readings due to illness

- Practical issues such as sleeping and bathing with the pump, wearing the pump, changing batteries etc
- How and where to contact the manufacturer in the case of technical difficulties

### Research and development

The Diabetes NSF states that resources need to be invested in researching treatments such as pump therapy. This could result in a delay in the onset and reduce the impact of complications, producing long-term cost benefits and improvements in the quality of people's lives.

### Accreditation

To the group's knowledge, there is no national quality indicator for pump therapy. Medtronic offers a Certified Pump Trainer programme for their pumps which healthcare professionals can complete and be re-assessed three-yearly.

### Educational needs assessment

Most centres recognise the critical importance of structured education, are assessing their patients' educational needs and recommending a structured education programme such as DAFNE prior to making the decision to commence pump therapy. The principles of a comprehensive structured education package for people with type 1 diabetes would cover the same principles as those needed for pump therapy.

### Current programmes

Pump Management for Professionals (PUMP) was set up to provide independent education and training for health professionals, and organises a yearly study day. Further details on PUMP and professional training are available from Joan Everett at [joan.everett@rbch.nhs.uk](mailto:joan.everett@rbch.nhs.uk)

A number of local diabetes services have been providing pump training for professionals since 2001. The first Warwick University pump course took place in May 2005 and featured exposure to all pumps.

Education of both healthcare professionals and patients is also provided by drug companies. Their involvement and sponsorship should conform to Department of Health guidance. The three companies currently selling insulin pumps in the UK offer training programmes for their use, and also offer one-to-one support for centres transitioning patients onto pump therapy if required. The pump manufacturers have carried out intensive training with diabetes teams in the south of England, which will help more diabetes teams become pump centres<sup>3</sup>.

### References

- <sup>1</sup> National Institute for Clinical Excellence (2002) Technical Appraisal Guidance No. 57: *Subcutaneous Insulin Infusion (Insulin Pump Therapy)* for Diabetes. NICE, London
- <sup>2</sup> Davies JM and Wilson VL (2004) 'NICE: the way forward with insulin pumps' *Diabetes and Primary Care* 6(2):72-6
- <sup>3</sup> Wilson VL (2004) 'Insulin Pump Therapy: a postcode lottery?' *Diabetes and Primary Care* 6(1): 49-52.

## 4.5 BME groups

### Current situation

There are differences in the prevalence and pathophysiology of diabetes between some black and minority ethnic groups.

Ethnicity in the context of provision of health education and care is a complex issue with language being only one factor. It is important that any self-management programme specifically addresses the issue of health beliefs. For example, it has been shown that individuals from black and ethnic minority backgrounds are less likely to: agree that their diabetes is a chronic condition; see it as a greater threat to their health; and feel that it had a greater impact on their lives<sup>1</sup>. This was reported in patients of South Asian origin compared to white Europeans.

There may be other widely held attitudes and beliefs, such as a strong motivation to comply with diet modification and treatment, which may be very positive factors. Family support plays a key role, both in terms of sharing knowledge and providing help with language problems. There may also be organisational considerations, such as a preference for separate gender education groups.

### Current programmes

The DESMOND Black and Ethnic Minority (BME) project is being carried out concurrently with the main study of the Newly Diagnosed module. The key objectives of the DESMOND BME project are fourfold. Firstly, to describe the methodology of adapting a patient-centred educational module in which the importance of health beliefs is central, in order to make it fit for purpose in ethnic minority populations; secondly, to test this methodology by piloting and evaluating the module, developed in the South Asian population in a centre in the UK. Thirdly, the project will test the transferability of the methodology in a South Asian population in a different area of the UK, and in a population of African-Caribbean origin, and at the same time identify appropriate tools for measuring the effectiveness such modules in ethnic minority populations. Finally, the project aims to gather information relating to the cost of developing and providing such educational modules for ethnic minority communities. The project is expected to report by April 2006.

Educational visual aids are paramount to the successful delivery of the Diabetes X-PERT Programme. In the RCT, 25% of participants were non-English speaking South Asian participants. Separate single sex sessions were held using the skills of an interpreter. The programme was shown to be beneficial for these individuals by improving clinical, lifestyle and psychosocial outcomes<sup>2</sup>.

A novel form of group education for BME patients – the so-called ‘sharing stories’ technique – has proved popular and feasible in a recent action research study<sup>3,4</sup>. In this approach, participants share stories about their experience of diabetes and the lifestyle challenges they face, working in informal small groups led by bilingual health advocates

(BHAs). The research team has developed an accredited training programme for BHAs called 'Storytelling for group learning in health and care', for which a training manual is available<sup>5</sup>.

Because stories are holistic in nature, image-rich, action-oriented and overlaid with emotion, they have (in theory) much greater potential to engage the listener, motivate, and prompt action than a simple 'talk and chalk' exchange. Some (but not all) BME groups have strong traditions of oral storytelling, and an oral storytelling approach may also have advantages in some sectors of the indigenous white British population (for example those with low health literacy).

The mechanisms by which storytelling in groups might achieve an effect on learning and health-related behaviour could include (in addition to transmission of formal knowledge):

- An enhanced learning environment (because multiple opportunities may exist to learn visually, aurally, and by doing)
- Social modelling (a critical dimension of all peer education)
- Collective sense-making (in which the group questions, negotiates and reframes the meaning of formal advice until it is expressed in a way that is acceptable, meaningful and sensible)
- Vicarious experience (being inspired to action [or warned off] by what happened to someone else)
- Reframing of identity (e.g. from 'victim of my diabetes' to 'on top of my diabetes')
- Development of social capital (such as friends, contacts, local knowledge)
- Transmission and personalisation of 'tacit' knowledge (practical know-how that is difficult to articulate formally and which cannot usually be found in books)
- 'Healing drama' (the enacting of a positive personal story)

It should be noted that whilst the sharing stories approach is popular with both staff and patients, and has a strong theoretical basis, it has not yet been prospectively evaluated either against no intervention or against more conventional educational approaches.

A randomised trial comparing BHA-led story-sharing groups with individual education through an interpreter (POSEIDON – Promoting cOllaborative Support and Education in Diabetes for minOrity ethNic groups) is planned to start in 2005.

The wider literature on intervention trials of group education in BME groups in diabetes is extremely sparse. A systematic review showed that group support was an independent critical success factor in diabetes education for African-Americans and Latinos<sup>6</sup>. A small US study randomised Mexican-Americans with type 2 diabetes to an 8-week programme of group education plus group support from a Spanish speaking community worker or usual care; significant improvements were obtained in diabetes knowledge and HbA1c levels in the intervention group<sup>7</sup>. Little detail was given, however, on the nature of the intervention or the role of the community worker.

In view of the sparseness of the research base for BME education, practitioners should try to link their BME patients with ongoing research studies (such as DESMOND or POSEIDON) if available in their area, and otherwise use their judgement when adapting mainstream educational programmes for their BME patients.

## References

- <sup>1</sup> Skinner, T.C., Tantam, L., Purchon, A., & John, M. (2002) Do illness beliefs explain poorer outcomes for ethnic minority populations: A pilot study. *Diabetic Medicine* 19 (suppl 2) P274
- <sup>2</sup> Deakin, T. A. Expert Patient Education versus Routine Treatment (X-PERT). PhD Thesis: 1-346; 2004. Nuffield Institute for Health, University of Leeds.
- <sup>3</sup> Greenhalgh T, Collard A, Begum N. Sharing stories: complex intervention for diabetes education in minority ethnic groups who do not speak English. *BMJ* 2005; 330: 628-634.
- <sup>4</sup> Greenhalgh T, Collard A, Begum N. Narrative based medicine: An action research project to develop group education in diabetes for health advocates and 'hard to reach' service users. *Practical Diabetes International* 2005; **22**: 125-9.
- <sup>5</sup> Greenhalgh T, Collard A. *Sharing stories – a new approach to multiprofessional training in diabetes care*. London: BMJ Publishing Group, 2003.
- <sup>6</sup> Sarkisian CA, Brown AF, Norris KC, Wintz RL, Mangione CM. A systematic review of diabetes self-care interventions for older, African American, or Latino adults. *Diabetes Educ.* 2003; 29:467-79.
- <sup>7</sup> Brown SA, Hanis CL. A community-based, culturally sensitive education and group-support intervention for Mexican Americans with NIDDM: a pilot study of efficacy. *Diabetes Educ* 1995; 21: 203-10.

## 4.6 Impaired Glucose Tolerance/Impaired Fasting Glucose

### Current situation

There is a growing evidence-base that the onset of type 2 diabetes can be delayed and potentially prevented in individuals with impaired fasting glucose (IFG) or impaired glucose tolerance (IGT).

Several published intervention trials have demonstrated the potential for lifestyle changes or medication to reduce the development of diabetes in people with impaired glucose tolerance<sup>1,2,3</sup>.

The Diabetes Prevention Program<sup>4</sup> was a large randomized clinical trial testing interventions to prevent or delay type 2 diabetes. The trial involved patients with a high risk of type 2 diabetes, and having impaired glucose tolerance and impaired fasting glucose. The trial concluded that lifestyle and pharmacological interventions were effective in short-term studies but that intensive lifestyle intervention was more effective than metformin at preventing diabetes.

The Finnish Diabetes Prevention study<sup>5</sup> aimed to assess whether the onset of type 2 diabetes can be prevented by lifestyle intervention in high-risk individuals. A total of 522 middle-aged, overweight men and women with impaired glucose tolerance were randomised into either intensive lifestyle intervention or control group. The subjects in the intervention group receive individual advice to reduce weight, intake of energy and total and saturated fat and to increase fibre intake and physical activity.

The risk of diabetes was reduced by 58% in the intervention group during the entire trial. After 1 and 3 years, weight reductions were 4.5 and 3.5 kg in the intervention group and 1.0 kg and 0.9 kg in the control group. The results show that it is possible to change behaviour and produce favourable changes in weight and in metabolic variables with a lifestyle intervention.

Strategies that encourage individuals to make nutritional modifications, lose weight if necessary, and be more physically active are therefore important.

There is currently no national programme in the UK to identify and treat IFG and IGT, although the *Choosing Health* White Paper set out a range of commitments designed to support people to reduce risk factors such as obesity and smoking.

### Current programmes

Standards 1 and 2 of the Diabetes NSF relate to the prevention of type 2 diabetes and identification of people with diabetes. Diabetes Networks should work in collaboration with Primary Care and Hospital Trusts to set local targets to help improve prevention and early detection.

There are currently a range of existing programmes that aim to promote healthy living and prevent the risk factors for diabetes. Specific examples include ‘exercise on prescription’, health trainers, and locally produced obesity management programmes.

To support this approach, education (especially about the risk factors and risk groups) needs to be provided to:

- the general population
- primary care, in its widest sense
- hospital (especially junior) staff

Health professionals such as pharmacists, dentists and optometrists can be incentivised, and risk engines used, to support early detection. The UKPDS risk engine<sup>6</sup> provides risk estimates and 95% confidence intervals, in individuals with type 2 diabetes not known to have heart disease, for:

- non-fatal and fatal coronary heart disease
- fatal coronary heart disease
- non-fatal and fatal stroke
- fatal stroke

## References

- <sup>1</sup> Knowler, W. C., Barrett-Connor, E., Fowler, S. E., Hamman, R. F., Lachin, J. M., Walker, E. A., Nathan, D. M., & Diabetes Prevention Program Research Group. 2002, “Reduction in the incidence of type 2 diabetes with lifestyle intervention or metformin”, *New England Journal of Medicine*, vol. 346, no. 6, pp. 393-403.
- <sup>2</sup> Pan, X. R., Li, G. W., Hu, Y. H., Wang, J. X., Yang, W. Y., An, Z. X., & et al. 1997, “Effects of diet and exercise in preventing NIDDM in people with impaired glucose tolerance. The Da Quing IGT and Diabetes Study”, *Diabetes Care*, vol. 20, no. 4, pp. 537-544.
- <sup>3</sup> Tuomilehto, J. 2001, “Prevention of type 2 diabetes mellitus by changes in lifestyle among subjects with impaired glucose tolerance. 41”, *New England Journal of Medicine*, vol. 344, no. 18, pp. 1343-1350.
- <sup>4</sup> Tuomilehto, J., Knowler, W. C., and Zimmet, P. Primary Prevention of Non-Insulin-Dependent Diabetes Mellitus. *Diabetes/Metabolism Reviews*. 1992; 8 (4): 339-353.
- <sup>5</sup> Prevention of Type 2 diabetes by changes in lifestyle among subjects with impaired glucose tolerance *N Engl J Med* 344: 1343-50, 2001 (known as Finnish Study)
- <sup>6</sup> Further information is available at <http://www.dtu.ox.ac.uk/index.html?maindoc=ukpds/>

## 4.7 Carers and significant others

### Current situation

There is currently no definitive or consistent education for carers of people with diabetes. The type of education required is dependent upon the relationship of the carer and the individual; the regularity of care required; the type of diabetes; the self-management knowledge and skills of the person with diabetes requiring care; and the desires and wishes of the patient.

Education for carers of people with diabetes might cover the following areas:

- Insulin and tablet dosage and administration
- The effects of diet, exercise and change of routine on blood glucose levels
- Blood glucose testing – importance and frequency
- Hypoglycaemia awareness and treatment
- Severe hypoglycaemia and Glucagon administration
- How to check the diabetic foot
- Awareness of complications and their symptoms including psychosocial issues
- The need for regular review
- How to access help and support

Where parents/guardians of children and young people are involved in the care of diabetes, there should be ongoing support available from an appropriate paediatric and young persons' diabetes team. The team should offer anticipatory guidance that enables family units to move the locus of control for diabetes from the adult carers to the self-care of the young person in a staged approach.

### Current programmes

Education for carers may be available to partners/parents/paid carers when attending diabetes clinic appointments and structured education programmes with the individual. For example, carers are invited to attend the DESMOND and Diabetes X-PERT patient education programmes, and some DAFNE modules.

However, these educational opportunities are dependent on the skills and knowledge of the educator, time constraints, patient and carer empowerment, and the level of explanation and understanding.

In addition to diabetes education provided by health professionals, educational materials could be made available via the internet or computer software from diabetes centres. For example, educational videos could demonstrate how to mix and inject insulin or how to check the diabetic foot. This would provide a useful source of education to reinforce and remind carers of such issues as and when required.

## 4.8 Pregnancy

### Current situation

Diabetes is the most common pre-existing medical disorder complicating pregnancy in the UK. Approximately one pregnant woman in 250 has pre-existing (type 1 or type 2) diabetes, and an increasing number of young people are being diagnosed with type 2 diabetes.

Four large surveys of pregnancies in women with diabetes were undertaken during the 1990s in England, Scotland and Northern Ireland<sup>1,2,3,4</sup>. These demonstrated perinatal mortality rates ranging from 18.9/1000 to 42.8/1000 total births. This compares with a perinatal mortality rate of 8.2 per 1000 total births in England in 2000. In the same surveys, congenital malformation rates in these babies ranged from 55 to 94 per 1000 live births, four to 10 times higher than in the general population.

Congenital malformations constitute the main cause of the high perinatal mortality seen in infants of diabetic mothers and result from abnormal fetal development during the six weeks following conception, i.e. often before a woman knows she is pregnant<sup>5</sup>.

The congenital malformation rate is related to the level of pre-conception blood glucose control. If near-normal blood glucose control is achieved at the time of conception, this can be reduced to a rate comparable to that seen in women who do not have diabetes<sup>6</sup>.

Pregnancy outcomes in women with pre-existing diabetes are highly correlated with the level of blood glucose control immediately before and during pregnancy. The achievement of tight blood glucose control (i.e. blood glucose and HbA1c levels within the non-diabetic range) before and during pregnancy improves outcomes.

There is increasing evidence to demonstrate that pre-conception counselling and care can reduce maternal morbidity and avoidable fetal morbidity and mortality, including congenital malformations, often to levels observed in the general population<sup>7</sup>. Pre-conception care has also been demonstrated to be cost-effective<sup>8</sup>.

Pregnant women and their partners are generally receptive to educational messages which promote healthier lifestyles for the benefit of the unborn child. All women with type 1 or 2 diabetes who are of childbearing age should as a minimum be offered, at least once a year, information about the risks associated with pregnancy and the benefits – and risks – of tight blood glucose control before and during pregnancy. They should have access to structured education as a priority.

Pre-pregnancy review should include:

- advice on the benefits of stopping smoking, where indicated, and support to give up smoking, including referral to smoking cessation services
- dietary advice, including advice and support to maintain or lose weight, where indicated
- advice about appropriate types of physical activity

- folic acid supplementation: women with diabetes should be prescribed the higher dose of 5mg folic acid/day
- assessment for the presence of any long-term complications, particularly eye and renal complications, and treatment, if indicated
- standard pre-pregnancy assessments, as for non-diabetic women, including rubella status
- review of all medication: the risks and benefits of continuing each medication should be carefully considered.

### Training

There is no standardised training for healthcare professionals specifically regarding pregnancy, although there is substantial guidance under Standard 9 of the Diabetes NSF. The DAFNE programme contains stated learning outcomes surrounding pregnancy.

### Research and development

The CEMACH Diabetes Project<sup>9</sup> comprises a number of related modules that aim to build up a picture of organisational facilities, care and outcomes of diabetic pregnancy in England, Wales and Northern Ireland and, ultimately, to make recommendations which will help the NHS to reduce the rate of perinatal deaths and congenital malformations in this group of women.

Specific research is needed to look at whether pregnancy support is most effective when delivered as part of a generic structured education course, or through specific pre-pregnancy sessions.

### Educational needs assessment

All pregnant women with pre-existing diabetes should be supported, as far as possible, to take control of their care and to enjoy a positive experience of their pregnancy. Women with diabetes, and their partners, where appropriate, should be involved in decisions about their care, and be offered the opportunity to make informed choices, through the provision of appropriate information.

Patients are often in frequent contact with their antenatal diabetes care team during their pregnancy and will regularly be assessed with respect to their educational needs. This usually takes place on an informal basis.

### Current programmes

The group are unaware of any current programmes involving structured education courses specifically designed for pregnant women. Some DAFNE centres fast-track women who become pregnant onto a course at an early stage of their pregnancy. In these centres, women with type 1 diabetes who don't attend courses are usually taught

the principles of carbohydrate counting and insulin dose adjustment on an unstructured one-to-one basis.

## References

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- <sup>9</sup> Confidential Enquiry into Maternal and Child Health (2004), *Maternity Services in 2002 for women with type 1 and type 2 diabetes*. Further information is available at <http://www.cemach.org.uk/programmes.htm>



# Patient Education Working Group – Membership

Suzanne Lucas	Consultant, Diabetes UK (Joint Chair)
Sue Roberts	National Clinical Director for Diabetes, Department of Health (Joint Chair)
Eleanor Bell	Senior Project Manager, Health and Social Care Information Centre
Stuart Bootle	Healthcare Continuum
Marian Carey	DESMOND Project Manager
David Cavan	Clinical Director, Royal Bournemouth Hospital
Helen Cooper	Director, Advanced Clinical Practice and Interprofessional Education, University of Liverpool
Sue Cradock	Consultant Nurse in Diabetes, Portsmouth Hospitals NHS Trust and Portsmouth City TPCT
Jo Dalton	Paediatric DSN, Morecambe Bay Hospitals NHS Trust
Melanie Davies	Consultant, University Hospitals of Leicester
Trudi Deakin	Dietitian, Burnley, Pendle and Rossendale Primary Care Trust
Sean Dinneen	National University of Ireland, Galway and University College Hospital, Galway
Yvonne Doherty	Clinical Psychologist, North Tyneside General Hospital
Ellis Friedman	Director of Public Health, Burnley, Pendle and Rossendale Primary Care Trust
Wendy Gatling	Consultant Physician, Poole Hospital
Simon Heller	Senior lecturer in medicine, University of Sheffield and honorary consultant physician
Jeremy Henley	Person with diabetes
Wilma McPhie	Regional Programme Manager, North West
Cathy Mittler	Somerset, Devon & Cornwall Workforce Development Confederation
Lindsay Mountford	Department of Health

Neil Munro	GP, Capelfield Surgery
Bill O’Leary	Head of Communications, National Diabetes Support Team
Simon O’Neill	Director of Care and Policy, Diabetes UK
Candice Philipps	Dietitian, Addenbrooke’s NHS Trust
Maxine Reynolds	Business Analyst, Health and Social Care Information Centre
Louise Stuart	Lecturer in Podiatry, University of Salford
Janet Sumner	DSN, Oxford Radcliffe NHS Trust
Matthew Thalanany	Director of Public Health, Billericay, Brentwood and Wickford Primary Care Trust
Jon Tuppen	Executive Committee Chair, Billericay, Brentwood and Wickford Primary Care Trust
Eileen Turner	Nurse Consultant, Kings College Hospital
Nick Vaughan	Consultant Physician, Royal Sussex County Hospital
Sarah Walter	Project Manager, Department of Health (Secretariat)
Neil Wilson	Carer
Valerie Wilson	Person with diabetes

The following websites provide valuable information about diabetes:

### Department of Health, Diabetes page

<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Diabetes/fs/en>

### Diabetes UK

<http://www.diabetes.org.uk/>

### National Diabetes Support Team

<http://www.cgsupport.nhs.uk/diabetes/default.asp>

### DAFNE

<http://www.dafne.uk.com/>

### DESMOND

[www.desmond-project.org.uk](http://www.desmond-project.org.uk)

### NICE Health Technology Appraisal – Patient-education models for diabetes

<http://www.nice.org.uk/page.aspx?o=68326>

### NICE Health Technology Appraisal – Subcutaneous Insulin Infusion (Insulin Pump Therapy) for Diabetes

<http://www.nice.org.uk/page.aspx?o=58213>





# Key criteria that a structured education programme should meet to fulfil the NICE requirements

## Philosophy

The programme will be evidence based, flexible to the needs of the individual and dynamic; users should be involved in its on-going development. The programme should have a specific aim and learning objectives which are shared with patients, carers and family. The programme should support self management attitudes, beliefs, knowledge and skills for the learner, their family and their carers.

## A structured curriculum

The curriculum needs to:

- 1 be person centred incorporating the assessment of individual learning needs;
- 2 be reliable, valid, relevant and comprehensive;
- 3 be theory driven and evidence based;
- 4 be flexible and able to cope with diversity;
- 5 be able to use different teaching media;
- 6 be resource effective and have supporting materials;
- 7 be written down.

## Trained educators

Trained educators need to:

- 1 have an understanding of education theory appropriate to the age and needs of the programme learners;
- 2 be trained and competent in the delivery of the education theory of the programme they are offering;
- 3 be trained and competent in the delivery of the principles and content of the specific programme they are offering.

## Be quality assured

A Quality Assurance programme needs to be in place. The programme needs to be reviewed by trained, competent independent assessors who assess against agreed criteria the:

- 1 environment;
- 2 structure;
- 3 process;
- 4 content;
- 5 use of materials;
- 6 whether the programme has actually been delivered;
- 7 evaluation and outcome information.

## Be audited

The outcomes from the programme need to be audited. The outcomes might include:

- 1 biomedical;
- 2 quality of life;
- 3 patient experience;
- 4 the degree of self management achieved as a result of the programme.

# International learning standards for diabetes educators

There is a need for high quality education programmes to train healthcare providers in the skills to deliver structured patient education<sup>1</sup>. Different international approaches have been taken to developing health professional training courses.

The National Certification Board for Diabetes Educators (NCBDE) was formed in 1985 under the auspices of the American Association of Diabetes Educators, the main professional body in the United States for healthcare professionals involved in diabetes education. The main purpose of NCBDE is to administer and deliver the Certified Diabetes Educator (CDE) credential. This is obtained by passing an examination; individuals must re-certify every 5 years. Healthcare professionals who have the CDE can be reimbursed for diabetes education.

The benefits of the CDE in the American context are that it protects the public from unqualified individuals claiming to deliver (and charging for) diabetes education. A disadvantage is that it has the potential to separate diabetes education from clinical care. Patients will often be referred by a physician to an educator and may see that person at a different site with little interaction between the provider and the educator. Given that diabetes care is best delivered by a team approach (and this is one of the strengths of the NHS) it is unlikely that the CDE approach to accreditation would be the best model for the UK.

The IDF and ADA modules specifically relevant to the diabetes educator are outlined below.

## IDF – Specific training for the diabetes educator<sup>2</sup>

Module	
<p><b>The role of the diabetes educator</b></p>	<p><b>Overview:</b> Diabetes educators are an integral part of the diabetes management team. The role of the educator is to enable people with diabetes to manage their diabetes-related health to the best of their abilities, to allow them to make choices and take actions based on informed judgement, and to enhance the quality of life of the person with diabetes.</p> <p><b>Objectives – after completing this module, the diabetes educator will be able to:</b></p> <ul style="list-style-type: none"> <li>■ describe the role of the educator in their particular setting;</li> <li>■ discuss methods of increasing and maintaining their own skills and knowledge;</li> <li>■ discuss methods of collaboration with the interdisciplinary healthcare team;</li> <li>■ discuss the expanding clinical role of the diabetes educator in relation to the increasing prevalence of diabetes.</li> </ul>
<p><b>Team management</b></p>	<p><b>Overview:</b> this module aims to provide participants with the opportunity to consolidate their understanding of the social, educational, dietary and psychological requirements of people with diabetes and how they need to be met using an interdisciplinary approach. It emphasises the need to have blended rather than discrete roles and discusses the need to extend traditional roles if specialised team members, such as dietitians or podiatrists, are not available. The module also emphasises the importance of ongoing education in diabetes care for all team members and the establishment of common protocols and management goals.</p> <p><b>Objectives – after completing this module, the diabetes educator will be able to:</b></p> <ul style="list-style-type: none"> <li>■ discuss why interdisciplinary care and the overlap of professional roles are important in the management of diabetes;</li> <li>■ identify the various members working within an interdisciplinary team and their primary roles;</li> </ul>

Module	
	<ul style="list-style-type: none"> <li>■ discuss the importance of the person with diabetes in the team;</li> <li>■ discuss the role of the co-ordinator of the team;</li> <li>■ identify how the roles of different team members can overlap and interact;</li> <li>■ discuss the importance of interdisciplinary communication, including team meetings;</li> <li>■ identify the ongoing educational needs of team members to enable them to function in an interdisciplinary environment at their best capacity and to allow them to contribute to team initiatives;</li> <li>■ identify the person responsible for ensuring all members of the team have access to ongoing training in diabetes care;</li> <li>■ discuss the need for a common protocol to ensure all members of the team work towards the same goal and use a common framework to avoid confusing a person with diabetes, duplicating care or miscommunication;</li> <li>■ discuss the importance of respecting and evaluating the performance of all team members.</li> </ul>
<b>Teaching and learning</b>	<p><b>Overview:</b> teaching skills are integral to the role of the diabetes educator. Diabetes educators should do more than give out information; they should have a good understanding of the principles of the education process and be able to apply those principles in practice. Education is an ongoing process of assessment, planning, implementation and evaluation.</p> <p><b>Objectives</b> – after completing this module, the diabetes educator will be able to:</p> <p><b>Introduction and theory</b></p> <ul style="list-style-type: none"> <li>■ differentiate between teaching and learning;</li> <li>■ discuss barriers to teaching and learning;</li> <li>■ explain the benefits of patient education;</li> <li>■ discuss the principles of adult learning theory and therapeutic learning;</li> <li>■ identify ways in which children learn;</li> <li>■ give examples of how learning can be applied in practice.</li> </ul>

Module	
	<p><b>Assessment of learning needs</b></p> <ul style="list-style-type: none"> <li>■ describe the components of a learning needs assessment in the following key areas: demographical; cultural; attitudes and beliefs; environmental; psychological; current health practices; developmental stage; socio-economic resources;</li> <li>■ describe how to undertake a learning needs assessment;</li> <li>■ determine how to assess a person's readiness to learn;</li> <li>■ discuss the implications of a person's readiness to learn;</li> <li>■ identify three general styles of learning;</li> <li>■ identify the role of the family/support people in the education process.</li> </ul> <p><b>Planning</b></p> <ul style="list-style-type: none"> <li>■ discuss the need for programme content to be culturally sensitive;</li> <li>■ identify the difference between goals and objectives;</li> <li>■ discuss the three domains of learning: cognitive, affective and psychomotor;</li> <li>■ discuss the levels of learning within each domain;</li> <li>■ write accurate and concise behavioural objectives in each domain;</li> <li>■ discuss advantages and disadvantages of different teaching methods;</li> <li>■ select the teaching methods that respond best to different learning styles;</li> </ul> <p><b>Implementation</b></p> <ul style="list-style-type: none"> <li>■ describe how to use each teaching method most effectively;</li> <li>■ discuss how to manage group dynamics;</li> <li>■ demonstrate active listening skills;</li> <li>■ demonstrate the use of open-ended questions;</li> <li>■ demonstrate giving positive feedback;</li> </ul>

Module	
	<p data-bbox="512 309 1082 344"><b>Evaluation (see also evaluation module)</b></p> <ul data-bbox="512 360 1270 801" style="list-style-type: none"> <li data-bbox="512 360 1187 472">■ distinguish between different types of evaluation, structures, processes, content, outcomes, impact and programmes;</li> <li data-bbox="512 499 1270 611">■ discuss evaluation methods, including how to evaluate the programme and the participant's achievement of the learning goals;</li> <li data-bbox="512 638 1129 707">■ design an instrument to evaluate participant's impressions of the programme;</li> <li data-bbox="512 734 1166 801">■ discuss the barriers to conducting a programme evaluation.</li> </ul> <p data-bbox="512 835 900 871"><b>Health education materials</b></p> <ul data-bbox="512 887 1254 1301" style="list-style-type: none"> <li data-bbox="512 887 1241 956">■ identify the magnitude of illiteracy or low literacy in the specific community;</li> <li data-bbox="512 983 1254 1052">■ explain strategies for teaching patients with low literacy skills;</li> <li data-bbox="512 1079 1217 1149">■ assess educational materials for their readability and therefore appropriateness of use;</li> <li data-bbox="512 1176 1187 1245">■ develop health education materials for low literacy groups;</li> <li data-bbox="512 1272 1198 1301">■ develop health education materials for general use.</li> </ul> <p data-bbox="512 1335 799 1370"><b>Special populations</b></p> <ul data-bbox="512 1386 1270 1547" style="list-style-type: none"> <li data-bbox="512 1386 1238 1456">■ describe teaching strategies for people who are either visually or hearing challenged;</li> <li data-bbox="512 1482 1270 1547">■ discuss teaching materials that would be appropriate for people with disabilities or handicaps.</li> </ul>

Module	
<p><b>Psychological and Behavioural Approaches</b></p>	<p><b>Overview:</b> diabetes mellitus is a chronic condition that has a major impact on the lives of people with diabetes and their families. In children and adolescents, diabetes can interfere with normal psychological and social development and complicate family functioning. People with diabetes are faced with the challenge to self-regulate their diabetes while living a full, normal life. Learning to perform diabetes self-care activities and integrate these health behaviours in daily life, in the face of other responsibilities and life stresses, is psychologically complex and burdensome. Acute and chronic diabetes complications can negatively affect the person's well-being and role functioning. People cope differently in their ability to cope effectively with the demands of diabetes self-management. Therefore, educators need, not only teaching skills, but also skills in approaches to behavioural change and motivational interviewing.</p> <p><b>Objectives – after completing this module, the diabetes educator will be able to:</b></p> <ul style="list-style-type: none"> <li>■ describe the psychosocial impact of diabetes and its treatment on the person with diabetes and individual family members;</li> <li>■ identify professional attitudes and behaviours that are helpful/harmful to people with diabetes;</li> <li>■ recognise that: adjustments to diabetes is ongoing and needs to be addressed both in the early stages and throughout the life-cycle; living with diabetes requires changes to lifestyle that are difficult for most people with diabetes; diabetes-related stress is common, particularly fear of hypoglycaemia and long-term complications; people can use different cognitive and behavioural strategies to cope with the demands of diabetes and treatment-related stresses;</li> <li>■ discuss cognitive, emotional, behavioural and social barriers to self-care and other strategies to address these barriers;</li> <li>■ identify and offer appropriate emotional and behavioural support to people with diabetes and their families within the context of diabetes education;</li> </ul>

Module	
	<ul style="list-style-type: none"> <li>■ discuss theories of behavioural change, including the role of motivation, and incorporate appropriate theories into diabetes education programmes;</li> <li>■ develop skills to incorporate appropriate behavioural approaches into clinical practice to effect change in a person with diabetes;</li> <li>■ have knowledge of prevalent psychological disorders among people with diabetes that warrant special attention and specialised mental healthcare (e.g. depression, anxiety, eating disorders, substance abuse) and understand the impact on emotional well-being, self-management behaviours and clinical outcomes;</li> <li>■ discuss community understanding and attitudes to diabetes;</li> <li>■ discuss the support services available to people with diabetes and their families.</li> </ul>
<b>Self-management</b>	<p><b>Overview:</b> self-management is the cornerstone of overall diabetes care. Optimal outcomes can only be achieved if the person with diabetes is willing to, and capable of, self-regulating their condition on a daily basis for life. While the increase in technology gives people more tools to manage their condition, it also increases the burden on, and expectations of, people with diabetes.</p> <p><b>Objectives – after completing this module, the diabetes educator will be able to:</b></p> <ul style="list-style-type: none"> <li>■ discuss the impact of living with diabetes;</li> <li>■ assist a person with diabetes in becoming competent with self-care behaviours appropriate to his/her needs, e.g. urine and blood glucose monitoring, need for annual complication assessment;</li> <li>■ inform the person with diabetes of his/her personal targets for treatment, e.g. blood glucose, lipid values, blood pressure, HbA1c, albumin excretion status, meal planning and activity;</li> <li>■ recognise and assess barriers to self-care;</li> <li>■ promote self-care as integral to effective management;</li> </ul>

<p><b>Module</b></p>	<ul style="list-style-type: none"> <li>■ adopt a flexible approach to the education and management of individuals;</li> <li>■ recognise that individuals manage their diabetes in different ways;</li> <li>■ prepare the young person for transition from the paediatric setting to the adult environment;</li> <li>■ teach people the importance of regular contact with both the medical practitioner and the allied members of the healthcare team and the need for regular education updates;</li> <li>■ give the person the self-confidence to advocate for their rights when dealing with health professionals.</li> </ul>
<p><b>Evaluation</b></p>	<p><b>Overview:</b> evaluation is a process by which practice can be justified. Evaluation can be used to assess learning, assess and improve the practice of healthcare professionals, assess the programme's viability and justify expenditure. All diabetes educators should understand that evaluation is integral to programme planning and should be incorporated into the education plan from the beginning. Teaching should be evaluated both at the individual level (did the person learn/make the behavioural change?) and at the programme level (did the programmes meet the needs of the participants?).</p> <p><b>Objectives – after completing this module, the diabetes educator will be able to:</b></p> <ul style="list-style-type: none"> <li>■ identify the purpose of evaluation;</li> <li>■ discuss how to evaluate an individual's learning, i.e. open-ended questioning, return demonstration, story telling;</li> <li>■ describe the difference between formative and summative evaluation;</li> <li>■ give examples of methods to conduct structure, process and outcome evaluation;</li> <li>■ discuss the importance of using validated questionnaires;</li> <li>■ discuss the use of skills checklists;</li> <li>■ discuss the importance of making evaluation a positive experience for the participant and not a threatening one.</li> </ul>

## ADA/AADE – National Standards for Diabetes Self Management Education

The National Standards for Diabetes Self-Management Education are designed to define quality diabetes self-management education that can be implemented in diverse settings and will facilitate improvement in health care outcomes. The standards provide a benchmark for quality assessment of Diabetes Self-Management Education.

**Standard #6:** The DSME instructors will obtain regular continuing education in the areas of diabetes management, behavioral interventions, teaching and learning skills, and counseling skills.

### Review Criteria:

### Indicator(s):

*a. If the instructor is a CDE, the certificate serves as documentation of the continuing education.*

1) Copy of CDE certificate is reviewed and is current.

*b. The non-CDE instructors will obtain continuing education in the areas of diabetes management, behavioral interventions, teaching and learning skills and counseling skills.*

1) Validate 6 hours/year of approved continuing education credits in the annual status report.

**Standard #7:** A written curriculum, with criteria for successful learning outcomes, shall be available. Assessed needs of the individual will determine which content areas are delivered.

<b>Review Criteria:</b>	<b>Indicator(s):</b>
<i>a. A written curriculum, with criteria for successful learning outcomes, is the basis for the DSME program.</i>	1) Validate that the curriculum and/or course materials contain the following 10 content area and learning objectives: <ul style="list-style-type: none"> <li>■ Diabetes disease process</li> <li>■ Nutrition</li> <li>■ Physical activity</li> <li>■ Medications</li> <li>■ Monitoring/using results.</li> <li>■ Acute complications.</li> <li>■ Chronic complications.</li> <li>■ Goal setting and problem solving</li> <li>■ Psychosocial adjustment</li> <li>■ Preconception care, pregnancy, and GDM (if applicable)</li> </ul>
<i>b. There is an annual review and revision of the curriculum.</i>	1) Documentation of review and revisions are up-to-date e.g. learning objectives, course outlines, handouts, A/V aides.
<i>c. Instructional materials support the curriculum.</i>	1) Review samples of the instructional material to ensure they support the curriculum.

<sup>1</sup> WHO Working Group 1998, *Therapeutic Patient Education: continuing education programmes for healthcare providers in the field of prevention of chronic diseases*, World Health Organization, Copenhagen.

<sup>2</sup> IDF Consultative Section on Diabetes Education (DECS) 2002, *International Curriculum for Diabetes Health Professional Education*, International Diabetes Federation, Brussels.

<sup>3</sup> Further information is available at <http://www.diabetes.org/for-health-professionals-and-scientists/recognition/edrecognition.jsp>









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