Health and Social Care Committee
Inquiry into the implementation of the National Service Framework for diabetes in Wales and its future direction
DB 24 Welsh Board BDA and the Welsh Dietetic Leaders Advisory Group

02/11/12

To examine the progress made on implementing the national service framework for diabetes in Wales across the local health boards and its adequacy and effectiveness in preventing and treating diabetes in Wales

Bwrdd Cymru BDA and the Welsh Dietetic Leaders Advisory Group would like to thank you for the opportunity to respond to the above Health and Social Care Committee inquiry.

Nutrition is the cornerstone of the management of long term conditions such as diabetes and dietitians are working across all areas of the diabetes care pathway from prevention and community health services through to specialist tertiary services.

Dietitians are playing a key role in empowering people and supporting self care for the people in Wales through delivery of structured patient education programmes.

The All Wales Diabetes Forum, of which dietitians are members, highlighted in a recent report (See Appendix) the key role of structured education for those with diabetes and despite the existing evidence of its benefits and the importance of this being detailed in key policy documents in Wales, recommendations regarding this remain unmet.

Diabetes is estimated as costing 10% of the NHS budget. 150,000 people are known to have diabetes in Wales. There are approximately 7,000 new cases of diabetes each year, equating to a 5% annual increase.

The paper highlights that there is a large body of research which demonstrates that structured diabetes education has been shown to lead to more effective self management and more specifically improvements in glyceamic control, HbA1c, total cholesterol and reduction in BMI.

There are several nationally recognised structured education programmes for diabetes, all of which demonstrate improvement in patient outcomes and associated cost benefits.

For example the DAFNE programme for Type 1 education has shown that overall there is a potential cost saving of £2,237 per patient over 10 years. The DAFNE programme is cost neutral at 4.5 years post intervention.(ref:www.dafne.uk.com)

Based on audit data, for X-PERT (programme for Type 2 diabetes)one organisation delivering X-PERT to 432 people with diabetes in one year could save £28,643 per year. The 2011 X-PERT Audit of 16,031 participants demonstrated that national implementation of the X-PERT Diabetes Programme could result in a cost saving to the NHS of £367 million per annum (Deakin 2011).

From the X-PERT national data the following results were demonstrated:

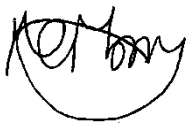
- HbA1c reduced by 0.5% at six months and by 0.6% (7mmol/mol) at 1 year.
- Weight loss 2.4kg at six months and 3.1 kg at 1 year.
- Lipids 0.4 mmol/l reduction (total & LDL)

(ref: www.xperthealth.org.uk)

The Diabetes NSF recommends that all people with diabetes have access to structured education. In current practice structured diabetes education appears to be viewed as a bonus element for a person with diabetes, often being considered when problems arise or as a last resort. A shift in attitude is required so that access to a programme is embedded as a mandatory component of the diabetes plan of care from diagnosis.

We would be grateful for feedback to this and to be informed of any further consultation.

Yours sincerely



BDA Policy Officer

The British Dietetic Association, founded in 1936, is the professional association for registered dietitians in Great Britain and Northern Ireland. It is the nation's largest organisation of food and nutrition professionals with over 6,000 members.

Registered dietitians are the only qualified health professionals that assess, diagnose and treat diet and nutrition problems at an individual and wider public health level. Uniquely, dietitians use the most up to date public health and scientific research on food, health and disease, which they translate into practical guidance to enable people to make appropriate lifestyle and food choices.

Dietitians are the only nutrition professionals to be statutorily regulated, and governed by an ethical code, to ensure that they always work to the highest standard. Dietitians work in the NHS, private practice, industry, education, research, sport, media, public relations, publishing, Non Government Organisations and government. Their advice influences food and health policy across the spectrum from government, local communities and individuals.

Structured Diabetes Education Wales 2011

Structured Diabetes Education is an essential component of patient care, without which all clinical interventions are undermined. A failure to adequately resource the provision of structured education for diabetes is unacceptable in the modern NHS in Wales, where both patient welfare and clinical excellence are non-negotiable

Executive Summary

1. There are 153,000 people with diabetes in Wales. Approximately 15,000 (10%) have Type 1 diabetes and 138,000 (90%) have Type 2. This equates to 4.9% of the population. An estimated 350,000 people have pre-diabetes in Wales (higher than normal blood glucose levels).

2. Diabetes costs NHS Wales £500m each year. This equates to 10% of the total NHS Wales budget. The vast majority of the cost is due to diabetes complications, which account for 80% of the total.

3. There have been approximately 7,000 new diabetes cases annually in Wales equating to a 5% annual increase. Diabetes is putting an increasing strain on health budgets. Diabetes will cost NHS Wales £1bn by 2025.

4. Poorly managed diabetes is associated with serious complications such as stroke, kidney disease, blindness and amputations that contribute a substantial financial cost to diabetes care as well as a significant impact on the quality of life for the individual.

5. 80% of people with diabetes do not comply with all aspects of their management plan. 5% of the population have diabetes but account for 15%-20% of hospital inpatients with a greater length of stay in hospital and more complex admissions.

6. Structured Diabetes Education delivered to groups of people with diabetes is the key facilitator for improved diabetes awareness and improvements in self management. A more informed and confident diabetes patient leads to fewer primary care consultations, reductions in visits to outpatient departments, reduced hospital admissions and a reduced length of stay in hospital.

7. The National Service Framework for Diabetes in Wales, the All Wales Consensus Guidelines and NICE Technological Appraisals provide clear guidance on the provision of Structured Diabetes Education. The guidance is not being followed.

8. In current practice, Structured Diabetes Education appears to be viewed as a ‘bonus’ element for a person with diabetes, often being considered when problems arise or as a last resort. A shift in attitude is required so that access to a programme is embedded as a mandatory component of the diabetes plan of care from diagnosis and beyond.

9. A large body of research has demonstrated that Structured Diabetes Education has been shown to lead to more effective self management and more specifically improvements in glycaemic control, HbA1c, total cholesterol and reductions in BMI.

10. All Health Boards have waiting lists for courses but in some localities no programmes are available. 2.7% of people with Type 1 diabetes and 1.4% of people with Type 2 diabetes were able to access a Structured Diabetes Education programme last year. Provision of Structured Diabetes Education in Wales would need to be tripled to meet only newly diagnosed cases annually.

11. All those with newly diagnosed Type 2 diabetes should have Structured Diabetes Education offered and delivered within 1 year of diagnosis. Those with newly diagnosed Type 1 diabetes should have Structured Diabetes Education offered and delivered as soon as possible but definitely within 6 months of diagnosis. In addition, provision needs to be retained for the existing Type 2 diabetes population. This is a minimum standard and should be implemented by April 2013.

12. Subsets of the existing Type 1 diabetes population have been identified and should be prioritised.

Diabetes Mellitus

Diabetes is one of the most common chronic disorders in the UK and it affects people of all age groups.

There are two main types of diabetes: Type 1 and Type 2. Type 1 diabetes is most commonly diagnosed in childhood or in young adults but can occur at any age. Without insulin the condition is usually fatal and those with diabetes must therefore self-inject insulin. Insulin must be carefully balanced to prevent the blood glucose being too high which raises the risk of life-threatening and disabling complications and to prevent the blood glucose being too low which may cause life-threatening hypoglycaemia. Those with type 1 diabetes must learn these balancing skills themselves.

Type 2 diabetes can progress slowly and with no obvious symptoms. Herein lies one of its grave dangers: at the time of diagnosis, around half of people with type 2 diabetes have unwittingly sustained tissue damage. The role of structured education in type 2 diabetes is to enable understanding of the condition, to promote healthy eating, exercise, weight loss and to empower the inclusion of these lifestyle changes in daily lives. This is the cornerstone of management of type 2 diabetes and without this; other expensive measures are often ineffective. In cases where blood glucose control is not being achieved through diet, weight control and exercise, treatment with tablets will commence. Ultimately, people with poor control of their type 2 diabetes will progress to insulin treatment. 20% of people manage on diet and exercise alone. 80% take medication: 50% take hypoglycaemic agents and 30% take insulin.

Both type 1 diabetes and type 2 diabetes are associated with devastating complications which are a heavy burden for the individual. Diabetes remains the commonest cause of blindness in the under 65's; it is the commonest reason for starting dialysis for kidney failure; it is the commonest cause of non-traumatic amputation. The risks of all these devastating complications may be reduced by good control of diabetes.

Diabetes in Wales

There are 153,000 people with diabetes in Wales. Approximately, 15,000 (10%) have Type 1 diabetes and 138,000 (90%) have Type 2. This equates to 4.9% of the population. 1,373 children and young people have diabetes in Wales (97% have Type 1 and 3% Type 2). An estimated 350,000 people have pre-diabetes in Wales (higher than normal blood glucose levels). This group has a fifteen times higher likelihood of developing Type 2 diabetes than the general population.

QOF data has shown a significant and consistent increase in prevalence each year. There have been approximately 7,000 new diabetes cases annually in Wales equating to a 5% annual increase. Increases in Type 2 diabetes are due to an ageing population and rapidly rising numbers of overweight and obese people. The Welsh Health Survey 2009 showed 57% of the welsh population are overweight or obese. In some respects, this upward trend is a global phenomenon. The World Health Organisation predicts a doubling of Type 2 diabetes between 1995 and 2025.

Some parts of Wales will be more adversely affected than others. Type 2 diabetes records higher prevalence levels in deprived communities and is more common in people of South Asian, African and African Caribbean origin. Up to 25% of people of Asian origin aged >60 have diabetes.

Diabetes Complications

Poorly managed diabetes is associated with serious complications that contribute a substantial financial cost to diabetes care as well as a significant impact on the quality of life for the individual.

- Cardiovascular disease is the leading cause of death in people with type 2 diabetes. Around 80% will die, many prematurely, as a result of heart attack or stroke
- 5% of the population have diabetes but account for 15-20% of hospital inpatients with a greater length of stay in hospital and more complex admissions.
- People with diabetes have a 2x higher risk of experiencing a stroke
- 1 in 3 people with diabetes will develop kidney disease; diabetes is the most common reason for starting dialysis.
- Diabetes is the leading cause of blindness in people of working age
- People with diabetes are 15x more likely to have an amputation

The Cost of Diabetes

Diabetes costs NHS Wales £500m each year. This equates to 10% of the total NHS Wales budget. At the current rate of increase in prevalence, it will cost £1bn by 2025.

The vast majority of the cost is due to diabetes complications, which account for 80% of the total. Average daily bed stay costs approx £215, a first amputation costs £6,535, and dialysis for the year costs £22,224

Diabetes medication costs approximately 7% of the total. In diabetes treatment, Glycaemia treatment such as Metformin costs £29 per year and Glitazone £337 - £516. Evidence suggests that the costs of medication are rising. Prescription of Metformin has increased by 73% in England in the last five years and there was an 89% increase in prescribing costs in England for type 2 diabetes between 1997 and 2007. Newer therapies now approved by NICE will increase the cost of diabetes medication significantly.

Self Management: the place of Structured Diabetes Education

Diabetes UK regularly surveys people with diabetes to ascertain how they are living with diabetes. A recent survey explored issues relating to self management.

- 60% of respondees did not understand their diagnosis or medication
- 65% did not take medicines as prescribed
- 80% did not comply with all aspects of their management plan.

People with diabetes only spend on average 3 hours per year with a health professional. They subsequently have to assume responsibility for the day to day management of their condition for the remaining 8,757 hours of the year. It is vital therefore that they have access to structured education programmes that aim to improve their knowledge, skills and confidence thus enabling them to take increasing control of their condition and integrate self management into their daily lives.

Appendix 1 - Effective approaches to Self care

Structured education is a key component for imparting knowledge and facilitates the utilisation of other self care methods – self management, lifestyle, food and exercise. It unlocks these approaches and enables their use.

It can facilitate a better understanding of how diet, exercise, lifestyle, blood glucose monitoring and medication can be used to control the condition. It enables improved

response to acute complications like hypoglycaemia, hyperglycaemia and inter-current illness. All three are significant health events requiring unscheduled/emergency healthcare.

Put simply, structured education is the key facilitator for improved diabetes awareness and improvements in a self management plan. A more informed and confident diabetes patient can lead to:

- More purposeful dialogue between the person with diabetes and the health professional
- Individualised and negotiated goal setting
- Fewer primary care consultations
- Reductions in visits to outpatient departments
- Reduced hospital admissions
- Reduced length of stay in hospital

Central Mandates for the Provision of Structured Education

The importance of structured education is underpinned by the emphasis placed on this in the following documents:

- National Service Framework for Diabetes (2003)
- The NICE Quality Standards for Diabetes (2011)
- The Technology Appraisal of Structured Education in Diabetes TA60 (2003)
- All Wales Consensus Guidelines for Diabetes (2008)
- All Wales Guidelines – Children and Young People (2007)
- The Health Foundation's Co-creating Health Model ©
- Improving Health & Wellbeing in Wales: Framework for Supported Self Care (2008)

National Service Framework
Standard 3.1

„Develop programmes to strengthen and support self care management to help empower all people with diabetes to maintain a healthy lifestyle. The Welsh Assembly Govt delivery strategy advocates the implementation of a structured education plan based on a self help programme for all people with diabetes".

NICE Guidance
NICE Quality Standards Programme (March 2011)

Thirteen standards of care were articulated for those with diabetes which will provide high quality, cost effective care. The first standard is structured education, "People with diabetes and/or their carers receive a structured education programme that fulfils the nationally agreed criteria from the time of diagnosis, with annual review and access to ongoing education"

NICE Technology Appraisal TA60 2003
(NICE) technical appraisal 60 'Guidance on the use of Patient Education Models for Diabetes', April 2003, reinstated in Wales in 2005 www.nice.org.uk/TA60 and NICE Clinical Guideline CG87 update 2008

„It is recommended that structured patient education is made available to all people with diabetes at the time of initial diagnosis and then as required on an ongoing basis, based on a formal, regular assessment of need." Sixth months is considered a reasonable expected time frame for NICE Technology Appraisals to be implemented

Designed for the Management of Adults with Diabetes Mellitus across Wales - Consensus Guidelines (Oct 2008)
Type 1 Diabetes / Type 2 Diabetes

All people with type 1 / type 2 diabetes need to have access to up-to-date and appropriate information to facilitate self-management. Systems need to be in place to ensure people with type 1 /type 2 diabetes have timely access to group (stage 5a) and/or one-to-one (stage 5b) education programmes dependent on individual need.

Designed for the Management of Type 1 Diabetes in Children and Young People in Wales: Consensus Guidelines – Standards 5&6: Diabetes National Service Framework for Wales (WAG 2007)

Successful education instils knowledge, but must also empower and motivate young people to use knowledge and practical skills in problem solving and self management. Diabetes education for children and young people needs to be:

Structured	Evaluated
Evidence-based	Inclusive and accessible
Adaptable and age appropriate	Delivered by specialists
Individualised	Continuous and lifelong

The Health Foundation's Co-creating Health Model©

It aims to achieve measurable improvements in the quality of life of people living with long term conditions and improve their experience of health services by embedding self management support within mainstream health services

Appendix 2 - How to better integrate a patient centred approach in the Care Pathway

Improving Health & Wellbeing in Wales: Framework for Supported Self Care (2008)

Self management education has been associated with improvements in knowledge, coping behaviour, treatment adherence, self efficacy and symptom management. There is a need to mainstream self care and ensure that a range of options are available to meet differing needs and are easily accessible to those in need

Appendix 3 – Framework for supported self care

Structured Education in Wales for those with Type 1 Diabetes

Structured Diabetes Education enables those with type 1 diabetes to self-manage their diabetes and as such is recognised as the corner-stone of diabetes care. It equips the person with type 1 diabetes with the skills and knowledge to calculate the required dose of insulin and to take account of activity levels. This leads to improved glycaemic (glucose) control with reduced insulin requirement, reduced hypoglycaemia and improved quality of life. These benefits have a marked impact for the individual and also healthcare provider, becoming cost neutral and subsequently cost saving.

Failure to provide this education results in poorer glycaemic (glucose) control with the subsequent increased risk of complications, increased risk of hypoglycaemia with the subsequent morbidity and increased mortality risk and reduced quality of life with incorrect insulin doses resulting in erratic blood glucose control and loss of freedom to participate in exercise and an unrestricted diet.

- ***DAFNE (Dose Adjustment for Normal Eating)*** is a five-day (38 hour) evidence based, NICE approved programme for people with type 1 diabetes. This programme is provided in 141 localities in the UK and Southern Ireland. The programme encourages the development of self management skills including carbohydrate counting, and equips the person with type 1 diabetes to determine the specific insulin requirements in a range of situations.

- ***WIDAC (Wrexham Insulin Dose Adjustment Course)*** and **DAFYDD (Dose Adjustment for Your Daily Diet)** are programmes for type 1 diabetes offered by some Health Boards in Wales based on the Bournemouth model (BIDAC). The programmes encourage skill acquisition in carbohydrate counting and insulin dose adjustment.

In Wales two centres provide DAFNE, one centre provides BIDAC, the other WIDAC. Others provide DAFYDD, derived BIDAC programmes. Some Health Boards provide no structured education for type 1 diabetes.

Structured Education in Wales for those with Type 2 Diabetes

As for people with Type 2 diabetes, Structured Diabetes Education is the cornerstone to achieving effective self management of the condition. Understanding the importance of controlling glucose, lipids and blood pressure coupled with the importance of healthy eating, exercise, weight loss and smoking cessation is critical to the prevention or minimisation of complications while optimising the person's quality and quantity of life.

- ***XPERT*** is a 6 week course (2.5 hours each session) for Type 2 diabetes which focuses on diet, medication and lifestyle adjustment. It is the most widely delivered programme for people with Type 2 diabetes in the UK

- **DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed)** is a 6 hour programme delivered over one or two days. Desmond is designed for people with newly diagnosed Type 2 diabetes, which covers diet, activity, lifestyle and medication. There are two additional DESMOND programmes that are not currently being delivered in Wales: DESMOND Foundation for people with established diabetes and DESMOND BME intended to be delivered in minority languages

Both DESMOND and XPERT are evidence based and meet the NICE guidelines on Structured Diabetes Education.

Structured Diabetes Education for Children and Young People

It is recommended that the care of children and young people with diabetes is delivered by an interdisciplinary paediatric diabetes team comprising, at a minimum, a consultant paediatrician with an interest in diabetes, a paediatric diabetes specialist nurse (PDSN) and a paediatric dietician with an interest in diabetes (Welsh Assembly Government 2007).

Ideally, the team should also include a child psychologist, a podiatrist and a social worker. The role of the team includes the provision of education and support to facilitate self-care in diabetes management by children and their families. Diabetes education from the paediatric diabetes team is on-going from diagnosis until the child moves to the adult services, because needs change at different stages of growth and development.

The target HbA1c for children and young people with type 1 diabetes is <7.5% (National Institute for Clinical Excellence [NICE] 2004) but this is often not achieved. A national audit of paediatric diabetes (the NHS Information Centre, 2010) identified

that, in Wales, there are worryingly higher rates of diabetic ketoacidosis (DKA – a life-threatening emergency) and a lower percentage of children with HbA1c ≤7.5% when compared to England.

Children with diabetes and their parents often struggle to achieve the complicated balance between carbohydrate intake, exercise and insulin requirements, which results in variable blood glucose levels. Hyperglycaemia (blood glucose levels >10mmol/L), which can occur for no apparent reason, causes feelings of frustration and concern, particularly in relation to diabetes-related complications. A fear of hypoglycaemia (blood glucose levels <4mmol/L), particularly nocturnal or severe hypoglycaemia, is overwhelming for both children and parents. Severe hypoglycaemia can be avoided to an extent but most children and young people will experience mild or moderate hypoglycaemic episodes, particularly if tight glycaemic (glucose) control is achieved, which is one reason why the target HbA1c of <7.5% is difficult to attain

National guidance recommends structured education programmes for children and young people with diabetes (Department of Health and Diabetes UK, 2005) but there are no validated structured education programmes that incorporate the specific needs of this population.

- Three programmes are currently being assessed and evaluated: KicKoff, FACTS, CASCADE
- The NHS Diabetes Paediatric Education Task and Finish Group are developing a programme for self-management in this age group, using findings from the EU SWEET Project (Waldron *et al*, 2011).

Northern Ireland and the Borders have made structured education mandatory for children and young people, adopting the CHOICE programme and employing more PDSNs and dieticians to deliver the programme.

Findings from a survey of Welsh paediatric diabetes clinics give cause for concern. Three clinics are delivering in-house courses that are not validated, and 8 have either discontinued courses or been unable to implement them due to a lack of nursing and dietetic time. Clinics that have implemented a structured education programme have approximately 5 sessions of dietetic input per 160 children.

Efficacy of Structured Diabetes Education

DAFNE
The DAFNE programme is in a unique position of having a solid evidence base and economic analysis. The programme has been shown to lead to significant improvements in:

- glycaemic control
- quality of life
- psychological wellbeing
- treatment satisfaction. (3,4,5,6,7).

DAFNE has an enduring effect on glycaemic control which will subsequently reduce the micro-vascular complication rate with this cost offset by the cost of delivering DAFNE and increased frequency of insulin injections.

- Overall, there would be a potential cost saving of £2237 per patient over 10 years
- The DAFNE programme would be cost neutral at 4.5 years post intervention.
- A DAFNE cost effectiveness study was published in 2004 (2).

DESMOND

- It has been shown to be a low cost and cost effective intervention
- It has demonstrated reductions in weight, depression, smoking and BMI.

X-PERT
The programme has demonstrated statistically significant improvements in:

- HbA1c (overall glucose control)
- total cholesterol
- in body weight
- BMI.
- It has also shown some patients can reduce medication and that patients are less likely to require increases in medication when compared to control groups.

Many research studies acknowledge the benefits of a patient-centred approach to health care and the importance of supporting and facilitating effective self management for long term conditions such as diabetes. Research has demonstrated that group interventions are more effective than 1-2-1 interactions.

Structured Diabetes Education: Provision in Wales

Based upon the information received following the Freedom of Information request made in August 2010:

	Type 1 Diabetes	Type 2 Diabetes	Comments
No of Courses Delivered	**51**	**182**	The provision and delivery of Structured Diabetes Education does not enjoy a dedicated resource. For this reason, services have developed along different lines within each Health Board. Organisational restructure has highlighted inequity of SDE availability
No of Individuals Accessed Course	**422**	**1907**	
Equates to % of people with Type of diabetes in Wales	**2.7%**	**1.4%**	
Equitable Access in all Health Boards	**No**	**No**	

3,900 people with type 1 diabetes (26%) of the total population have no course provision in their locality.

Service provision is largely ad-hoc, is not clearly established or secured in many areas and there appears to be no long term planning for the delivery of SDE.

Provision of courses would need to be tripled to meet on only newly diagnosed cases for the twelve month period assessed.

Appendix 4 – Course delivery (health boards / health boards & localities)

Structured Diabetes Education: Staff resource and capacity

Structured Diabetes Education: Staff Resource & Capacity			
	Type 1 Diabetes	**Type 2 Diabetes**	**Comments**
Recurring Resource	No. Mostly within resource development from Diabetes Specialist Teams	No. One example of SDE planned into resource for Community Diabetes Service (Torfaen). Temporary contracts or within resource / service restructure predominates	**Improving Efficiency** Evidence that where admin support does

WTE Diabetes Specialist Nurse correlated to % prevalence of Diabetes	No	No	exist, course promotion and data management activities maximise the Educator time and capacity for course delivery. Data collection activities are more robustly managed where consistent admin support is defined
WTE Diabetes Specialist Dieticians correlated to % prevalence of Diabetes	No	No	
Evidence of Non-Diabetes Specialists providing SDE	Type 1 Diabetes SDE – All Specialist delivery	Evidence that generic dieticians and Practice nurses are accredited to deliver SDE for Type 2 SDE programmes	
Admin Support	Some evidence (eg DAFNE) no defined resource in other areas	Responses report loss of admin support for Type 2 programmes affecting the number of courses organised, delivered and data collected	

Further information on recommendations for future staffing resource and capacity are included in the appendix.

Appendix 5 – Staff resource and capacity

Structured Diabetes Education: Course Delivery

Structured Diabetes Education programmes have been delivered in health boards for between 3-5 years and in that time, generic models of delivery have been gradually adapted to meet local needs and to some degree staff resource. In some instances, this has led to programmes being delivered over a shorter timeframe than if the standard model were followed or some aspects of the course not being followed. These adaptations are inconsistent with the available evidence base for specific courses and have become an unsatisfactory compromise for service providers.

Where DESMOND has been provided in Wales, there have been responses that it is most suitable for newly diagnosed Type 2 diabetes. It was originally designed for this purpose. The DESMOND group have now developed an additional course 'DESMOND Foundation' for people with established diabetes but as yet this is not being delivered in Wales

Patients are made aware of courses available through a number of channels. In addition to clinical referral (by consultant, DSN, dietician or GP), many health boards also use more standard marketing techniques such as posters and flyers in local health and community venues. Many health boards find that they have long waiting lists but they also experience quite high DNA rates. Often groups are overbooked to ensure they run at full capacity.

Health Professionals often view SDE as a bonus element for a person with diabetes' care; often referring when problems arise, or as a last resort. A shift in attitude is required for Health Professionals to refer to SDE as an integrated component of the diabetes plan of care and to convey the responsibility that the person with diabetes has to acquire self management skills. Some centres offer participant accreditation by linking the course completion to an Agored Cymru (formally known as Open College Network) award.

Lack of access to health board venues is an issue in some areas and costs can be high if external venues are required. There is evidence that where Primary Care venues have been utilised by diabetes educators, the referral rate to the programme and patient engagement has increased. These venues are offered free of charge in recognition of the benefit to the person with diabetes and the drive to support locally accessible condition specific structured group education.

A number of staff directly involved in Structured Diabetes Education delivery desire a more centrally co-ordinated programme of delivery within each health board area. A hub and spoke approach for Health Boards may offer the opportunity to offer a more cohesive service.

Appendix 6 – Course delivery

Structured Diabetes Education: Training & Quality Assurance

Training and quality assurance are essential components of structured education to ensure that the courses delivered continue to be evidence based and of the required standard. Educator training has been accessed by health professionals in Wales since 2005. Not all trained educators continue to deliver the programmes due to changes in workforce, and there is evidence to suggest that not all active educators have accessed the necessary programme update sessions. Elements of their course delivery may therefore be outdated and remain unrevised. The cost of updates and releasing staff may be contributory factors.

External peer review is a mandatory component for DAFNE and is directly linked to initial and ongoing accreditation, for both the DAFNE centre and each individual educator. An educator is required to deliver a minimum of 2 courses per year and provide evidence of critical reflection within their portfolio. Each DAFNE centre must send a representative to the DAFNE network and collaborative meetings to maintain accreditation. Data input for every course participant is mandatory.

XPERT does have quality assurance and audit / monitoring systems available but they are not routinely utilised and the ongoing accreditation/review process is currently not mandatory but seen as best practise. The central XPERT database team produce an annual data report for each area. These results can be compared to other providers.

DESMOND providers are externally peer reviewed as part of the DESMOND mandatory programme. External peer reviews take place after 6 months then again at 3 years. For other programmes (Bournemouth based / locally developed models), peer review is provided internally or by a neighbouring provider.
There are attempts by course providers to populate the required databases; however there is evidence that data input has been compromised or even stopped in some centres due to loss of administrative support.

Most educators report that they would like to improve their review, audit and evaluation systems, and see this as a necessary requirement of the SDE services provided; however, they are restricted from achieving this objective by the lack of administrative resource, a lack of secured funding for educators and a budget to ensure educators are updated.

There is no central process in Wales to monitor the rate or quality of programmes delivered

Appendix 7 – Training and quality assurance

Structured Diabetes Education: Funding

In the majority of health boards, funding streams are not clear and not ring-fenced. In consequence, SDE courses across health boards receive funding from a range of sources; some from core funding, some aligned with staff resource but not all costs, and in some cases charitable funds or pharmaceutical company money is used to aid delivery of programmes.

Staff have reported a desire for funding clarification and if possible agreed budgets to enable longer term planning. Dietetic input particularly suffers without an identified resource stream.

Some health boards have lost admin support and almost unanimously, staff report that this is a false saving. Admin support is essential to free up the DSN and dietetic resource so it can be used more effectively. Course educators often undertake lower band admin duties such as course planning, booking patients, and database management. This has a significant impact on the time spent delivering programmes.

Appendix 8 – Funding

KEY RECOMMENDATIONS

1. The Department for Health & Social Services and Health Boards should work towards the provision of Structured Diabetes Education for all with diabetes as recommended by the NSF, the Consensus Guidelines and NICE recommendations.

2. All those with newly diagnosed Type 2 diabetes should have Structured Diabetes Education offered and delivered as soon as possible but definitely within 1 year of diagnosis . This is a minimum standard and should be implemented by April 2013.

3. All those with newly diagnosed Type 1 diabetes should have Structured Diabetes Education offered and delivered as soon as possible but definitely within 6 months of diagnosis. This is a minimum standard and should be implemented by April 2013

4. Particular subsets of the existing diabetes population should be offered structured education. The impact of the condition on them and the benefits that can be achieved through better self management and a reduction in complications are irrefutable:
   - All those with type 1 diabetes with difficulties from hypoglycaemia should have Structured Diabetes Education offered and delivered within 1 year.
   - All those with type 1 diabetes being considered for insulin pumps should have Structured Diabetes Education offered and delivered within 1 year.
   - All those with type 1 diabetes planning pregnancy with an HbA1c > 7.0% should have Structured Diabetes Education offered and delivered within 1 year.
   - Young Adolescents in transition to adult services should have Structured Diabetes Education offered and delivered within 1 year.
   - Those with type 2 diabetes being considered for additional therapies e.g. introduction of oral hyperglycaemic agents or conversion to insulin therapy should have Structured Diabetes Education offered and delivered within 1 year.

5. Acknowledging high levels of demand for structured education in the existing diabetes population and almost all health boards reporting long waiting lists, in addition to the recommendations above, some provision of structured education needs to be ring-fenced to enable health boards to meet the needs of the existing population of people with diabetes.

6. Structured Diabetes Education programmes that are provided should meet NICE guidelines, be evidence based and have outcome data and evidence to show benefit (e.g. DAFNE programme, X-PERT programme, DESMOND etc). Each health board should determine which programmes are used in their area to best meet the needs of their population demographics.

7. All structured education programmes should be delivered by trained educators who have attended the relevant initial and update training sessions and undergo external peer review. Trained educators should be staff who provide diabetes care as a significant part of their role and who are skilled and confident in adult education principles and group management facilitation.

8. For children and people with Type 1 Diabetes trained educators must be specialised in the management of multiple dose insulin injection regimes in a range of situations and have sound knowledge of the role of carbohydrates on glycaemic (glucose) control, and a recognised qualification in adult education principles. It is recommended that SDE programmes for type 1 are delivered jointly by Diabetes Specialist Nurses and dieticians.

9. Quality Assurance and audit needs to be an integral part of the programmes provided.

10. A Wales wide evaluation of the impact of structured education conducted in 2013-2014 would provide important efficacy data for the Welsh Government, health boards and health practitioners. Agreement on a way forward for an IT system to capture intelligence, like SCI-DC in Scotland would help facilitate this. It would enable refinement of SDE delivery and better utilisation of resource applied to the area.

11. The provision of structured education in languages other than English is desirable in areas where a large population cohort does not or prefers not to speak English.

12. A small central administration and co-ordination team would be a highly cost effective and efficient means of creating a step change in the provision and availability of Structured Diabetes Education in Wales. A central team would ensure health board staff such as diabetes specialist nurses and dieticians could better focus on programme delivery and facilitate more rigorous and standardised audit and evaluation systems.

13. Work exploring the potential role of pharmacies across Wales in diabetes risk assessment, information provision/education and support should be considered in parallel with health board SDE provision to better achieve integrated diabetes care.

14. Structured education needs to be embedded in the care pathway for individuals with diabetes. Evidence supports that engagement increases when SDE is offered for people with Type 2 diabetes within the locality setting and is then seen by the individual with diabetes and the health professional as an integral part of the diabetes primary care plan.