

# Evidence Based Scan for My Health My Community (MHMC)

Pennine Care NHS Foundation Trust

Structured diabetes education programmes (SDEP) for children and young people,  
(CYP) their parents and carers

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## Executive Summary

### Structured Diabetes Education Programmes (SDEP) for Children and Young People, (CYP) their parents and carers

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#### Aims of the Evidence Based Scan

- To identify and appraise co-designed, robust, structured diabetes educational programmes (SDEP) for parents/carers and/or children/adolescents with Type 1 Diabetes Mellitus and Type 2 Diabetes Mellitus.
- To identify and report on any gaps in the educational programme developed by PCFT
- To provide guidance on the development of an initial questionnaire for carers for the evaluation of the educational programme

#### Methods

The approach taken is pragmatic and uses principles of 'evidence scans' as described by the Health Foundation (The Health Foundation 2010) and will be called an Evidence Based Scan (EBS) from here on. This approach provides information to help those involved in improving the quality of healthcare to understand what research is available on particular topics. The purpose is to provide a synopsis of evidence to help inform discussions and to help identify if there is need for further research or development in the area covered. It can also provide a rapid collation of empirical research about a topic.

A Flag system designed by the reviewer has been used to denote the levels and qualities of the programmes and initiatives. This appraisal is based on the evidence available and offers the reader a rapid reference guide to services and resources available or in development. The introduction explains UK paediatric and policies and guidelines for children and young people (CYP), what needs to be considered when planning structured diabetes education for this age group, and what elements help to increase the efficacy of such programmes.

Colour coded tables are the main source of information in this document. Following an overview of programmes, tables expand upon details of each programme and initiative and offer appraisals of these. In addition, there is a detailed section on '*Transition to adult care*' and programmes relating to this which are currently in development based on adult programmes.

## Findings

### Existing CYP programmes

Seven existing structured diabetes education programmes (SDEP) for CYP were identified and are described; BERTIE, CASCADE, CHOICE, DOLPHIN, FACTS, KICK-OFF AND WICKED (Acronyms are explained in the report). These covered age ranges from to 0 years to 25 including WICKED which is a transition to adult care programme. Many are co-designed and/or with feedback from CYP, their families and HCPs, with many being endorsed by organisations in the field of CYP diabetes care including NHS and European organisations.

Motivational Interviewing (MI) is an effective and non-coercive way of instigating behaviour change which can be learnt by lay and professionals alike. The evidence scan highlighted the lack of teaching skills of health care professionals (HCPs).

This is understandable, they are a completely different skill set to acquire in addition to clinical skills. A lack of these, however, can affect the delivery and efficacy of a SDEP. In section 3, existing SDEPs for HCPs have been described and appraised. These also include courses for parents. International diabetes Federation (IDF) and SWEET are the most important in this context. Other local /regional initiatives /interventions for HCPs will offer food for thought for PCFT development of multi-disciplinary teams.

Type 2 Diabetes is addressed with existing initiatives again being rooted in an additional existing adult programmes including DESMOND. CLAHRC Leicester Northamptonshire and Rutland has three on-going projects using this programme. Black, Asian, Minority Ethnic (BME) has been addressed; the main established adult programmes here comprising three additional programmes, DESMOND, IDF & X-PERT. CLAHRC South Yorkshire is a leader in this field regionally in this area. Available written materials for lay and professionals have been appraised. Awards given for work in Children and Young People diabetes have been described, as have e-health apps, some of which have a sound research base and are co-designed.

A mapping exercise of modules proposed by Pennine Care Foundation Trust using NHS recommendations, ISAD guidelines for SDEPs and suggestions from the author of this review is offered both in this document and in the form of an A1 poster. This is an aide memoire for PCFT to assess their provision, where there are gaps and how these can be filled. A final section takes into account all the above and offers detailed recommendations for setting up and running a successful, evidence based, quality, SDEP for CYP based on recent NHS, ISPAD guidelines. CYPs should be offered a “**good start**”, that is, this education should begin at diagnosis, be individual, age appropriate, family focussed and on-going. This has the potential to reduce the burden of diabetes, maintain optimum quality of life, and instil life time self-management skills and knowledge potentially resulting in a reduction of HbA1c and optimal glycaemic control.

From the Evidence Based Scan there are recognised and evaluated programmes both existing and in development which could assist PCFT in developing a complete educational programme for children and young people with diabetes, as part of My Health, My Community.

## **Structured Diabetes Education Programmes (SDEP) for Children and Young People (CYP), parents and carers.**

### **Aims of Phase 2a of the EBS**

- To identify and appraise co-designed, robust, structured diabetes educational programmes (SDEP) for parents/carers and/or children/adolescents with Type 1 Diabetes Mellitus and Type 2 Diabetes Mellitus.
- To identify and report on any gaps in the educational programme developed by PCFT
- To provide guidance on the development of an initial questionnaire for carers for the evaluation of the educational programme

### **Approach taken**

This Evidence Based Scan (EBS) is pragmatic and uses some of the principles of 'evidence scans' as described by the Health Foundation (The Health Foundation 2010). This approach provides information to help those involved in improving the quality of healthcare to understand what research is available on particular topics. The purpose is to provide a synopsis of evidence to help inform discussions and to help identify if there is need for further research or development in the area covered. It can also provide a rapid collation of empirical research about a topic. Although all of the evidence is sourced and compiled systematically, this is not classed as a systematic review. That is, it does not seek to summarise theoretical literature or to explore in any depth the concepts covered by the scan or those arising from it. Elements of 'Berry picking' were also used. This is another structured method of searching which also allows for an iterative and creative searching process to take place (Barroso and Gollop 2003 ).

In this review current information on local, regional, national and international, using the following criteria, being co-designed where possible, robust, SDEP and additional resources for parents/carers and children/adolescents with diabetes was needed. This information was prolific and available in various formats. The process involved:

- Meetings and communications with stakeholders
- A Google search identifying all SDEPs for CYP in the grey literature
- Linking identified SDEPs to their research protocols, related academic papers, reports, conference presentations, websites
- A library academic search for related papers
- Personal communications with programme leads and researchers
- A critical appraisal of existing programmes meeting the criteria above
- A critical appraisal of existing materials developed by PCFT

Grey literature and all websites of relevant agencies for existing co-designed, robust, current educational programmes and for other information available from October 2014 to February 2015 cited in this scan were searched. In addition to following up references, authors and researchers were contacted, associated conference papers and presentations were also identified.

Following this, and to support the information with an academic evidence base, a more conventional, formal library database search was undertaken with 7 bibliographic databases. The databases incorporated material from many different disciplines (see Table 1 below). All databases were searched from 2009 until December 2014 in the English language using the search terms in Table 1; project specific and other articles were identified. Abstracts were scanned to identify relevant articles. This enabled the maximum information to be accessed. Project specific papers identified in order to present a background and support the recommendations of the scan were selected. In some cases papers written earlier than 2009 have also been included in order to underpin some theoretical concepts present in programmes and methods.

**Table 1. Search terms for paediatric diabetes**

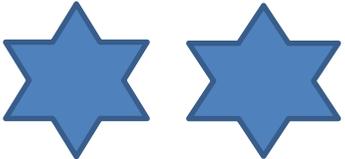
Search terms	Search Criteria	Sites/Databases
'Diabetes' and... 'paediatric' 'adolescent' 'education' 'needs' 'structured education' 'user involvement' 'co-design' 'parent' 'carer' 'child' 'disease' 'understandings' 'self-management' 'schools' 'support' 'legal obligations' 'social support' 'social capital' 'behaviour change theory' 'M/health'	2009 to current English language Not US No age limit Grey and Academic Literature	Google scholar Google Health Foundation HMIC SIGN (The Scottish Intercollegiate Guidelines Network) SCIENCE <a href="http://www.nice.org.uk/guidance/ta60/chapter/the-technology">http://www.nice.org.uk/guidance/ta60/chapter/the-technology</a> SIGLE (System for Information on Grey Literature) Local and National health authorities, foundation trusts Diabetes UK International Diabetes Federation IDDT Insulin dependent diabetes trust National Diabetes Programme ISPAD International society for paediatric and adolescent diabetes Juvenile Diabetes Research Foundation Diabetes Education network BSPAD British society for paediatric and adolescent diabetes Diabetes Management and Education group <a href="http://ndep.nih.gov/publications/PublicationDetail.aspx?PubId=4">http://ndep.nih.gov/publications/PublicationDetail.aspx?PubId=4</a> British society for paediatric endocrinology and diabetes

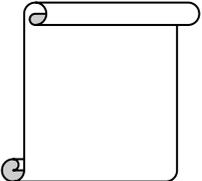
'health Technology' 'service Development' 'culture' 'ethnic minorities'		NHS The National Institute for Health and Clinical Excellence NICE Guidelines for Diabetes <a href="http://www.evidence.nhs.uk/">http://www.evidence.nhs.uk/</a>  Databases: Embase, ERIC, the Cochrane Library and Controlled Trials Register, PsychLit, HealthStar. Cinahl, Medline, Web of Science
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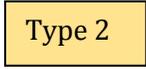
### Flag system

Table 2 denotes the Flag system to show how programmes and initiatives have been appraised by the reviewer throughout the document. For each programme or initiative, one or more of the symbols has been denoted to show the level of the quality of the programme. This appraisal is based on the evidence available and offers the reader a rapid reference guide to services and resources available or in development.

**Table 2. Flag system**

	<p><b>DENOTES VERY GOOD PRACTICE</b></p> <p><b>This could mean that the programme:</b></p> <ul style="list-style-type: none"> <li>✓ is established practice</li> <li>✓ has been stringently tested</li> <li>✓ has won an award</li> <li>✓ meets all CYP diabetes related guidelines</li> </ul>
	<p><b>DENOTES GOOD PRACTICE</b></p> <p><b>This could mean that the programme:</b></p> <ul style="list-style-type: none"> <li>✓ has been nominated for an award</li> <li>✓ Is a completed successful pilot</li> <li>✓ Is part of a larger programme</li> <li>✓ Is the subject of a peer reviewed paper</li> </ul>

	<p><b>DENOTES A USEFUL RESOURCE</b></p> <ul style="list-style-type: none"> <li>✓ For CYP</li> <li>✓ HCPs</li> <li>✓ Parents</li> </ul>
	<p><b>DENOTES THE POTENTIAL TO CONTACT/BECOME INVOLVED</b></p> <p>These initiatives offer PCFT the opportunity to:</p> <ul style="list-style-type: none"> <li>✓ Be part of a research project</li> <li>✓ run a pilot of this programme</li> <li>✓ Could contribute as a site</li> <li>✓ Apply for an award/grant</li> </ul>
	<p><b>DENOTES ENDORSEMENT /FUNDING/METHODOLOGICAL APPROVAL OF PROJECT OR INITIATIVE</b></p> <p><b>These include:</b></p> <p><b>APEG</b> - Australasian Paediatric Endocrine Group  <b>BRC</b> - Biomedical Research Centre  <b>CRC</b> - Children and Young People's Research Network  <b>ISPAD</b> - International Society for Paediatric and Adolescent Diabetes  <b>HTA</b> - Health Technology Assessment Programme  <b>JDRF</b> - Juvenile Diabetes Research Foundation  <b>MCRN</b> - Medicine for Children Research Network  <b>MRC</b> - Medical Research Council  <b>NCCSDO</b> - National Institute for Health Research Service Delivery and Organization Programme  <b>NHS</b> - UK National Health Service  <b>NIHR</b> - National Institute of Health Research  <b>NSF CYP</b> - National Service Framework for Children, Young People and Maternity Services – Diabetes Type 1 in childhood  <b>OFSTED</b> - The Office for Standards in Education, Children's Services and Skills  <b>PARIHS</b> - Promoting Action on Research Implementation in Health Services  <b>RCN</b> - Royal College of Nursing  <b>RCT</b> - Randomised Controlled Trial (Gold standard test of an intervention)</p>

	<b>HS&amp;DR</b> -The Health Services and Delivery Research programme Other, less well known ones are added individually to appropriate programmes/initiatives
	<b>Denotes a BME component</b>
	<b>Denotes a programme for Type 2 Diabetes</b>

### Structure of the scan

The scan is divided into sections as described in the contents with page references. Each section contains an introductory evidence based comment and a brief conclusion. The tables and boxes in this document are the main sources of information. Most of them incorporate the flag system above. Following all sections are recommendations for the implementation of a successful, evidence based structured diabetes education programme for children and young people and their carers.

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## Section 1. Introduction

### UK paediatric and adolescent structured diabetes education: current considerations

The UK has the fifth largest population of CYP with T1DM diabetes in the world, in England and Wales. Our CYP with diabetes have extremely poor glycaemic control and present far more with DKA admissions than their German and Austrian counterparts, these having good-to-reasonable glycaemic control across all age groups (Waldron, Allgrove et al. 2011). There is no UK validated paediatric diabetes educational intervention which impacts on diabetic clinical outcomes, unlike Germany which has given every patient with Type 1 Diabetes the legal right to receive a structured, specific and evaluated diabetes education. This has had a vital impact on HCP training in Germany in order to meet this legislation resulting in establishing SDEP in-patient education of CYP and their parents, as an integral, well established and quality assured component of multi modal diabetes care and has been in place for over two decades. The German model of SDEP has resulted, along with other therapies, in an improvement in the quality of the metabolic control of CYP with diabetes.

Initial education for children in Germany usually occurs in the inpatient setting over a period of 12 – 14 days and is delivered by a multi-professional team. There also follows long term educational sessions tailored to CYP cognitive and developmental status with sessions on specific themes such as preparation for starting school or starting insulin. The concepts and curricula of such a programme focus on nutritional advice, and the support of balanced and age-appropriate eating behaviour, as well as the prevention of eating disorders. Programmes are also presented to participants in the context of modern diabetes technology, such as insulin pump therapy (Lange, Swift et al. 2014).

This is *not* the case in the UK at present and could, in part, be responsible for our poor outcomes (NHS 2013). UK data from a EU project [www.sweet-project.eu/](http://www.sweet-project.eu/)<sup>1</sup> which aimed to establish centres of reference for children and young people (CYP) across Europe in order to improve standards of care and considered the education of CYP, their families, school staff and Health Care Professionals (HCPs). The main hindrance to the implementation of a standard, accredited, educational curriculum linked to diabetes outcomes is that CYP diabetes is not recognised in the UK as a speciality service and advertised posts in CYP services do not demand prior experience from HPCs, unlike in other European countries. On the whole, NHS Trusts generally do not commission CYP as a speciality and do not support educational programmes, mainly due to lack of a lead for these and suboptimal MDT working (Waldron, Allgrove et al. 2011).

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<sup>1</sup> SWEET ('Better control in Paediatric and Adolescent diabetes: Working to create Centres of Reference') originally started as a three-year European project, its main aim being to improve secondary prevention, diagnosis and control of type 1 and type 2 diabetes in children and adolescents by supporting the development of centres of reference (CORs) for paediatric and adolescent diabetes services across the EU.

Current education is mainly around adjusting carbohydrates/insulin requirements and pump therapy when facilitating communication, psychosocial, continuing education and transition programmes would be useful. In addition, learning outcomes are not always adequately assessed and programmes are rarely linked to diabetes outcomes (Waldron, Allgrove et al, 2011). The SWEET project found overwhelming support for the development of a National Paediatric Diabetes Framework that includes accredited, validated, SDEPs for CYP, their families, schools and HCPs although only 4% of respondents in this project reported evidence of these.<sup>2</sup> Diligent HCPs often develop in-house, bespoke programmes and, although commendable, a national repository of audited resources is considered a better alternative along with the adoption of a standardised, accredited approach to the training of HCPs. Evidence suggests that reducing the current UK paediatric mean HbA1c by 1% would reduce by up to 50% the risk of developing retinopathy and renal impairment over a 10 year period (Christie, Vicki et al. 2009). Thus education for long term management has major health implications for CYP in the UK, the lack of which has left many adults without a full understanding their condition, and the tools to successfully self-manage it (Hannan 2011). In order to standardise the approach to CYP diabetes education, a curriculum for the training of multi-disciplinary teams (MDT's) of Health Care Professional (HCP's) has now been developed from the EU SWEET project and adapted for use in the UK (Waldron, Allgrove et al. 2011). This and the closely related IDF curriculum initially devised in 2002 and updated in 2008, are both described in SDEP training for HCP's in Section 3. Existing structured diabetes educational programmes for HCPs below, page 49.

### **CYP as a distinct population**

Caring for CYP with diabetes is a different task to that of caring for adults, comprising a complex process of engaging with them and their families and other carers such as teachers, alongside the skills and clinical experiences of HCPs. CYP are continually developing physically, physiologically and emotionally in a complex social milieu and they need information and motivation for the lifelong task of effectively managing their condition (Christie, Vicki et al. 2009). CYP and their families themselves are also complex systems in which each member interrelates in order for the family to function (Featherstone 1996). A CYP diagnosed with diabetes could upset this balance significantly and this can be addressed to facilitate maximum family support for the CYP's medical condition. Interventions which neglect emotional, social and family processes have been found to be ineffective with CYP with diabetes (Hood, Rohan et al. 2010). Some models of family functioning are ethnocentric however, and influenced by certain assumptions. For example, this model is not appropriate for many BME and LGBT groups who often have alternative gender roles, family types, perceptions of health and values to those in the West, and/or Western middle class white, society in general. Occupations and unemployment also affect and shape unique dynamics within families, determining family structure and problems. In miners' families for example, it was once considered more appropriate to work with communities rather than single family units and this may still be the case in some communities in the PCFT geographical area. Social, ecological theoretical frameworks have also been

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<sup>2</sup> These were from 68 separate hospitals, representing 33% of services currently supplying care to CYP. Except for the North East, all regions of the UK were represented, 25% of replies being from the Yorkshire and Humber region (Waldron, Allgrove et al, 2011)

advocated for current CYP research and practice because they place CYP as part of a larger structure. That is, CYP are part of a social ecological context - a macro structure comprising a particular culture or cultures, educational organisation, and at another (meso) level, friends, diabetes teams, and family interact with the individual at the micro level all influencing their knowledge, beliefs and practices (Featherstone 1996).

## **Policies and guidelines for CYP**

The recent Children's Charter developed in collaboration with children and young people with diabetes, their carers and healthcare professionals has stated that children and young people should be given the opportunity to have a say in the individual management of their condition and in influencing NHS services. In addition, they should be supported at school by staff and by diabetes aware professionals working with children and young people in various other settings. A major statement in this charter is that every child and young person with diabetes, their parents and carers should have access to high-quality education, information, emotional and psychological support, to aid self-management of the condition (Diabetes 2010). Under the current 2013/2014 Quality and Outcomes Framework, all newly diagnosed patients with diabetes should be referred to a local structured education program (Steven 2014 ). In addition, following the introduction of the Children and Family Act 2014, schools now have a legal obligation, supported by local authorities and the NHS, to support children with diabetes so that they can manage their diabetes in school and partake of all aspects of school life, including extra-curricular activities, in order to reach their full potential (Diabetes 2010). In 2009, 10 regional CYP Diabetes Networks (CYPDNs) were set up across England with support from NHS Diabetes. Their aim was to provide consistent, high-quality diabetes care to CYP with diabetes and their families. These networks form the National CYP Diabetes Network, which is committed to develop a National Paediatric Diabetes Service Improvement Delivery Plan - its main aim being is to significantly improve clinical and psychosocial outcomes of CYP diabetes by 2018. The best way to achieve this is being explored. In terms of social capital, there is good, anecdotal evidence that great benefit, knowledge and empowerment can be gained from participation in organised Diabetes Association meetings and in holiday or camping experiences for CYP and their families.<sup>3</sup>

The NHS National Paediatric Diabetes Service Improvement Delivery Plan for 2013-2018 (NHS 2013) examines how this can plan be translated into a service for CYP. CYP and their families occupy an ambiguous position in UK policies and constitutions relating to patient knowledge and engagement with their health conditions and increasing their capacity to self-care for their wellbeing and continuing health. When considering CYP, age appropriate information could be critical to self-care, as this group move towards adult services. The Children's National Service Framework (NSF 2010) specifically cites as central, information needs and informed choice via the provision of high-quality, age-appropriate, child-centred information.

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<sup>3</sup> Diabetes UK run residential courses for age groups 7 - 18 which employ trained staff. Various funding options are available to attend these. Family events are free and extremely informative. [careevents@diabetes.org.uk](mailto:careevents@diabetes.org.uk) <http://www.diabetes.org.uk/careevents>

## **Evidence for the usefulness of SDEP for CYP**

Evidence to date shows that, in eight randomised controlled trials (RCTs) undertaken dealing with components of care and education, results from five of these have not shown a positive change in glycaemic control in CYP with T1DM (NHS 2013). This highlights the question of what outcomes should be expected from SDEPs. A systematic review recommended that HbA1c is not the appropriate primary outcome on which to assess benefits of an intervention designed to more directly affect behaviour/self-management (Noyes, Williams et al. 2010). Alternative primary outcome measures could be diabetes self-efficacy and quality of life. However, given the support of a diabetes consultant is important for any educational programme, including HbA1c as an outcome measure in order to maintain this support by offering them clinical outcomes is advised (pc, BJ, 17/12/2014). These could be included in secondary outcome measures alongside, generic quality of life, routinely collected NHS/child-held data, costs, service use, acceptability/utility for example (Noyes, Williams et al. 2010).

A three year study with CYP aged 6 - 25, and their parents (n= 250) in the Yorkshire and Humber region explored their experiences of diabetes care provision with a process-mapping approach to map out the T1DM journey for CYP who had the condition from diagnosis through to transition from paediatric to adult services. Key areas for improvement in future diabetes care included; provision for CYP, including communication and support, schools, structured education and transition. In terms of the provision of structured education, most participants reported that they had learnt the majority of what they knew about their condition from others with T1DM. They did, however, welcome the opportunity to attend structured education such as the DAFNE course. The minority of CYP who had attended structured education commented on how helpful it had been, in particular, carb-counting and reading food labels. Generally, there appeared to be a lack of education provided by diabetes staff in relation to healthy lifestyles, sexual health and pregnancy, many participants accessing the internet for this information. CYP felt isolated among their peers and wanted to meet and talk with others in their situation. Diabetes camp initiatives had been very helpful for some and the SWEET project advocates this in their curriculum. Some parents reported access to a support group, but most had no access and thought that counselling or other individual or group psychological support would help them in supporting their CYP. CYP also thought that some psychological support would help them cope better with their condition suggesting the presence of a psychologist at the clinic would be beneficial for coping and stress management. The study recommended that CYP and their parents are involved in the process of any service redesign (Kime 2013).

In terms of the relevance of child development theory to SDEPs for CYP's, a systematic review identified perceived control of risks and stereotyped conceptions regarding susceptibility to negative outcomes as important in relation to adolescents' health behaviour. These, and other age related, factors need to be considered in communicating risk and in supporting self-care among this group (Larsman, Eklöf et al. 2012).

## **What works to support self-management: engaging CYP and their carers**

The role of parents in adolescent diabetes management is complex and requires a balance of involvement. Anecdotal evidence has suggested that parents can receive mixed messages from clinicians regarding their involvement in their child's diabetes. That is, to encourage the independence of their children in diabetes management, they may be encouraged not to attend appointments whilst simultaneously being expected to have knowledge of the condition (Ridge, Thomas et al. 2014). Current guidance about adolescent-friendly health care emphasises the benefits of seeing young people alone for confidential consultations. One study surveyed parents of CYP aged 12 – 21 years old about how this tension can be managed in clinical practice. It transpired that 13% of adolescents with T1DM had never been seen alone for a confidential consultation with their doctor. If they had, the most common concern for parents about confidential care when it occurred was not being informed about important information they may need, both in terms of the condition itself and the potential risky behaviour of their CYP. That CYP are not being seen routinely for confidential consultations with clinicians can be put down to various factors; parents or CYP declining this; time factors in the clinic and/or lack of clinical skills; an uncertainty about the efficacy of this level of care.

Given the importance of parental input to effective diabetes management, it is important to consider how to enact adolescent-friendly diabetes care, whilst giving parents the necessary information to safeguard their child and support them in the present and in the future (Duncan, Jekel et al. 2014). On the other hand, other evidence suggests that parental involvement increases adherence and glycaemic control during adolescence but does not always equate to improved outcomes. Higher parental involvement can be seen as rigid and controlling, inhibiting the development of autonomy among some adolescents (Coates, Chaney et al. 2013).

The National Service Framework (NSF) for CYP state that parents and carers must be supported to attend educational courses such as those for insulin pump therapy. In addition, the idea of training parents in therapeutic skills fits into current paediatric guidelines which all state the necessity of integrating psycho- educational principles into routine care via problem solving, goal setting, communication skills, family conflict resolution, coping and stress management skills (Waldron, Allgrove et al. 2011).

## **Conclusion**

Guidance from NICE (NICE 2004) [nice.org.uk/cg15](http://nice.org.uk/cg15), recommend that structured education should be made available to everyone with diabetes, with education provided at diagnosis and be on-going. Paediatric diabetes care should be a specialist service delivered locally whereby CYP with diabetes should have timely access to high quality medical, nursing, dietetic and psychological support from a paediatric diabetes specialist team, who should have individuals with teaching skills and expertise amongst them. CYP should experience services that address all their needs in a joined-up manner, which facilitates a smooth transfer to adult diabetes services at a stage and time that is right for them (Waldron, Allgrove et al. 2011). Any programme offered should also be suited to the social learning needs of the person with diabetes. Details of what constitutes optimum CYP structured diabetes education is described in detail below in Section 11. Recommendations for SDEP's for

CYP and their lay and professional carers – a good start. Essentially, it should consider divisions into age ranges in order to meet the developmental needs of each age group (NHS 2013). Evidence from adult diabetes research is that structured diabetes specific medical education is more effective than informal unstructured education in improving metabolic control. ISPAD guidelines for the planning, implementation and content of a good SDEP for CYPs are described more fully below in the Recommendations section, page 110. (Swift 2009; Cameron, Amin et al. 2014; Lange, Swift et al. 2014).

## Section 2. Existing, structured diabetes education programmes for CYP & lay and professional carers

Table 3 offers an overview of SIX available programmes for CYP from ages 0-25 year old, it includes the acronym of each programme; whether co-designed; whether for children, adolescents, adults, parents, other carers; HPCs; and whether they contain a Black and Minority Ethnic (BME) element. Table 4 contains more detail about them; explanations of the acronyms; the aims of each programme the content/curriculum of the programme where available; any identified aims and findings; contacts; and an appraisal from the UoM. In addition, Table 4 incorporates the flag system which depicts different attributes of the programme and which is described above in Table 2, page 13.

Some adult programmes have been described because of their suitability for adolescents. For example, the adult DAFNE programme is described because this programme was adapted into the KICK-Off and WICKED programmes And the modules for 13-16 year olds in the Hannon manual is also based on this (Hannan 2011). CHOICE and DAFNE (also called Freedom 4 life) are both based on the adult SEP Berger programme originating in Germany (Coates, Chaney et al. 2013).

**Table 3. Existing SDEP for CYP – an overview**

	Acronym	CYP ages	Parent/carer/family	Co-designed/feedback	HCP's
1	BERTIE	14-16		Adolescents and parents via focus groups	
2	CASCADE	8-16	Actively encouraged to participate		Trained to deliver programme
3	CHOICE	0-16+	Invited to sessions	Designed with input from young people	
4	DOLPHIN CLAHRC SOUTH YORKSHIRE	10 -18	For parents and carers	Parent and CYP involvement	
5	FACTS	13- 15	Family sessions		
6	KICK-OFF pilot	11–13 14–16	Family sessions	Paediatric specialist nurses/ children/parents/secondary school teachers	Training including experience in a secondary school.
7	WICKED CLAHRC SOUTH YORKSHIRE (in development)	16- 25	An adjunct session for parents, partners and friends	Designed with input from young people/educators/health psychologists. On-going interviews/focus groups with young people, parents & staff	

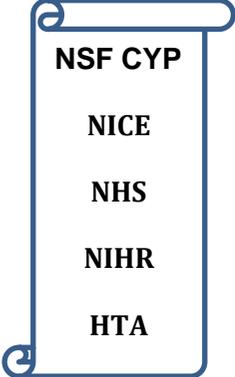
## Programme descriptions and brief appraisals

**Table 4. Existing structured diabetes educational programmes for CYP. Descriptions and appraisals.**

FLAGS	TITLE AND DETAILS	PROGRAMME AIMS & APPRAISAL	PROGRAMME CONTENT
	<p><b>BERTIE</b> The BERTIE (Bournemouth Structured Education) programme is also adapted for use with adolescents from a BERTIE programme originally for adults with type 1 diabetes A Northern Irish local initiative with 15 adolescents and their parents. The adolescents wanted sessions:</p> <ul style="list-style-type: none"> <li>• without parents present</li> <li>• not to interfere with their school or social activities.</li> <li>• to be practical and informal</li> <li>• to be out of the clinic</li> </ul> <p><b>CONTACT:</b> Rhonda Bleakly. Paediatric DSN</p> <p>Alison McKee Paediatric Dietician</p> <p>Northern Health and Social Services Trust, Coleraine, Northern Ireland.</p>	<p><b>AIMS</b> To provide an arena for parents and adolescents to:</p> <ul style="list-style-type: none"> <li>• inform all of the proposed content of the education sessions.</li> <li>• help structure their own education sessions with parental input</li> <li>• provide an opportunity for participants to express their views independently.</li> </ul> <p>The learning needs of each individual on carbohydrate foods, insulin action and hypoglycaemia treatment were assessed pre course. At the end of the course there was an overall improvement in diabetes knowledge, ability to carbohydrate count and to adjust insulin.</p> <p>Due to different mathematical abilities, some found concepts of the carbohydrate counting and calculation of insulin to carbohydrate</p>	<p><b>BERTIE</b> took place one day per week over 4 weeks in four 2-hour sessions at weekly intervals in the local leisure centre. Comprising a mixture of group discussions, reflection, and practical application.</p> <p>A meal was taken together each evening facilitating discussion of carbohydrate estimation in different foods.</p> <p>Packed lunches were brought on two evenings, which gave opportunity to read labels and identify healthy and unhealthy choices.</p> <p>The adolescents were asked to keep a record of their blood glucose levels, insulin dose and carbohydrate taken at each meal. Diaries were used as a basis for weekly discussions.</p> <p>All sessions were led by a senior doctor, dietician and DSN, with the exception of the exercise sessions, which were led by a trained instructor.</p> <p>Session 1:</p>

	(Bleakly and McKee 2010)	<p>ratios difficult. Other findings are as follows:</p> <ul style="list-style-type: none"> <li>• Feedback on venue and content was positive.</li> <li>• HbA1c levels were recorded pre and post sessions at 3, 6, 9 and 12 months during routine clinic visits.</li> <li>• There was a small improvement in HbA1c after 3 months for 4 individuals with a slight deterioration for one.</li> <li>• After 3 months participants retained knowledge and self-management skills.</li> <li>• Carbohydrate-counting was found to be time consuming and not always calculated accurately.</li> <li>• Overall improvements in blood glucose measurements were reported.</li> <li>• Glycaemic control was sustained at 6 and 9 months, with one exception.</li> <li>• HbA1c levels showed a very slight increase in two cases after 12 months.</li> <li>• Results indicate that more regular contact with the diabetes team offers valuable support in achieving glycaemic control and</li> </ul>	<ul style="list-style-type: none"> <li>• Introductions of team and group</li> <li>• Introduction to aims and objectives of sessions</li> <li>• Pre-course questionnaire</li> <li>• General physiology of diabetes</li> <li>• Carbohydrate counting and food labels</li> <li>• Weighing foods and portion estimation</li> </ul> <p>Session 2:</p> <ul style="list-style-type: none"> <li>• Discussion of diaries from previous week</li> <li>• Practical session: group cook meal together</li> <li>• Estimation of carbohydrate in meal</li> <li>• Calculation of carbohydrate to insulin ratio</li> <li>• Injection technique</li> <li>• Insulin regimens and blood glucose monitoring</li> </ul> <p>Session 3:</p> <ul style="list-style-type: none"> <li>• Management of exercise</li> <li>• Insulin adjustment and correction bolus</li> <li>• Discussion of diaries from the previous week</li> <li>• Hypoglycaemia</li> <li>• Practical exercise session</li> </ul> <p>Session 4:</p> <ul style="list-style-type: none"> <li>• More exercise</li> <li>• Hyperglycaemia</li> </ul>
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		<p>maintains motivation.</p> <p>Small attendance may have been down to reluctance to attend a group, preferring one to one support.</p> <p><b>APPRAISAL</b> The development of this programme is rooted in the needs of adolescents and their parents. It is very practical and focuses on exercise and food with individual attention given. Given adolescents did not want their parents present in sessions, the pre programme focus groups ensured parental involvement. They gained information and contributed to the structure and design of the sessions. They could potentially, be offered additional sessions. This small study shows promise. It fulfils ISPAD guidelines. Further/larger studies would help confirm the efficacy of BERTIE.</p>	<ul style="list-style-type: none"> <li>• Insulin adjustment for sick days</li> <li>• Review of carbohydrate counting</li> <li>• Take-away meal: pizza</li> </ul>
<b>FLAGS</b>	<b>TITLE AND DETAILS</b>	<b>PROGRAMME AIMS &amp; APPRAISAL</b>	<b>PROGRAMME CONTENT</b>
	<p><b>CASCADE</b> Child and Adolescent Structured Competencies Approach to Diabetes Education</p> <p>A Gold standard Trial with integral process and economic evaluation of</p>	<p><b>AIMS</b></p> <ul style="list-style-type: none"> <li>• To bring together children and young people of similar ages, with their parents.</li> <li>• To motivate them to manage their diabetes more effectively.</li> <li>• To maximise engagement,</li> </ul>	<p><b>CASCADE</b> consists of four modules delivered in 4 group sessions, over a 4 month period. Delivered by diabetes multidisciplinary teams as part of routine care. Led by a Paediatric Diabetes Specialist Nurse with an additional member of the diabetes team. A</p>

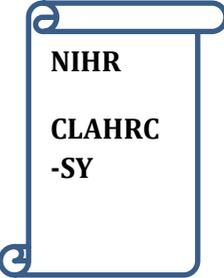
 <p><b>NSF CYP</b></p> <p><b>NICE</b></p> <p><b>NHS</b></p> <p><b>NIHR</b></p> <p><b>HTA</b></p>	<p>a structured education programme using psychological approaches to increase engagement and enhance behaviour change in children, young people and families. Involving 26 clinics and 572 children and young people.</p> <p>NIHR Journals Library  <a href="http://www.journalslibrary.nihr.ac.uk">www.journalslibrary.nihr.ac.uk</a>          Accessed 11/11/2014          Study complete.          (Christie, Thompson et al. 2014)</p> <p><b>CONTACT:</b>          The Institute of Education, University of London. 20 Bedford Way, London WC1H 0AL, UK - Tel: +44 (0)20 7612 6000</p> <p><a href="http://www.ioe.ac.uk/research/departments/cfhh/41745.html">http://www.ioe.ac.uk/research/departments/cfhh/41745.html</a>          accessed 29/10/2014</p> <p>(Christie, Thompson et al. 2014)</p>	<p>motivation and long term change</p> <ul style="list-style-type: none"> <li>To improve HCPs skills in the field</li> </ul> <p>Intervention group parents at 12 months and young people at 24 months had higher scores on the diabetes family responsibility questionnaire.</p> <p>Young people reported reduced happiness with body weight at 12 months. 68% of groups were run. Of the 180 families recruited, 96 attended at least one module. Reasons for low uptake included difficulties organising groups, and work and school commitments. Young people with higher HbA1c levels were less likely to attend.</p> <p><b>APPRAISAL</b>          Although final results have not been published yet, the trial has already drawn confident conclusions about the effects on:</p> <ul style="list-style-type: none"> <li>control of diabetes (measured by change in HbA1c)</li> <li>patient management of diabetes</li> <li>the use of health service</li> <li>patient health related quality of life</li> </ul> <p>The family therapy based approach</p>	<p>developmentally appropriate curriculum delivered to groups of 3 - 4 families, focusing on achievement of increasing competency in self-management of diabetes.</p> <p>Parents are actively encouraged to participate.</p> <p>Four Modules entitled:</p> <ol style="list-style-type: none"> <li>Living with diabetes. Challenges and Choices</li> <li>BFG testing: Pros and cons</li> <li>Adjusting insulin - pros and cons</li> <li>Food activity and exercise</li> </ol> <p>Key topics include:</p> <ul style="list-style-type: none"> <li>family cohesion</li> <li>functioning</li> <li>diabetes skills training</li> <li>adolescent development</li> <li>communication and conflict resolution skills</li> </ul> <p>Deliverer training          Two 1-day workshops taught delivery of the structured education programme.</p> <p>Training resources are available for HCPs</p>
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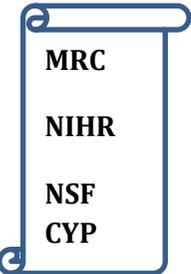
		<p>to this study appears to have facilitated positive family dynamics. CYP and their parents reported improved family relationships, knowledge and understanding, greater confidence and increased motivation to manage diabetes.</p> <p>24 months after the intervention nearly half of the young people reported that the groups had made them want to try harder and that they had carried on trying. <b>This programme shows promise.</b></p>	
<b>FLAGS</b>	<b>TITLE AND DETAILS</b>	<b>PROGRAMME CLINICAL AIMS/BRIEF EVALUATION</b>	<b>PROGRAMME CONTENT</b>
	<p><b>CHOICE</b> (Carbohydrate, Insulin, Collaborative Education)</p> <p>A structured education programme for children and young people with diabetes (aged 0-19 years) and their parents and carers. Adapted from a German SDEP programme <sup>4</sup></p>	<p>AIMS Research questions were;</p> <p>1) Does a structured education programme for adolescents improve glycaemic control and dietary adherence at 1, 3, 5, 12 and 24 months post intervention? 2) Does improved ability to manage</p>	<p>The <b>CHOICE</b> programme was delivered on four consecutive weekly sessions, for three hours in the evening. The programme was to be transferable into routine practice.</p> <p>Parents were invited to an information session one week before the programme to answer questions and illustrate how</p>

<sup>4</sup> Developed by Michael Berger et al and comprising; a curriculum guide for planning and organising sessions, a CD illustrating meal plates depicting standard meals, illustrations of individual portions to construct customised meals, question sheets to be completed at the end of each teaching session, teachers' answers for the questions and flash cards to promote dialogue during teaching sessions. For patients, there is a book designed to accompany the teaching and a customised daily log book. The programme is delivered as an inpatient over five days and focuses on the carbohydrate content of food and drinks, the interaction of carbohydrates and insulin requirements, timing of food and the effects of exercise and sickness on blood glucose levels and insulin. (Muehlhauser et al. 1987, Jorgens et al. 1993 in Chaney 2010)

	<p>The aim of the programme is to give children, young people and their families /carers, the skills and knowledge they need to manage their diabetes and facilitate discussion on practical daily aspects.</p> <p>The intervention was designed to enable adolescents to adjust diet and insulin regimens, liberating their lifestyle to more closely match that of their diabetes free peers.</p> <p>Multi-centred pragmatic RCT across seven hospital sites in Northern Ireland, with 24 month follow-up. 135 adolescents between 13 – 19 years with Type 1 diabetes involved.</p> <p><b>CONTACT:</b> Dr. David Chaney (Lecturer in Nursing, University of Ulster)</p> <p>(Chaney, Coates et al. 2012) (Coates, Chaney et al. 2013)</p> <p>(Chaney, Coates et al. 2010)</p>	<p>diabetes in adolescence lead to weight gain?</p> <p>Clinical measurements were:</p> <ul style="list-style-type: none"> <li>• glycosylated haemoglobin</li> <li>• body mass index</li> <li>• episodes of hyper and hypoglycaemia and</li> <li>• dietary adherence</li> </ul> <p>Results: No significant improvement in HbA1c at any time point post intervention.</p> <p>However, the complexity of the subject and wide numeracy and literacy abilities were a challenge to deliver effectively in a short time. Further support or ‘top ups’ are indicated and over time.</p> <p><b>APPRAISAL</b> Only 135/400 eligible adolescents took part in this trial and it would be interesting to know the reasons for this. A robust analysis on the data was not possible. However, of those participating in the intervention retained adolescents’ interests with only four not completing the programme. This offered clinicians opportunities to establish clinical relationships with their patients.</p> <p>Despite a much more liberal diet,</p>	<p>they could support their CYP.</p> <p>Sessions were attended by adolescents alone with the exception of one session on the final week ‘Family / friends, lows and highs’ in which assistance during times of erratic blood glucose control were discussed.</p> <p>Activities explored:</p> <ul style="list-style-type: none"> <li>• the interaction of carbohydrates and insulin requirement</li> <li>• timing of food and effects of exercise on blood glucose levels and insulin.</li> <li>• each session included an evening meal to give the participants supervised experience in assessing carbohydrate content and insulin requirements.</li> </ul> <p>13-16 year olds and over 16’s were in separate sessions with the exception of the final programme in which a wider span of age groups were included.</p> <p>All delivered independently from the regular outpatient clinic and was run 14 times delivered by an experienced diabetes specialist nurse and one of two experienced diabetes dieticians.</p> <p>Participants in the intervention group were texted by the nurse to check on progress and encourage communication.</p>
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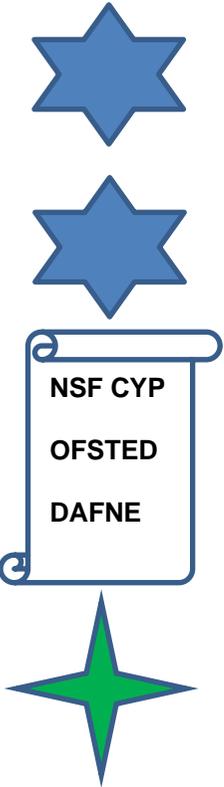
		<p>those in the intervention group did not experience deterioration or any weight gain during the first 12 months – this was not the case at 24 months however. At 24 months there was a significant rise in HbA1c amongst the intervention group. The intervention was complete at month five indicating that top up sessions may be needed.</p> <p>Adolescents in this study had been diagnosed for at least a year. It may be the case that education needs to be delivered individually, immediately upon diagnosis alongside education about insulin and blood glucose monitoring equipment before inappropriate diabetes related behaviour is established.</p> <p>Despite the fact that the study was based on a family therapy approach, parental involvement appeared to be minimal.</p> <p>This project has since been modified and is being re-evaluated.</p>	<p>CHOICE materials included a curriculum guide, food plates of standard meals, illustrations of individual portions to construct customised meals, flash cards to promote dialogue during teaching sessions and a flip chart to aid education. Participants kept the 14 education units.</p>
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FLAGS	TITLE AND DETAILS	PROGRAMME AIMS/BRIEF OUTCOMES	PROGRAMME CONTENT
	<p><b>DOLFIN</b> (Diabetes Oriented Learning Family Intervention)</p> <p>CLAHRC FOR SOUTH YORKSHIRE DIABETES INITIATIVES Self-Management of Diabetes Adolescent Programme of Research</p> <p>This is an exploration (using findings from 3 pilots) of a group intervention for parents of young persons aged between 10-18 and diagnosed with Type 1 diabetes for more than a year.</p> <p>It can be used as a stand-alone intervention (or as a component in a complex intervention). It offers parents skills in motivational interviewing designed to empower and support children in diabetes self-care and the opportunity to share experiences and expertise.</p> <p>12 months' duration in two inner-city South London hospitals.</p> <p>In order to identify the clinical themes that carers brought for exploration, a qualitative analysis of</p>	<p><b>AIMS</b></p> <ol style="list-style-type: none"> <li>1. involve parents in diabetes care whilst respecting clinic recommendations for adolescent independence;</li> <li>2. empower carers as collaborators in diabetes management;</li> <li>3. increase positive interactions between parent and child;</li> <li>4. identify trends in intervention effects</li> </ol> <p>Carers were invited to attend six sessions and were taught motivational interviewing techniques and behaviour change theory.</p> <p><b>APPRAISAL</b></p> <p>Out of 106 who were invited to attend, 31 families agreed to participate. Numbers attending sessions varied with only 17 attending more than 4 sessions.</p> <p>Feedback suggests timetabling, childcare difficulties and other commitments interfered with a weekday clinic attendance. An initial preparatory session may be advantageous followed by 4 rather than 6 additional sessions.</p>	<p>From six sessions in total, the first session focused upon introductions, sharing information and allowing carers to highlight the topics regarding diabetes and the family that were most pertinent to them. These included:</p> <ul style="list-style-type: none"> <li>• the increasing difficulty of diabetes management as children grow older</li> <li>• parenting techniques for managing diabetes in the home and</li> <li>• the emotional challenges of having a child with a chronic condition</li> </ul> <p>Subsequent group sessions followed a schedule allowing for:</p> <ul style="list-style-type: none"> <li>• The receipt of emotional support</li> <li>• diabetes education</li> <li>• discussing issues emerging each week</li> <li>• learning new psychological skills</li> <li>• role play and practice</li> <li>• testing out acquired skills</li> <li>• reporting back on what worked well and what did not</li> </ul> <p>Motivational interviewing techniques were taught to use as a framework to practice techniques for sidestepping expressed emotions and increasing positive</p>

	<p>the first session of each pilot was completed.</p> <p>Participants were asked what they wanted from a diabetes family programme and asked to rank these. They considered Diabetes education for parents, basic psychology skills and diabetes education for children as the most important aspects for a diabetes family intervention to address.</p> <p>CONTACT: CLAHRC for South Yorkshire</p> <p>See note ii for details of MI courses (Ridge, Thomas et al. 2014)</p>	<p>Sessions for adults could be held alongside those for their children.</p> <p>This exploratory study gave parents and carers a grounding in:</p> <ul style="list-style-type: none"> <li>• Behaviour change theory</li> <li>• MI skills</li> <li>• Peer support</li> <li>• Diabetes knowledge.</li> </ul> <p>Biomedical and psychological measures of carers and children were collected from 17 families who attended the most sessions. There was a slight fall in HbA1c.</p> <p>Engaging parents in a carer intervention for Type 1 diabetes was challenging. Some parents thought the intervention was too late for their age of child. However, parents appeared to value the intervention.</p>	<p>interactions.</p> <p>Parents/carers were given information on how to use the principles of the trans-theoretical model of change to think about supporting someone during the behaviour change process. They learned to consider the antecedents of behaviours in family situations.</p> <p>Each carer was provided with a 'Carer's Toolkit' summarizing the skills of each session with all accompanying slides and materials.</p>
<b>FLAGS</b>	<b>TITLE AND DETAILS</b>	<b>PROGRAMME AIMS/BRIEF OUTCOMES</b>	<b>PROGRAMME CONTENT</b>
 <p>MRC NIHR NSF CYP</p>	<p><b>FACTS</b> Families, Adolescents and Children's Teamwork Study</p> <p>A Multi centre RCT to test a family-centred group education programme with potentially beneficial effects on parental involvement and glycaemic</p>	<p><b>AIMS</b> To evaluate the effectiveness of a family-centred group education programme, for adolescents with Type 1 diabetes.</p> <p>Primary outcome HbA1c at 18 months (12 months</p>	<p><b>FACTS</b> intervention consisted of six 90-min monthly group education sessions (4–6 families per group) delivered by multidisciplinary health professionals</p> <p>Consists of conventional diabetes self-education management incorporating skills training and family communication/</p>

	<p>control.</p> <p>Delivered in 10 UK paediatric diabetes clinics. 305 adolescents with Type 1 diabetes</p> <p>FACTS education programme incorporated conventional diabetes self-management education and family communication training with external peer review of selected sessions by a trained peer reviewer.</p> <p><b>CONTACT:</b> University of Cambridge Metabolic Research Laboratories NIHR Cambridge Biomedical Research Centre, Cambridge, Diabetes Centre, Ipswich Hospital NHS Trust, Ipswich, UK</p> <p>(Murphy, Wadham et al. 2007)</p> <p>(Murphy, Wadham et al. 2012)</p>	<p>post intervention).</p> <p><b>Secondary outcomes</b> HbA1c at 9 months (3 months post-intervention) psychosocial outcomes at 12 months (6 months post-intervention) episodes of severe hypoglycaemia and diabetic ketoacidosis at 18 months</p> <p><b>Results</b> Of those recruited, 30% did not attend any education sessions, with less than 50% attending four or more sessions. Of this 50% an analysis showed no beneficial effects on biomedical or psychosocial outcomes.</p> <p>There were no differences over time between the control and intervention group in: glycaemic control; severe hypoglycaemia; diabetic ketoacidosis adolescent quality of life and well-being.</p> <p>There were increases in the frequency with which participants adjusted their insulin dose, for snacks, meals and based on recent blood glucose levels.</p> <p><b>APPRAISAL</b> Adolescents perceived no changes</p>	<p>teamwork training.</p> <p>The curriculum is divided between family and patients concerns</p> <p>FACTS Sessions</p> <ol style="list-style-type: none"> <li>1. Carbohydrate counting Family communication about food, snacking, stealing food “food policing” Parental support for carbohydrate counting</li> <li>2. Feedback on 3-day food diaries Effects of carbohydrates on BG Portion sizes, snacking and food craving Family communication re BG monitoring &amp; responses to out of range BG levels</li> <li>3. Feedback on BG diaries and responding to out of range BG levels BG monitoring/insulin dose adjustment BG &amp; HbA1c targets/puberty/growth Insulin action/timings and types Family problems solving and shared decision making</li> <li>4. Feedback from family problem solving Managing diabetes at school and communicating with school staff Hypoglycaemia and physical activity Adolescent and parent confessions (Most stupid thing you’ve ever done – learning from past mistakes)</li> <li>5. Feedback from overcoming mistakes and getting back on track</li> </ol>
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		<p>in parental input at 12 months. No change was found in diabetes family responsibility and there was no effect on biomedical outcomes.</p> <p>Poor attendance of group education sessions delivered in routine clinics was a major challenge. Higher recruitment and attendance was experienced in centres which fixed times and dates of sessions.</p> <p>While positive changes increased proactivity regarding insulin dose adjustment were noted, only one third to a half of adolescents reported routinely adjusting prandial insulin doses.</p> <p>Families were of varied demographics, employment status and education levels thus the programme was targeted to specific needs.</p> <p>There appeared to be a skills deficit regarding carbohydrate counting and insulin dose adjustment and an inadequate understanding of the barriers and strategies of overcoming these. Knowledge accumulated may have been inadequate and support provided was not enough to empower and motivate families.</p>	<p>Challenges of adolescence from parent and adolescent perspectives  Family communication strategies for dealing with diabetes conflict  Family role reversal (Parents to monitor BG, count carbohydrates and maintain BG diary for 3 days – adolescents to practice positive communication and support)</p> <p>6. Feedback on role reversal activity  Teenage issues: eating out, parties, alcohol and contraception  Clinic consultations/communicating with HCPs  Interdependence – letting go but staying involved</p> <p>Delivered by multidisciplinary health professionals who attended programme specific 4 day training delivered by trained educators.</p> <p>A structured written curriculum and summary lesson plans are provided</p> <p>Full details of the structured curriculum and questionnaire packs are available</p>
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FLAGS	TITLE AND DETAILS	PROGRAMME AIMS/BRIEF OUTCOMES	PROGRAMME CONTENT
 <p>NSF CYP OFSTED DAFNE</p>	<p><b>KICK-OFF (Kids In Control OF Food)</b></p> <p>KICK-OFF (KO) is a 5 day group self-management skills and education course for 11–16 year olds with type 1 diabetes using DAFNE principles of care and within an intensive insulin regime.</p> <p>Developed at Sheffield Children’s Hospital, it aims to provide better knowledge about diabetes and the skills needed to manage it successfully.</p> <p>The Curriculum is closely linked with the National Schools Curriculum. Following a successful pilot with 48, 11–16 year olds with type 1 diabetes, findings justified conducting a 2 year RCT cluster trial was run which was completed in 2012. This incorporated an adjusted curriculum, a larger study population/control group and longer follow-up.</p> <p><b>CONTACT:</b> Dr. Kath Price, Consultant Paediatrician, Sheffield Children’s Hospital.</p>	<p>Six 5-day courses on carbohydrate counting and insulin dose adjustment comprised an age-appropriate curriculum which employs a range of teaching methods and uses a progressive modular-based structure a modular approach with clear learning objectives and building on skills acquired during the week. It aims to improve self-management in a variety of medical and social situations.</p> <p>Additional support is provided through dedicated parent sessions, involvement of friends and the provision of a school resource pack. Separate courses were held for 11–13 and 14–16 year olds. Courses were held during school time in secondary schools or an education centre.</p> <p><b>Aim</b> To assess whether the course improved biomedical and psychological outcomes over 2 yrs.</p> <p><b>Method</b> Four hundred thirty-six participants</p>	<p><b>MONDAY</b> Introduction to the course What is diabetes? Snacks Signs and symptoms Insulin:- action, times, types Types of food and Carbohydrate Portion booklet and diary Insulin/CHO relationship Food labels Insulin/CHO relationship continued Introduction to correction doses Monitoring KICK-OFF quiz Recap objectives for the day Plan evening insulin dose Personal interviews</p> <p><b>TUESDAY</b> Discuss overnight blood glucose levels Hypoglycaemia Hypoglycaemia and KICK-OFF treatment continued Insulin /CHO ratio Work out CHO for packed lunch Practicing counting grams of CHO and practical cookery Practical session continued KO Quiz Recap objectives for the day Plan evening insulin dose</p>

	<p><a href="mailto:Kath.price@sch.nhs.uk">Kath.price@sch.nhs.uk</a></p> <p>A teaching skills course is now available for paediatric HCPs, see page 49.</p> <p>The changes to the curriculum centred on introducing new or difficult concepts in the morning with the afternoons left for more practical reinforcement of learning.</p> <p>(Price, Knowles et al. 2013)</p> <p>(Waller, Eiser et al. 2008)</p>	<p>were recruited from 31 UK centres, randomized to control (n=14) or intervention (n=17). Control centres continued their usual care and education. Children in KO centres attended one of the 31 KO courses.</p> <p>Primary outcome measures HbA1c, Quality of life generic (PedsQL-G) diabetes specific (PedsQL-D) measured at 6, 12, and 24 months.</p> <p>Secondary outcomes measures BMI, DKA, hypoglycaemia rates</p> <p>Results</p> <ul style="list-style-type: none"> <li>• Baseline data were collected on 396 participants.</li> <li>• At 6 months the KO group showed significant improvement in.</li> <li>• PedsQL, physical, social, and psychosocial scores.</li> <li>• Diabetes symptoms</li> <li>• Treatment adherence at 12 and 24 months.</li> <li>• Overall HbA1c did not significantly change over time.</li> <li>• A sub-group with an HbA1c of &gt;80 mmol/mol at baseline showed a steady improvement in mean HbA1c for KO at 6, 12 and 24</li> </ul>	<p>WEDNESDAY</p> <p>Discuss overnight blood glucose levels How to adjust insulin How to manage illness using KICK-OFF guidelines Diabetes and long term health discussion Healthy lifestyle vs unhealthy KO Quiz Students to plan evening insulin dose Recap objectives for the day</p> <p>THURSDAY</p> <p>Discuss overnight blood glucose levels Exercise [theory] Exercise continued Healthy eating/weight control Sweets, treats and snacks Poster display Healthy eating lunch Exercise - practical session. Post exercise discussion KO Quiz Recap objectives for the day</p> <p>FRIDAY</p> <p>Discuss overnight blood glucose level Everyone discusses using KICK-OFF in school Alcohol Revision of CHO counting The teenage years, What happens next? Follow-up after the course</p>
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		<p>months.</p> <p><b>APPRAISAL</b> This appears to be an effective SDEP. A recent presentation concluded that participation in KICK-OFF resulted in significantly</p> <ul style="list-style-type: none"> <li>• improved psychological outcomes at 6 months, improved diabetes.</li> <li>• symptoms and adherence to treatment.</li> </ul> <p>For those with the poorest control at baseline, glycaemic control improved during the 2 year study reaching significance for participants at 24 months.</p> <p>If sustained, this is likely to reduce their risk of long-term complications. A team in Kuwait are now running KO as part of their service and are collecting data for the Sheffield study.</p>	<p>Discuss school packs Recap weeks learning objectives Evaluation Parents discuss the KO course, follow-up care and continued support</p> <p>Students to do fun activity/presentation to quiz winners.</p> <p>Various teaching resources and ideas are used in a flexible curriculum and carb counting practice is included at every opportunity.</p> <p>Each course was taught by three educators (a KICK-OFF paediatric diabetes specialist nurse (PDSN) and dietician and the PDSN from each centre). All educators attended a 3-day training course to improve teaching skills and gain experience in a secondary school.</p>
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### **Transition from paediatric to adult care (16-18 years)**

There appears to be a dearth of information available for young people and their families about the transition from child to adult service provision, and many young people seem unprepared to manage their own care and live independently (Noyes, Williams et al. 2010). NHS guidelines recommend that health providers develop a diabetes programme specifically for 16-18 year olds to ensure that they are able to self-manage their diabetes before transfer to adult services. In tandem an education package for MDTs should also be developed for both paediatric and adult services on the essential features of transition and how to incorporate advice/education to young people on what to expect in adult services (NHS 2013) .

CYP and parents commented that the period of transition is vital to how they manage their diabetes as adults. What the term transition actually means in practice should be made clear and everyone needs to be better informed of the process, which could be confusing. CYP felt that both services should communicate about individual patients and needs (Kime 2013).

ISPAD GUIDELINES are very clear about what is optimum care for adolescents, this being a transitional phase of development between childhood and adulthood. Transition from paediatric to adult services should be an organised process of preparation and adaptation. Multi-disciplinary Diabetes Services should be involved and the different systems of care (from family centred to adult oriented, secondary care) should be described and explained. The age at which transition happens varies and may be determined by local regulations, (as it is in Sheffield) or according to the maturity of the adolescent involved. Developmental psychology theory suggests that the transition should be toward emerging adulthood and not to young adult status.<sup>5</sup> There is a gap in the evidence base on best transitional models and this is currently being addressed. However, ISPAD recommend the following steps based on expert consensus opinion for successful transition to adult services:

- Identify an adult service able which can accommodate the needs of young adults with diabetes (e.g., a joint adolescent or young adult clinic, involving both professional teams, adolescents and their parents).
- Identify a key worker such as a specialist nurse for adolescence to liaise between paediatric and adult services.
- Plan in advance for the adolescent and parent as to the best time for transfer, subject to the availability of services and their own readiness.
- Develop clear, documented plans for transition, ideally providing a detailed, clinical summary of the young person's medical history, a written patient care pathway and protocol.

### **The WICKED programme**

The 'WICKED' Programme at Sheffield University is currently being piloted and communicating with other centres about its implementation. The following section is based on a telephone conversation with the researcher on this project (17/12/2014).

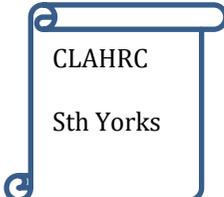
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<sup>5</sup> The theory of emerging adulthood is a useful way of conceptualizing the lives of people from their late teens to their mid- to late 20s in industrialized societies. It is usually experienced as positive but the developmental challenges it encompasses could be very difficult for CYP with diabetes Arnett, J. J. (2007). "Emerging Adulthood: What Is It, and What Is It Good For?" Society for Research in Child Development 1(2): 68-73.

Young people with type 1 diabetes aged 16–24 often have poor glycaemic control, with 33% having an HbA1c above 86 mmol/mol. In their transition from child to adult services young people become responsible for their own self-care with very little education and training (Beer, Eiser et al. 2014). Transition is a difficult period for parents too with this group having very distinct needs from the paediatric and adult community. Medical regimens may alter and parents can then become de skilled in new technologies, giving them less authority and skills to help their adolescents. Parents have to balance their involvement by allowing them to self-manage whilst, knowing their own child, requiring them to be vigilant on their adolescent’s behalf in order to keep them safe. This group may have sexual partners, have their own children and/or are trying to conceive. They may be away from home in flat shares or in other care situations.

In Sheffield, where this pilot was held, the transition from hospital based CYP services to adult services is at 16 years old and is not a staged transition as in other parts of the UK. Following an in-depth examination of the needs of young adults with Type 1 diabetes conducted by a team from the Psychology Department at the University of Sheffield, nurses in the city developed an age specific course for teaching the skills of diabetes self-management to this group. The development was based on an understanding of the challenges and lifestyle decisions that young people with Type 1 diabetes face and which often prevent them managing their diabetes effectively leading to serious long term effects on their health. Ethnographic observations of a traditional adult DAFNE course were made and the programme was adjusted for this project.

A very pragmatic, practical approach was taken in this pilot. Based on a constructivist approach, that is, the age and stage of emerging adulthood and the implications of this for managing Type 1 diabetes, was the main focus. Keeping this group safe until they reached the stage where they wanted to learn how to self-manage their life- long condition as adults was a main criterion. For example, relationships between healthy eating and diabetes can be difficult to grasp and come to terms with for some and others do not like injecting in front of their peer group. The nature and philosophy of the course and a built in follow-up succeeded in engaging this group to a great extent although the implications of potential on-going dependence needs to be considered. Programme designers envisage that a traditional DAFNE course with structured learning outcomes can then be accessed by CYP in the future when they may be more motivated to alter their behaviour.

FLAGS	TITLE AND DETAILS	PROGRAMME AIMS/BRIEF OUTCOMES	PROGRAMME CONTENT
	<p><b>WICKED</b> (Shortlisted in the 2012 Nursing Times Awards.)</p> <p><b>Working with Insulin Carbs, Ketones and Exercise to manage Diabetes</b></p>	<p>This is a structured education course based on elements of DAFNE and KICK off principles with a more flexible curriculum which includes dealing with social issues to encourage young people in transition</p>	<p><b>WICKED</b> is delivered in informal settings and begins by addressing the physiology of diabetes, moving onto skills for correction doses, treating hypos and applying these skills in everyday life. Complications and targets such as</p>



Phase 2 of a NIHR project to develop and assess a new model of care for young people with Type-1 diabetes living in Sheffield.

40, 16-25 year olds with type 1 diabetes

CLAHRC FOR SOUTH YORKSHIRE DIABETES INITIATIVES  
Self-Management of Diabetes Adolescent Programme of Research  
<http://clahrc-sy.nihr.ac.uk/theme-diabetes-adolescent.html>

WICKED educators

Vanessa Whitehead  
Diabetes Specialist Nurse

Kay Bottrell  
Diabetes Specialist Nurse

<http://clahrc-sy.nihr.ac.uk/theme-diabetes-wicked.html>  
Accessed 16/12/2014

CONTACT:  
If you would like access to data, tools, models and materials under CLAHRC SY's open access policy, please email the lead author [rebekah.beer@sth.nhs.uk](mailto:rebekah.beer@sth.nhs.uk)

to engage with the service and take ownership of their condition.

This is phase 2 of a longer term project (the antecedents of which are described in detail on page 51). It is one of the first of its kind in the UK and will inform whether there is a need to develop specific interventions to target problems to improve care of young people with Type-1 diabetes.

#### APPRAISAL

This carefully researched programme, underpinned by young people's views, and designed to match their needs continually is already benefiting patients transitioning from paediatric to adult care in Sheffield. Staff hope it can be evaluated across South Yorkshire in advance of a national trial to establish its effectiveness.

Six WICKED courses have been informally evaluated. Additional pilots in Leeds and Harrogate will add to the power of these, and before a RCT is considered.

Measurements taken thus far are;

- Self-efficacy
- QALYs
- Knowledge

avoiding hypos are also a facet of the course. It was delivered by Diabetes Specialist Nurses and Diabetes Specialist Dieticians with input from Clinical Psychology. Educators are trained in MI skills (see page 46).

- A five day structured age-appropriate education programme for young people with Type 1 diabetes making the transition from paediatric to adult care
- Four follow-up sessions in the 12 weeks following the course including a group session at 3 weeks, followed by 3 individual sessions by 'phone or face-to-face. This affords the opportunity to tailor education to the individual's needs where more information is needed in a specific area e.g. pump users, athletes or those with additional health concerns.
- It also addresses exercise, socializing, sex, drugs, alcohol, pregnancy, driving and other stresses which may affect diabetes management.
- An invitation to an annual WICKED weekend of activities providing opportunities for continued support from peers and the WICKED team.
- If the young people agree to this, a half-day session for parents/partners/friends giving an

	(Beer, Eiser et al. 2014)	<ul style="list-style-type: none"> <li>• fear of hypo</li> </ul> <p>This is an intense course in terms of staffing and mentor follow up by DSNs. It is very flexible and accommodates patients on different regimens including, MDI, TD and pumps. It was held in a Diabetes centre with very good attendance. Reasons for not attending sessions were due to leisure, college activities, signing on as unemployed and other commitments.</p> <p>It is on-going developmentally and it may be that a conversation with this group with a view to some level of collaboration could yield benefits for PCFT.</p>	<p>overview of the WICKED programme if offered. This enables them to provide on-going support and guidance to their young person in line with the WICKED philosophy.</p> <ul style="list-style-type: none"> <li>• Dietetic components are integrated into the course by feeding providing a realistic food diet for the week. One meal is taken out too experience diabetes management in this context.</li> <li>• Given the socio economic status of some participants, they are all issued with a transfer and travel card.</li> </ul>
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### DAFNE Adult Programme.<sup>6</sup>

FLAGS	TITLE AND DETAILS	PROGRAMME AIMS/BRIEF OUTCOMES	PROGRAMME CONTENT
	<p><b>DAFNE</b> The Dose Adjustment For Normal Eating course</p> <p>(Keen, Duncan et al. 2012)</p>	<p>AIM</p> <p>The aim is to help adults with Type 1 diabetes achieve dietary freedom by increasing their ability to adjust insulin doses to carbohydrate intake</p>	<p><b>DAFNE</b> is a structured diabetes education programme based on a German model consisting of 38 h of training delivered to between six and eight participants over five consecutive days.</p>

<sup>6</sup> KICK OFF, WICKED and education for 13 – 16 in the Hannon Manual are based on DAFNE.

		<p>on a meal-by-meal basis. It is associated with improved glycaemic control and quality of life in adults with type 1 diabetes.</p> <p>All DAFNE facilitators are experienced diabetes professionals who receive approximately 100 hours of structured training as part of the DAFNE educator programme, which includes peer-review of course delivery.</p> <p>DAFNE utilises an extensive quality assurance programme to ensure consistency and quality of course delivery. Regular audits are conducted, and results are fed back to diabetes centres for action. As per standard practice, DAFNE graduates are provided with a follow-up group meeting 6–8 weeks post-course that lasts approximately 2.5 h, and a group annual review meeting that lasts approximately 2.5–3 h. These meetings are conducted by trained DAFNE facilitators.</p> <p><b>APPRAISAL</b> Over the past decade, it has been adopted by more than 70 diabetes centres in the UK and Ireland and this had resulted in the delivery of the course to over 12 000 adults with Type 1 diabetes by 2009.</p>	<p>The topics are covered are</p> <ul style="list-style-type: none"> <li>• What is diabetes?</li> <li>• Food and diabetes</li> <li>• Insulin management</li> <li>• Management of hypoglycaemia</li> <li>• Monitoring</li> <li>• Sick day rules</li> <li>• Living with diabetes</li> <li>• School and diabetes</li> <li>• Transition of care</li> <li>• Nutrition</li> <li>• insulin dose adjustment</li> <li>• General diabetes advice (managing hypoglycaemia and other risks, sick-day rules and so on).</li> </ul> <p>DAFNE is founded on an experiential learning paradigm, uses various educational strategies to achieve its aims, including group discussions; structured presentations and practical tasks.</p> <p>The DAFNE course appears well suited to young people as regards the short-term gains of dietary freedom and flexibility.</p>
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### DAFNE Centre in Galway

This is a DAFNE centre which aims to develop something specifically for young adults. They are engaging with Sheffield NHS programme WICKED <http://clahrc-sy.nihr.ac.uk/theme-diabetes-wicked.html> (see Transitional programmes above, page 36).

Health Research Board-funded Health Research Award entitled “Improving Outcomes for Young Adults with Type 1 Diabetes in Ireland” Study recently commenced focusing on Young Adults with Type 1 Diabetes commences in DAFNE Centre in Galway  
Dr Sean Dinneen, lead DAFNE Doctor at University Hospital Galway



**Aim** - To establish a Galway-based user group (18-25 years) to help guide the research and be a voice for young adults with diabetes.

Mary Clare O'Hara  
Young Adult T1D Study

#### **Saolta University Health Care Group**

Endocrinology & Diabetes Centre, Galway University Hospitals

Tel: +353 (0)91 542840 | Fax: +353 (0)91 542107 | Mob: +353 (0)86 4108366

[www.saolta.ie](http://www.saolta.ie)

[MaryClare.OHara@hse.ie](mailto:MaryClare.OHara@hse.ie)

Personal Communication between MO & VF 20/10/2014 revealed that this work is very fledgling at present. Currently a systematic review is being conducted on interventions that improve outcomes for young adults with type 1 diabetes. Interviews are also being conducted with young adults and other stakeholders. Any intervention/ programme would be about take about 18-24 months to get underway.

#### **OTHER AWARDS**

Health Research Board-funded Health Research Award entitled “Improving Outcomes for Young Adults with Type 1 Diabetes in Ireland” for a study focusing on Young Adults with Type 1 Diabetes commences in DAFNE Centre in Galway. Dr Sean Dinneen, lead DAFNE Doctor at University Hospital Galway.

## CLAHRC South Yorkshire additional transitional initiatives.

### CLAHRC for South Yorkshire diabetes initiatives

#### Self-Management of Diabetes

#### Adolescent Programme of Research

<http://clahrc-sy.nihr.ac.uk/theme-diabetes-adolescent.html>

NIHR project to develop and assess a new model of care for young people with Type-1 diabetes living in Sheffield. The model of care will be tailored to the needs of each individual and their families and may include structured education, targeted skills training, psychosocial support, and peer support. The model of care will be delivered by Diabetes Specialist Nurses and Diabetes Specialist Dieticians with input for Clinical Psychology.

**Phase 1** Sheffield Teaching Hospitals, Sheffield Children's Hospital, Barnsley Hospital, and Rotherham Hospital. **The views of Young People, 11-21, Families and Staff on Current Services**, barriers to good self-management, views about possible interventions.

#### **Prevalence of depressive symptoms, diabetes distress and eating disorder in young people with type - 1 diabetes**

Questionnaire study aims to find out how common depressive symptoms and eating disorders are among young people aged 16 -25 years with type-1 diabetes . Data collected in this study will be linked to clinical data, such as blood sugar, collected from the service evaluation (see below). This study will be one of the first of its kind in the UK and inform whether there is a need to develop specific interventions to target these problems to improve care of young people with Type-1 diabetes.

#### **Service Evaluation**

Will assess the current provision of service for young people aged 16 -25 years with type-1 diabetes and the outcomes of care. Data will provide an indication of keys areas in which change is needed. The results will act as a baseline in which to measure the impact of any future changes in service.

**WITHCARE** – development of a telemedicine intervention which will allow the remote monitoring of blood glucose by the clinical care through real-time automated transmission of results from the patients monitor. It is hoped that this may allow more timely support to young people to assist them in managing their diabetes.

**Phase 2** will involve a multi-disciplinary team of dieticians, Diabetes Specialist Nurses, psychologists and clinicians developing a new model of care.

**The WICKED STUDY is part of this programme, see page 37.**

## Other local, regional and national training

Table 5 below contains some examples of training in the regions and beyond. Information was collated via Google searching and personal communications with the people involved. It may be worth a conversation with these providers to gain their views and details of successful programmes of work and/or ways of working with CYP and their families.

**Table 5. Other local, regional and national training**

Bury Fairfield hospital Bury Community Diabetes Service 0161 351 2137	<b>Workshops for teenagers and their families by arrangement.</b> Run by Claire O'Conner, Diabetes Specialist Nurse.
Tameside Hospital Paediatric Diabetes	Education and training manager; <a href="mailto:rehana.begaum@tgh.nhs.uk">rehana.begaum@tgh.nhs.uk</a>
Manchester (South) University Hospital, Wythenshawe Hospital 0161 2912472 Children's Ward F8  Judith Lickley DSN Miles Riddell Consultant	Telephone conversation 20/10/2014 with JL.  Tailor their teaching to <b>individual patient/families</b> on home visits. Two diabetes nurses know their families and all have very individual educational needs, medically and otherwise. They have tried group training sessions and people did not attend. Participant feedback suggested that families did not want to expose any lack of knowledge of the condition in front of others even though the sessions were informally run. Caseload of 100 children aged 0-19 years.
Epsom and St Helier University Hospitals NHS Trust Paediatric diabetic nurse specialist (Epsom Hospital) Tel: 01372 73 5443  Lorraine Laccohee Chris Bowyer Paediatric diabetic nurse specialist  <a href="http://www.epsom-sthelier.nhs.uk/our-services/a-">http://www.epsom-sthelier.nhs.uk/our-services/a-</a>	Paediatric and adolescent  This site manages all types of diabetes in CYP. Full multidisciplinary team on each hospital site compliant with requirements for the Paediatric Diabetes Best Practice Tariff. Offer regular structured education on all aspects of diabetes care for children and young people, both on an individual basis and a group setting. Feedback and input is welcomed from the children and young people in the service and their parents/carers so that the service provided is positive for those using it. Offer home and school visits to educate children and young people with diabetes and their family and carers including school staff. An interpreting service is available if required. An insulin pump service is run by certified pump trainers, both initiating the pump and on-going care and monitoring. A continuous glucose monitor system (CGMS) is available for diagnostic and therapeutic need.  Personal communication 22/10/2014

## Theoretical underpinnings for programmes

### Strategies for behavioural change

There are several psychological models which are used to guide and measure behaviour change. An analysis of 15 intervention RCT studies totalling n= 997 CYP with T1DM which contained adherence/self-management promoting intervention components demonstrated very modest improvements in glycaemic control with great variation in pre- to post treatment effects. It appears that multicomponent interventions, that is, those that targeted emotional, social, or family processes that will facilitate diabetes management are more potent than interventions that neglect these variables and simply target a direct, behavioural process (such as monitoring increase in blood glucose monitoring frequency). Multicomponent interventions, on the other hand, showed more robust effects on A1C and it is important to refine these interventions and examine their effect on CYP with diabetes health outcomes (Hood, Rohan et al. 2010).

### Trans theoretical model (TTM) of behaviour change

Diabetes self-management involves learning and implementing a complex set of behaviours. Whether a person will change their behaviour is related to a number of issues:

- How serious a person considers a condition to be
- Whether they consider they are responsible for it
- Whether they feel they can control it
- What the consequences of the particular disease/behaviour are

The Transtheoretical Model of Behaviour Change (TTM) explains the process of how people attempt to modify health-risk behaviours. It is based on 20 years of research and has been successfully applied to a variety of health behaviour areas. Within this model, there are sets of common principles that explain why people succeed or fail in changing their behaviour. Research has provided strong support for the reliability and validity of the model's core constructs, including stages of change, processes of change, decisional balance, and self-efficacy. The TTM helps individuals to move through a series of stages of readiness in the adoption of a healthy behaviour or cessation of an unhealthy behaviour. Many people need to bring about dramatic lifestyle changes to achieve ideal diabetes control after diagnosis and, based on the premise that

people are at different stages of readiness for engaging in health behaviours, intervention approaches using TTM are likely to be most helpful when they are matched to the individual's current stage of change. See Table 6 below for examples of these.

Mothers in particular are very involved with CYP care and equipping them with skills to affect the behaviour of CYP can have beneficial effects. A study working with 100 mothers taught them to use a stage-based behaviour change model; the Transtheoretical Model (TTM), with their children in an attempt to positively modify their diabetes behaviour. Measures were taken for changes in children and mothers. Following the intervention, there was a significant increase in CYP experiencing having diabetic complications. In terms of the mothers themselves, use of the TTM brought a positive change in stages of mothers' behaviours related to dietary management, blood glucose monitoring by using the home device and preparation and insulin administration. (Mohsen, Saafan et al. 2014).

**Table 6. Stages of change**

<b>Five stages of change</b>	
<b>Stage 1</b>	Not thinking seriously of changing behaviour
<b>Stage 2</b>	Thinking seriously of changing behaviour but not before a months and/ or no attempts to do so
<b>Stage 3</b>	Thinking seriously of changing behaviour within a month and made at least one attempt to do so lasting over a day within the last year
<b>Stage 4</b>	Behaviour has not changed but for less than 6 months
<b>Stage 5</b>	Behaviour change has been maintained for over 6 months

### **Motivational interviewing (MI)**

MI is another, very effective empirically supported, way to work with people without directing their behaviour. It is also based on stages of change models, its main principle being that, if given good information and space and time to think things through, people are inclined, and able, to make good decisions. It is essentially, a patient-centred approach to health behaviour change that helps patients to resolve ambivalence about change and enhances intrinsic motivation (Miller and Rollnick 2013) .

Originally used with adults, MI has now been extensively used with adults and other age groups. A meta-analysis of 37 MI interventions examining behaviour change and health outcomes for CYP (including diabetes) showed that MI is an effective and appropriate intervention for targeting child health behaviour changes. The effect of MI varied by health condition, the health domains with the largest overall effect sizes including Type 1 diabetes (Gayes and Steele 2014), asthma (Barone 2014), and paediatric oral health care (Freudenthal and Bowen 2010).

The effectiveness of MI in CYP populations and domains is also moderated by factors such as practitioner background, and the family member who participated. MI is most effective when both parent and child participate in sessions or when the cultural background of the practitioner matches the family (Gayes and Steele 2014).

The spirit and practice of MI particularly lends itself to resistant CYPs because MI 'conversations' about behaviour change are led by the CYP. MI is not about telling them they have a problem/ they need to change and to push them into lifestyle changes because this will be counter-productive. Instead, MI would view CYP as being experts in their own condition and life, rather than being passive recipients of advice and health care. A person practicing MI explores and facilitates decision making with CYP. They could not give direct advice or solutions without encouraging CYP to consider and talk about the choices available. Verbalising inner conflict helps a person resolve this whereas confrontation simply elicits denial and resistance. An MI therapist does not do most of the talking nor behave in a coercive manner.

Guiding principles of MI include:

- Not about telling patients what to do
- Connect with, and be guided by, the patient
- Curiosity - discovering what would make it easy (or difficult) to change their behaviour
- Helping people to do something differently

## Conclusions

MI as a mode of practice which is premised on the stages of change models and can be used by both lay and professional carers. It is not difficult to learn and an initial presentation/education session to parents and lay and professional carers would be useful in the first instance (Featherstone 2012). Training is readily available in the UK and VF has personally attended these and recommends them suggesting a basic course in the first instance. Details of upcoming courses are:

Forthcoming Cardiff MI workshops with Professor Stephen Rollnick are outlined below.

Cardiff Motivational Interviewing: Summer School 8-11 June 2015 (2 x Two-day training workshops)

### **1. MI Intermediate-Advanced Workshop: Mon 8th & Tue 9th June 2015**

Trainers: Stephen Rollnick (Cardiff, Wales) & Terri Moyers (Albuquerque, USA)

*Stephen Rollnick*, one of the co-founders of MI, will team up with *Terri Moyers* to provide a 2-day workshop, designed to provide a stimulating atmosphere for practice, discussion, demonstration and more. Terri is a very experienced MI trainer, and an old friend of Steve's, and their exchanges offer the promise of clarifying lots of things. What unites them both is a commitment to helping people to integrate MI into every practice and services. If you are new to MI, it is also possible to attend, provided that you commit to some preparation beforehand. Further details about the workshop and registration can be found [here](#).

## **2. MITI-4 workshop: Moyers & Ernst, Wed 10th & Thu 11th June 2015**

Trainers: Denise Ernst (*Oregon, USA*) and Terri Moyers (*Albuquerque, USA*.) *Denise Ernst* and *Terri Moyers* have been in the MI field for a long time, and work together on the development of the Motivational Interviewing Treatment Integrity (MITI) scale. A new version of the MITI has recently been developed, offering a substantial amendment to the currently used version 3. The workshop will be based on the new version 4.0. MITI is frequently used in assessing MI fidelity in research, and is also used to offer structured feedback to trainees through supervision and coaching. This workshop will appeal to those new to or familiar with Motivational Interviewing, particularly those wishing to better understand the micro-processes of MI or those conducting MI research.

Further details about the workshops and registration can be found [here](#).

<http://www.micardiff.co.uk/>

### Section 3. Existing structured diabetes educational programmes for HCPs

#### Comment

Specialist diabetes nurses (SpDN) have a significant impact on CYP and their families who rely on them for support, advice and guidance in terms of achieving good diabetic control and overall management. CYP and their families are the key decision makers and nurses can assist them in managing all aspects of their diabetes care including its physiological, physical, social, psychological and spiritual effects. Royal College of Nursing (RCN) guidelines are useful here and signpost new diabetes specialist nurses to resources and support and signpost other issues to be considered by them and their employers. Their educational role is discussed and the RCN offers advice on continuing professional development with appropriate study days, conferences and journals, academic courses and ideas for clinical supervision being included (RCN 2013).<sup>7</sup>

If a new diabetes service is being set up such as a SDEP for CYPs , involving other HCPs, it is important for SpDN and their employers, (in this case PCFT) to consider, and communicate with, the wider MDT in order to evaluate the skills, knowledge and attitudes of team members. The same applies to any other agencies they will be working alongside such as secondary care staff, GPs, school and nursery staff, and any other adults caring for CYP in other contexts (youth workers for example). Using various teaching tools, nurses should offer education to fellow professionals and the community using best practice guidelines. For example, the Medical Devices Agency guidelines (2002) <http://www.hra.nhs.uk/research-community/applying-for-approvals/medicines-and-healthcare-products-regulatory-agency-mhra-notice-of-no-objection-medical-device-research/> require training to be provided in the use of blood glucose and ketone monitors and insulin pens using a competency-based system.<sup>8</sup> In addition, all staff involved in the care of CYP with diabetes, should complete the e-learning package on the safe use of insulin (James, Atkins et al. 2011). In order to ensure 24/7 support to CYP it is important to work collaboratively and on an on-going basis with inpatient services, update regularly all staff involved in diabetes care ward(s), outpatients and accident and emergency departments. The RCN also offers guidance for planning care in school time (RCN 2009 ; RCN 2013).

Finding in the literature was that HCPs lack the skill set necessary for teaching, group work and for applying behaviour change techniques. This is understandable given they are two completely different skill sets. The DEPICTED study addresses this in part because it entails HCPs training in Motivational Interviewing skills (MI), a method which has already had success in many areas of health requiring behaviour change by CYP. See section on Theoretical underpinnings for programmes above, page 45.

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<sup>7</sup> This publication is due for review in November 2015.

<sup>8</sup> Support to undertake this training can be provided by companies that supply the blood glucose monitors and pens, as well as from organisation's education and training departments.

IDF's Diabetes Education Modules are intended to be used by health professionals wishing to develop a high quality education programme. They offer facilitators' notes and activities in order to increase participation and allow some practical application of the discussion material and are available on CD rom with a Facilitator's Guide containing information to assist in planning, implementing and evaluating the programme. Although they are for adults courses only, their content could be adapted to complete some gaps in PCFT's CYP proposed programme (see C, page 84).

The KICK-OFF teaching skills course is now available as a generic resource for paediatric HCPs. This includes time in a secondary school observing experienced teachers and delivering small group teaching, which is an extremely useful thing to do for those who are unused to school settings.

It is, however, the SWEET curriculum adapted from a European curriculum and rooted in a sound research base which meets all general and specific diabetes guidelines. It acknowledges that training should be theory based and family, culture, developmental age, and psychological factors play a part, over time, in the self-management learning process. It also advocates delivering diabetes education to other agencies (e.g. clubs and nurseries).

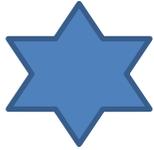
## Programme descriptions

**Table 7. Existing structured diabetes educational programmes for HCPs**

FLAG	NAME & DETAILS
 <p>HTA NSF CYP RCT</p>	<p><b>DEPICTED STUDY</b> RCT. Development and Evaluation by a cluster randomised trial of a Psychosocial Intervention in Children and Teenagers Experiencing Diabetes. (Gregory, Robling et al. 2011)</p> <p>Objectives</p> <ol style="list-style-type: none"> <li>1. To survey existing evidence regarding the effectiveness of psychoeducational interventions applied in paediatric diabetes services.</li> <li>2. To assess children's and their families' expectations from consultations with HCPs working in children's diabetes services.</li> <li>3. To develop a training package for paediatric diabetes HCPs to help them counsel their patients and families more skilfully during routine health-care encounters, particularly in relation to issues requiring behaviour change.</li> <li>4. To evaluate the effect of communication skills training for HCPs on HbA1c levels and psychosocial outcomes on</li> </ol>

	<p>patients and on the latter in their careers. 5. To evaluate the costs associated with this intervention.</p> <p>A previous pilot and RCT showed the effectiveness of Motivational Interviewing skills (see page 46) in facilitating behaviour change in teenagers with diabetes, leading to falls in their HbA1c levels.</p> <p>However, these techniques require training for HCPs. Given the shortage of trained psychologists, there is a need to improve the skills of paediatric diabetes health-care professionals in counselling their patients and carers during routine clinical encounters, particularly in relation to issues requiring behaviour change.</p>
<b>FLAG</b>	<b>NAME &amp; DETAILS</b>
	<p><b>KICK-OFF</b></p> <p>The <b>KICK-OFF</b> course (Kids In Control OF Food) course is a five-day program aiming to provide better knowledge about diabetes and the skills to manage it successfully.</p> <p>The course included the development, with Sheffield Hallam University School of Education, of a bespoke teaching skills training course, to provide the paediatric nurses and dieticians who would teach KICK-OFF with better understanding of educational theory and practice.</p> <p>According to an observation of teaching sessions by study staff, the course had excellent feedback. However, it needs to be related more directly to the KICK-OFF curriculum by using exemplars from it. Identifying and developing strategies to help educators with the course's more challenging areas such as how to teach skills required by students such as maths, how to monitor and assess student learning and strategies for behaviour management.</p> <p><a href="http://connect.qualityincare.org/diabetes/self_care/case_studies/kick-off_supporting_self_care_for_paediatric_type_1_diabetes">http://connect.qualityincare.org/diabetes/self_care/case_studies/kick-off_supporting_self_care_for_paediatric_type_1_diabetes</a></p> <p>Accessed 24/02/2015</p>

FLAG	NAME & DETAILS	CURRICULUM
	<p><b>IDF</b></p> <p>These have been developed to support the education and training of health care professionals with the latest evidence-based material. They are not intended for commercial use.</p> <p>IDF uses the most up-to-date information and guidance on diabetes education in the Modules and carefully evaluates users' feedback.</p> <p>In Arabic, Chinese, French, Russian, Spanish and English</p> <p>© International Diabetes Federation. All rights reserved. All intellectual property relating to the Modules and the suite of tools they provide are IDF's. ISBN: 2-930229-44-6 02 Please see note i</p> <p><a href="http://www.idf.org/diabetes-education-modules">http://www.idf.org/diabetes-education-modules</a></p> <p>Accessed 28/01/2015</p>	<p><b>Section 1</b> – Self-Management Education consists of two modules that cover the role of the diabetes educator, principles and practical application of teaching and learning and psychosocial issues and counselling for behaviour change.</p> <p><b>Section 2</b> – Diabetes and Lifestyle Intervention consists of six modules the basics of diabetes management; pathophysiology, classification and prevention, the basics of nutrition and physical activity, and an overview of clinical monitoring.</p> <p><b>Section 3</b> - Pharmacotherapy consists of three modules covering blood glucose-lowering medicines, insulin therapy and an overview of complementary therapies.</p> <p><b>Section 4</b> – Glycaemic Excursions consists of modules devoted to hypoglycaemia, managing sick days, diabetic ketoacidosis and hyperosmolar hyperglycaemic state.</p> <p><b>Section 5</b> – Diabetes-Related Complications consists of five modules focusing on the long-term complications of diabetes.</p> <p><b>Section 6</b> – Special Situations contains one module on planning for disasters.</p>
FLAG	NAME AND DETAILS	CURRICULUM
	<p><b>National Health Service (NHS) National Curriculum for the training of HCP who care for CYP with DM.</b></p>	<ul style="list-style-type: none"> <li>• Aetiology, epidemiology and diagnosis</li> <li>• Phases of type 1 diabetes</li> <li>• Other types of diabetes</li> <li>• Insulin therapy</li> </ul>



The HCP curriculum developed for the EU SWEET project has been adapted for use in the UK. This three year project aimed to improve standards of care for CYP with diabetes and create centres of reference. The curriculum was developed using the following:

- Examination of currently available curricula
- A PubMed search
- Currently available guidelines covering broad spectrum of diabetes and specific aspects (e.g. Ketoacidosis)
- Number of meetings with European MDT members involved in the SWEET project.
- Consultant consultation

<http://www.sweet-project.eu/>

(Waldron, Allgrove et al. 2011)

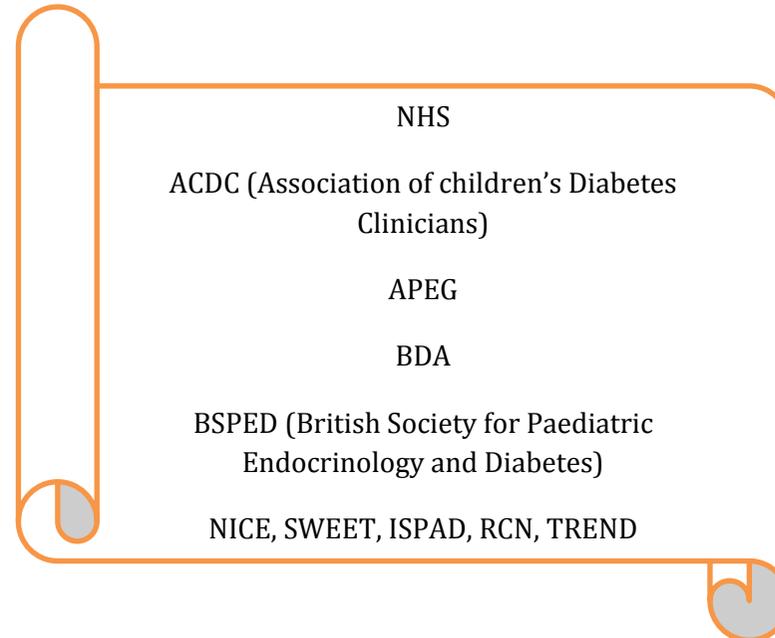
SWEET developed a core (basic knowledge and competency framework for all members of a diabetes MDTs and the extended curriculum (covering specific issues pertinent to individual team members). The course has a hierarchical structure which defines increasing levels of knowledge within categories and can relate to particular disciplines.

The five levels of expertise are:

- Basic awareness
- Factual knowledge
- Working knowledge
- In-depth understanding
- Critical understanding

- Complications, acute and chronic
- Defining the MDT and delivery of ambulatory services
- Education of CYP and carers
- Nutrition
- Management of physical activity and exercise
- Monitoring of diabetes and screening for associated conditions
- Psychological aspects
- Surgery, fasting and sick day rules
- Young people and transition to adults care
- Vision of the future for CYP diabetes services

Every topic covers four/five levels of expertise (see first column). Each MDT should have members who, between them, have all been trained in all aspects of the competencies at all levels.



	<p>The DETAILED MULTI LEVEL curriculum is available  <a href="mailto:diabetes@leicester.prontaprint.com">diabetes@leicester.prontaprint.com</a>  0116 275 3333 quote Diabetes 192</p>	
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## Local /regional initiatives/interventions for HCPs

**The Health Foundation  
Co-creating Health 2012 programme.**



**Inspiring Improvement 2007 – 2012**

The [Co-creating Health Programme](#) is designed to demonstrate how self-management support can be embedded in mainstream healthcare. It draws on international research into how best to support self-management and combines three interlinked approaches:

- Practitioner development that builds their skills and techniques in proactively supporting self-management
- A patient skills programme that builds people’s knowledge and confidence to better manage their own condition
- Service improvement so that systems and processes that services use are designed to support self-management

### **Phase one: build patient and clinician skills and evidence (2007- 2010)**

By the end of July 2010, 882/1114 patients had completed the programme. Statistically significant changes in positive engagement in life, adopting a more constructive attitude and approach to their condition, having more positive emotional wellbeing and using self-management skills and techniques. At the end of May 2010, 437/510 clinicians had completed an Advanced Development Programme. Evaluation has shown that clinicians are more likely to apply self-management support practices in their consultations

### **Phase two: sustain and spread the approach 2011-2012**

Eight demonstration sites were chosen to deliver the three training and information strands of the programme. Each site focused on one of four clinical areas: chronic obstructive pulmonary disease (COPD), depression, diabetes and musculoskeletal pain. The sites dealing with Diabetes; Guy’s & St Thomas’ Hospital NHS Foundation Trust with Lambeth and Southwark & Whittington Health with Islington and Haringey, have issued a joint report entitled “Co-creating Health. Phase2. Local Evaluation. January 2013. Guys & St Thomas NHS Foundation Trust & Whittington Health”

[http://www.health.org.uk/media\\_manager/public/75/publications\\_pdfs/Local%20evaluation\\_GSTT%20and%20WH.pdf](http://www.health.org.uk/media_manager/public/75/publications_pdfs/Local%20evaluation_GSTT%20and%20WH.pdf)

Accessed 31/10/2014

### **Engaging people**

Ideally the Self-Management Programme needs to be built into the diabetes care pathway. It was found that patients are more likely to attend the SMP if encouraged to by their clinician. The most successful method was a personal letter of invitation from the Diabetes Consultant.

<http://www.health.org.uk/areas-of-work/programmes/co-creating-health/related-projects/whittington-health/whittington-health-learning/>

Accessed 31/10/2014

The Co-creating Health project was associated with statistically significant and clinically important improvements in HbA1c and most of those who went through the programme supported it. However, challenges remain in engaging local populations of both NHS staff and patients

<http://www.health.org.uk/areas-of-work/programmes/co-creating-health/>

Accessed 31/10/2014

### **Linked projects for adults**

#### ***Guys and St Thomas's***



<http://www.health.org.uk/areas-of-work/programmes/co-creating-health/related-projects/guy-s-and-st-thomas-nhs-foundation-trust/Guys-and-St-Thomas-NHS-Foundation-Trust-work-so-far/>

#### **National Diabetes Quality Award. *"The best initiative for supporting self-care"*. Whittington Health.**

As part of a twin site for the above programme, Whittington Health focussed on self-management support for people with diabetes, delivering Co-creating Health across primary and secondary care in the following ways:

- Self-Management Programme (SMP) for people with long term conditions
- Advanced Development Programme (ADP) for clinicians
- Service Improvement Programme (SIP) to redesign services



260 people with diabetes completed the Self-Management Programme with positive feedback from participants. Many SMP graduates continue to meet at regular course reunions. Evaluations found that the course helped with problem solving, goal setting and peer support and gave people a better understanding of their condition. Audits of blood tests before and over one year after attending the SMP has also shown significant improvements in HbA1c for people who attended.

10-12 SMP courses per year have been run. 12 local patients and clinicians have been trained to deliver the programme. 22 courses were delivered.

The team found it slightly harder to engage with clinicians about the Advanced Development Programme. However at the end of phase one, 148 local clinicians have completed 11 ADP courses. 97% of respondents said the ADP had provided them with new skills to use. 91% said they had implemented parts of the ADP into their daily professional practice. Confidence to use the ADP skills was scored as 7.1/10, indicating on-going learning needs.

A number of teams have been involved in quality improvement exercises such as developing an agenda/goal setting tool to use in patient consultations; designing a ruler measuring patient confidence; and adapting the diabetes template on the electronic patient record. Training provided to clinicians in improvement models has also been highly valued and used to redesign and improve the quality of services.

### ***Action for Diabetes***

#### **Improving diabetes care across Calderdale and Greater Huddersfield Calderdale and Kirklees Primary Care Trusts**

In common with the two other pilots, patient focus groups were held to introduce the idea of the Year of Care and find out what patients want from their diabetes care.

In terms of emotional support, patients wanted:

- someone to talk to a buddying system/peer support
- support for families and carers
- 24 hour telephone helpline with trained staff
- less busy staff with time to listen
- more recognition, help and support with depression
- massage and meditation

On access to services, they wanted them:

- closer to home

- a one-stop shop – e.g. pharmacists offering phlebotomy
- do not want to attend hospital for blood tests
- weekend/evening clinics with eye specialists
- easier/more access to foot care services
- longer opening hours with drop in clinics
- professionals to keep to appointment times
- professionals to follow-up on what they say they will do

On information, they wanted:

- clearer access to results with explanations
- innovative use of technology
- information available in different languages
- information for people who are deaf/blind
- high quality information throughout care not just at onset
- more advice on food and weight management
- a plan of what to expect in the next 12 months
- more group education evenings

Lifestyle and social aspects included:

- more dosette boxes (boxes which help people manage their medicines) for medicines provided free of charge
- a greater range of activities to support a healthy lifestyle e.g. tai chi or yoga
- subsidised private gym membership
- subsidised weight loss classes
- training for staff at leisure centres
- more emphasis/guidance from doctors and nurses on non-medical lifestyle activities
- single sex groups for some people
- more local support groups to encourage lifestyle change

## Professional conferences and websites

Key conferences to attend:

Diabetes UK – [www.diabetes.org.uk](http://www.diabetes.org.uk)

British Society for Paediatric Endocrinology and Diabetes International Society for Paediatric and Adolescent Diabetes. (For a full listing of international events visit <a href="http://www.ispad.org">www.ispad.org</a> ) Lilly paediatric symposium. RCN Children and Young People's Diabetes Community <a href="http://www.rcn.org.uk">www.rcn.org.uk</a>
Useful web sites: <ul style="list-style-type: none"><li>• <a href="http://www.nhsig.nhs.uk">www.nhsig.nhs.uk</a></li><li>• <a href="http://www.yorkshirediabetes.com">www.yorkshirediabetes.com</a></li><li>• <a href="http://www.ispad.org">www.ispad.org</a></li><li>• <a href="http://www.jdrf.org.uk">www.jdrf.org.uk</a></li><li>• <a href="http://www.childrenwithdiabetes.com">www.childrenwithdiabetes.com</a></li><li>• <a href="http://www.sign.ac.uk">www.sign.ac.uk</a></li></ul>

## Other resources for HCP skill acquisition

Skills required by CYP diabetes specialist nurses include:

- non-medical prescribing and patient group directives
- pump courses
- RCPCH e-learning adolescent health module
- motivational interviewing
- teaching skills
- group facilitation

There are existing training modules on insulin pumps and psycho-social management. These are run by York, Sheffield Hallam & Warwick Universities, Sheffield Children's Hospital & NHS Diabetes.

The following teaching skills training courses for paediatric health care professionals have the potential to be developed:

- Training HCPs in the Transition diabetes care
- Certified Diabetes Educators Course
- E-Learning Psycho-social Management Module

## Recommendations

As discussed earlier in this section, an understanding by HCPs that CYP and their families are, as well as individual beings in small groups, are also part of larger social systems/cultures/families/economic groups, could aid them in understanding where an individual or family sits in these structures. This knowledge helps support necessary and appropriate behaviour in order to improve and maintain family/community cohesiveness and support (The Health Foundation 2010). Interventions and programme deliverers who ignore these influences are unlikely to succeed (Hood, Rohan et al. 2010). A systematic review suggested that HCPs should adopt a person centred strategy and strive to determine each young person's status regarding risk perception, knowledge, and perceived control, as well as perceived benefits and costs of health behaviour group.<sup>9</sup> Person centred care will ensure that the personal situations, attitudes, knowledge, skills of CYP are assessed and acted upon (Larsman, Eklöf et al. 2012). Matching and adjusting insulin profiles to quantified food intake and exercise levels have become an important part of modern intensified management with multiple injection treatment, the availability of analogue insulins and infusion pumps. Higher levels of education and understanding are required for these interventions to be successful and require more time, skill and greater resources from the educational team. Age appropriate social activities with CYP build up self-efficacy to manage diabetes management and are part of their education and as such, should be included in working hours (RCN, 2013). SWEET in particular advocate the use of CYP camping trips away from home for example:

### Multidisciplinary teams need to:

- Become teachers from basic to expert level
- Understand their own limitations in teaching different age groups
- Explore ways to enhance teaching skills
- Have their educator-training needs assessed and addressed

### Recommendations from the appraisal of the evidence suggest that HCPs undertake to learn:

- Teaching skills and methods
- Child development, stages of learning, levels of understanding, risk taking
- Counselling skills and/or MI skills
- Behaviour change strategies

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<sup>9</sup> This would require the provision of, and training in, psychological based measurements.

### **Requirements for a re-design of HCP standardised training involves ensuring that:**

- There is evidence of listening, communicating and collaborating with CYP, families, carers and HCPs in all disciplines
- There is standardised and accredited training developed for all HCPs.
- At the very least an e-learning foundation package based on the first level of the NHS curriculum (see page 52 above) should be mandatory for all HCPs working with CYP with diabetes (NHS 2013).

### **Conclusions**

Existing structured educational programmes for HCP's have been described with some recommendations for practice. In particular, the evidence highlights the importance of teaching skills acquisition necessary for HCPs to successfully deliver SEDP's to SYP. Given the shortage of trained psychologists, there is a need to either train health psychologists to undertake diabetes education, and/or improve the skills of paediatric diabetes HCPs so they can work alongside each other, or complement each other's skills. MDT diabetes teams should be cohesive, integrated and highly skilled with various levels of skills across the team which, as a unit, fulfils the criteria for the NHS training curriculum for HCPs looking after CYP with diabetes (NHS 2013). Highly skilled MDT members are key to a successful SDEP as the German model has shown. Their HCPs undergo strict training and this has been shown to help to improve the situation and prognosis of CYP with diabetes (Lange 2013).

## Section 4. Type 2 Diabetes

### Comment

Type 2 Diabetes Mellitus (T2DM) is a serious, progressive long-term condition affecting over 2.5 million people in England and when not managed well, can result in blindness, kidney damage, foot ulceration and amputation. Furthermore, it is often associated with complications, which together with chronic high blood glucose levels and additional risk factors increase the risk of stroke, myocardial infarction, peripheral vascular disease and death. The prevalence is greatly increased in certain black and minority ethnic (BME) populations.

CYP with type 2 diabetes are a high risk group. Research is urgently needed on drug therapy, training and long-term lifestyle modification for this group of patients (Lange 2013). The self-management of T2DM largely focuses on modifying lifestyle behaviours. Supporting these patients requires a multifaceted solution embedded with behaviour change mechanisms, whereby the patient is involved in their own care and is receiving regular feedback from their health care providers. Telemedicine delivered through web and mobile phone systems overcome geographical barriers, providing frequent follow-up and feedback to diabetes patients but is challenging and costly (Cafazzo and Goyal 2013).

Diabetes UK new Parliamentary report “State of the Nation: Challenges for 2015 and beyond” examines the quality of diabetes care being provided, and gives a snapshot of how well people living with both Type 1 and Type 2 diabetes are being supported. One of the first activities of this partnership is to help reduce risk levels and raise awareness of this condition.



State of the nation  
2014.pdf

### DESMOND adult programmes

#### Background to DESMOND (Diabetes Education Self-Management On-going & Newly Diagnosed)

**DESMOND** is the only programme that currently meets the standards identified by NICE and its implementation would fulfil the obligations of various health organisations obligations for structured education for Type 2 Diabetes. It comprises a structured, nationally recognised education programme for patients with Type 2 diabetes. Each 6 hour DESMOND course, presented by two health professionals, is mapped to an accredited curriculum and is delivered to 10 patients (who may be accompanied by a friend, relative or carer). A randomised controlled trial provided evidence that patients participating in DESMOND demonstrated greater understanding of diabetes and decreased depression scores

compared with patients in the control group exposed to a spectrum of routine care. Furthermore, DESMOND appeared to elicit greater improvement in lifestyle measures (propensity to smoke and weight loss), as well as significantly greater improvement in risk scores for Coronary Heart Disease (Davies, Heller et al. ND).

Each module is delivered by 2 trained DESMOND Educators who are registered health care professionals. The modules can be delivered in 1 day or 2 half day formats. Further training of 1 day is required to deliver the BME modules. DESMOND offers a variety of evidence based modules to support self-management for either people at risk of diabetes or those who are already identified as having diabetes. It also offers a variety of evidence based modules to support self-management for either people at risk of diabetes or those who are already identified as having diabetes. Desmond is a cost effective treatment in the management of diabetes (Davies, Heller et al. ND).

<http://www.desmond-project.org.uk/commissioningdesmond-305.html>

## Programme descriptions

**Table 8. CLAHRC LNR Initiatives for Type 2 Diabetes**

National Institute Of Health Research Collaboration For Leadership In Applied Health Research And Care Leicester Northamptonshire And Rutland (NIHR)		
Type 2 Diabetes Initiatives <b>Self-Management and Education</b>		<b>Type 2 diabetes</b>
A localised (Nottinghamshire) curriculum for a structured education programme for people with Type 2 diabetes has been developed and agreed. The PCT is now seeking expressions of interest for delivery of this service across the greater Nottingham area in partnership with Nottinghamshire County PCT.		
<b>Three main areas of investigation:</b>		
<b>1</b> Partners: CLAHRC for South Yorkshire, University Hospitals of Leicester NHS Trust, NHS Leicestershire County and Rutland, NHS Northamptonshire Teaching PCT, NHS Sheffield PCT, NHS Rotherham PCT, University of Leicester, University of	<b>2</b> <b>Principal Investigator:</b> Professor Melanie Davies	<b>3</b> Partners: University Hospitals of Leicester NHS Trust and the University of Leicester <a href="http://www.leicestershirediabetes.org.uk/748.html">http://www.leicestershirediabetes.org.uk/748.html</a>  Principle Investigator: Professor Melanie Davies

<p>Sheffield</p> <p>Principal Investigator: Professor Melanie Davies</p>		
<p>1</p> <p><b>DESMOND On-going Educational programme.</b> See Going Forward, Table 9. DESMOND Research Projects, page 65.</p> <p>A cluster randomised controlled trial to test an integrated approach for promoting effective self-management in people with established Type 2 Diabetes Mellitus -</p> <p>01/2011 and is expected to end 06/2013</p> <p><b>Aims</b> To test the effectiveness of an ongoing programme of education and care planning in people with established type 2 diabetes</p> <p><b>Summary</b> The DESMOND Newly Diagnosed programme fulfils national standards for structured education and has been shown to be effective in the newly diagnosed population (Davies, Heller et al. ND). It is believed that for the benefits of education to be sustained, continued support for patients is required on top of an initial programme. In addition, patients need to work with health care</p>	<p>2</p> <p><b>DESMOND Foundation Study</b> A RCT of the DESMOND Foundation Programme for people with established Type 2 Diabetes Mellitus in a multi-ethnic population in Leicester and South Birmingham</p> <p>This study is in follow up.</p> <p><b>Aims</b> To test the effectiveness of the DESMOND Foundation programme in a multi-ethnic population with established Type 2 diabetes</p> <p>The DESMOND Newly Diagnosed programme fulfils national standards for structured education and has been shown to be effective in the newly diagnosed population (Davies, Heller et al. ND). DESMOND programmes have now been developed for the South Asian population (DESMOND BME, Section 5. Existing structured educational programmes for BME. Page 68) and for those who have had diabetes for some time (DESMOND Foundation).</p> <p>The present study will test the effectiveness of the DESMOND</p>	<p>3</p> <p>DESMOND Quality Development Study Work on quality development as part of the structured Self-Management and Education Theme</p> <p><b>Aims</b> The QD team (CLAHRC) sought to answer the following questions:</p> <ul style="list-style-type: none"> <li>• Are the current assessment tools reliable in terms of capturing the educator processes?</li> <li>• If the tools are used by 'experts' to view the same programme, do they get the same results?</li> <li>• What are the views of the assessors about the QD process and how would it need to change?</li> <li>• What are the challenges in operating such a system from the perspective of the educators and coordinators</li> <li>• What are the costs associated with the current QD approach?</li> </ul> <p><b>Summary</b> The QD process for the current DESMOND programme consists of internal and external processes. The internal processes are focused on the educator undertaking personal and peer reflection on their practice following the delivery of a set number of programmes. The external component starts with the initial training support and is followed by the application of external review tools (at predetermined</p>

<p>professionals who are trained to consult in a way which values their contribution and encourages them to participate in every aspect of their care, including decisions about therapy (i.e. the 'Care Planning' approach).</p> <p>The study will evaluate the on-going effective self-management of people with type 2 diabetes within a primary care setting. The intervention will be delivered over the two years of the study and follow-up will be at 12 and 24 months. The aim is to recruit 532 patients from 19 practices (split between the two sites).</p> <p>Study outcomes The primary outcome is change in HbA1c Secondary outcomes include biomedical, lifestyle and psychological variables</p> <p>A localised (Nottinghamshire) curriculum for a structured education programme for people with Type 2 diabetes has been developed and agreed. The PCT is now seeking expressions of interest for delivery of this service across the greater Nottingham area in partnership with Nottinghamshire County PCT.</p>	<p>Foundation programme in a multi-ethnic population with established type 2 diabetes.</p> <p>The aim is to recruit 640 patients from 16 practices (320 from eight practices in each site). Participants in the intervention arm will attend a DESMOND Foundation Programme delivery is in English or a South Asian language (Gujarati, Urdu or Punjabi). Follow-up will be at six and 12 months.</p> <p>Study outcomes The primary outcome is change in HbA1c Secondary outcomes include biomedical, lifestyle and psychological variables</p>	<p>times).</p> <p>The DESMOND observation sheet (DOS) is a paper-based assessment tool designed to assess the extent to which the content and process indicators of observable educator behaviours are being delivered. The DESMOND Observational Tool (DOT) is a quantitative measure of who is talking at 10 second intervals and is designed to assess the interaction of the educator and the participants of the group.</p> <p>A review of the QD processes over the past year has raised concerns about the objectivity of the QD tools, the quality of the feedback from 'assessors' and the system's cost effectiveness</p>
<p>Further information</p> <p>If you would like to be involved in this project, or for more information, please</p>	<p>Further information</p> <p>If you would like to be involved in this study, or for more information, please</p>	

<p>contact:</p> <p>Dr Helen Dallosso (Research Associate)</p> <p>or visit</p> <p><a href="http://www.desmond-project.org.uk/desmondongoing-300.html">www.desmond-project.org.uk/desmondongoing-300.html</a></p>	<p>contact:</p> <p>Dr Helen Dallosso (Research Associate)</p> <p>or visit</p> <p><a href="http://www.desmond-project.org.uk/foundationstudy-274.html">www.desmond-project.org.uk/foundationstudy-274.html</a></p>	
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**Table 9. DESMOND Research Projects**

<p><b>DESMOND Research Projects</b></p> <p>The DESMOND Project continues to be at the forefront in developing Diabetes Education and continue to ensure that the programmes it has developed are constantly being tested, evaluated and improved. DESMOND Programmes Researchers are currently involved in the following studies:</p> <p><b>The Lay Educator study</b> <span style="background-color: yellow; padding: 2px;">Type 2 diabetes</span></p> <p>This is being funded by Diabetes UK, it will be looking at whether or not lay people can be trained to successfully deliver DESMOND, to people newly diagnosed with Type 2 Diabetes, in partnership with Health care Professionals. <a href="#">Read more</a> about the study</p> <p></p> <p><b>Let's Prevent</b></p> <p>A Randomised Controlled Study for the Prevention of Diabetes using an Educational Intervention and Continuous Support Programme in those with Pre-Diabetes in a Multi Ethnic Population. Funded by NIHR programme grant. <a href="#">Read more</a> about the study.</p> <p><b>SMBG Monitoring Study (Self-Monitoring Blood Glucose)</b></p> <p>The study, funded by Diabetes UK, is a multi-site study being run in 8 PCTs around England. Patients newly diagnosed with type 2 diabetes were referred to the trial. Participants attended a DESMOND course during which they learnt about self-monitoring using either blood glucose testing or urine testing. <a href="#">Read more</a> about the study.</p> <p>The latest DESMOND research news can be found on the <a href="#">Desmond-project website</a>.</p>
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### **New Wave Of DESMOND Programmes and Modules**

Building on the foundation of existing DESMOND programmes. A new wave of DESMOND programmes will soon be emerging from research, fit for purpose, evidence-based, and ready to be made available throughout the UK. Because these programmes build on existing DESMOND training, they require less additional resources and represent excellent value for money.

#### **DESMOND On-going Model – GOING FORWARD**

##### **Walking Away from Diabetes**

Module

[A Safer Ramadan: An exciting new initiative to support safer fasting and feasting](#) (see Section 5. Existing structured educational programmes for BME. page 68)

During Ramadan 2010 a new education programme for people with Type 2 Diabetes will be available in Leicester, Preston, Harrow, Reading and Kirklees. This pilot project is the start for a full future programme.

<http://www.leicestershirediabetes.org.uk/424.html>

Accessed 20/11/2014

### **Celebrating DESMOND Annual Awards Programme, which aims to reward excellence and share learning across the DESMOND community has been recognised in the annual DESMOND awards**

Team of the Year – Local Community Partnerships

Educator of the Year – Ciara Heverin, Galway University Hospitals and Galway, Roscommon PCCC

Excellence in Type 2 diabetes structured education – Cumbria Partnership NHS Foundation Trust

Innovation Award – Lancashire Care Foundation Trust

Patient of the Year – Clare nominated by Eleanor Gemmell, Great Yarmouth and Waveney CCG

[www.celebratingdesmond.org](http://www.celebratingdesmond.org)

Accessed 21/11/2014

## **Conclusion**

Although the scan focuses on T1DM, information on T2DM is included because of the increasing prevalence of this condition. Courses for adults with Type 2 diabetes have been described with the understanding that these could be adapted for CYP and their carers. Given the prevalence of Type 2 diabetes world-wide, this is a service which could be developed and implemented using the excellent resources already in use and those in development most having been, or are in the process of being, empirically tested by stringent research methods.

## Section 5. Existing structured educational programmes for BME.

### Comment

Structured diabetes education for BME is an area identified by PCFT as currently lacking. PCFT is already actively engaging with the Jewish community in Prestwich and working to identify what they want in terms of diabetes structured education and where and who they would prefer this to be delivered by. Oral health care may be an issue for CYP in this community and in relation to potential heart problems in adulthood. It is suggested that the provision of a module on this subject is included in any future educational programme. PCFT is also beginning to engage with other minority groups.

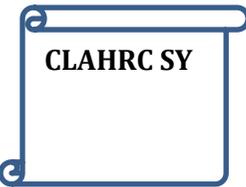
Issues to address in relation to BME education include the difficulty of involving such groups as expert patients in their own care. Although encouraged lay led 'expert patient' programmes oriented to increasing self-efficacy are widely encouraged, recruitment to such programmes from lower socio-economic and minority ethnic groups is difficult and (along with people with low health literacy) have limited attendance at such initiatives. Group education in diabetes, when intensively delivered, culturally tailored, and closely linked to clinical care does improve long-term outcomes.

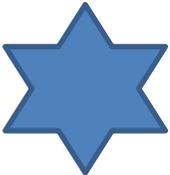
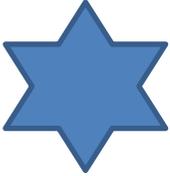
Self-management education programmes are usually directed mainly or exclusively towards biomedical goals (focusing, for example, on a structured curriculum of knowledge and skills). This could explain their limited success because, for some people, self-management is highly constrained by social and economic factors (Greenhalgh, Campbell-Richards et al. 2009). The routines necessary for good metabolic control and for minimising future cardiovascular health complications are particularly challenging for underprivileged CYP groups with minority backgrounds. Restraints to achieving these can consist of resource constraints in health care organisation and cultural explanations of health care failures and successes. An individual's personal prerequisites should, therefore, be integrated into any SDEP and self-care routines (Boman, Bohlin et al. 2015). For CYP with minority backgrounds with type 1 diabetes there are, internationally, constraints and implications for their care. It has been shown that belonging to a minority ethnic group might contribute to poor metabolic diabetes control among young people, and thus to poor long-term quality of life. Perceptions of risk is a factor here and a systematic literature review identified, amongst other factors, ethnicity, socio-economic status, and levels of knowledge regarding risk and health outcomes as covariates of adolescents' risk perceptions with regard to health risks with delayed but long-term health consequences. When caring for BME adolescents it is important for HCPs to gain an in depth picture of their particular ethnic background, their knowledge and experiences of diabetes, self-care, social situation and what they expect from health care services (Davies, Heller et al. ND) (Larsman, Eklöf et al. 2012).

## Details of DESMOND and X-PERT adult programmes

Given that the programmes described below are based on both DESMOND and X-PERT adult programmes, these are briefly described below in Table 10.

**Table 10. Details of DESMOND and X-PERT adult programmes**

FLAGS	TITLE AND DETAILS	PROGRAMME AIMS/BRIEF EVALUATION	PROGRAMME CONTENT
  	<p><b>DESMOND</b></p> <p><b>CLAHRC FOR SOUTH YORKSHIRE DIABETES INITIATIVES</b> Self-Management of Diabetes</p> <p>The team at CLAHRC-SY have developed a new care package called Going Forward (See Table 8. CLAHRC LNR Initiatives for Type 2 Diabetes, page 62} with Diabetes, and are trialling as a Cluster RCT comparing the effectiveness of the intervention with standard care (The DESMOND-Ongoing study)</p>	<p>The model includes:</p> <ul style="list-style-type: none"> <li>• 1:1 care</li> <li>• Annual care planning</li> <li>• A rolling programme of group education delivered in 4 x 3-hour sessions over two years</li> </ul> <p>The course is built around group activities, with individuals able to speak to an educator.</p>	<p>The intervention package includes:</p> <ul style="list-style-type: none"> <li>• On-going group education for patients and family that includes topics on diet, foot care, exercise and managing hypoglycaemic episodes.</li> <li>• Annual care plan review undertaken by specially trained GPs and Practice Nurses in the DESMOND philosophy.</li> </ul>
FLAGS	TITLE AND DETAILS	PROGRAMME AIMS/BRIEF EVALUATION	PROGRAMME CONTENT
	<p>X-PERT courses do not currently cover children or educate parents to look after children with diabetes. They are designed for adults at risk or with diabetes.</p> <p><a href="http://www.xperthealth.org.uk/">http://www.xperthealth.org.uk/</a></p>	<p>The most clinically effective structured education programme having been fully evaluated with a randomised controlled trial - a recognised gold standard for assessing the efficacy of a programme such as this.</p>	<p><b>Week 1</b> Diabetes, insulin &amp; healthy living Goal setting: lifestyle experiment to address the diabetes health profile.</p> <p><b>Week 2</b> All about insulin</p>

   	<p>e mail personal communication 17/10/20104</p> <p>Health structured education programme delivered by health professional.</p> <p>Enables providers to fulfil the NICE Quality Standard [March 2011] and the 2013/14 QOF indicators for diabetes, especially NM013 and NM014</p> <p>Although not specifically for children or adolescents, the X-PERT Diabetes Programme demonstrating highly statistical significant reductions in blood glucose, blood pressure, blood cholesterol, body weight and waist circumference and an improvement in quality of life.</p> <p>It is considered to be the most cost effective diabetes self-management programme. It demonstrates cost saving through a reduced requirement for diabetes medication and also demonstrates an <i>excellent return on investment</i>.</p> <p>Proven to work in newly diagnosed and people with existing diabetes Demonstrable improvements for both white Caucasians and non-English speaking BME groups.</p>	<p><b>APPRAISAL</b> (Deakin in press)</p> <p><b>Audit findings thus far</b> A clinical trial demonstrated that the X -PERT Diabetes Programme significantly improved health and quality of life. A continuous audit is being undertaken in order to determine if the national implementation of the X-PERT Programme meets standards identified in the published trial.</p> <p>To meet the key criteria to implement NICE guidelines, educators are trained to deliver X-PERT Diabetes and X-PERT Insulin Programmes and submit baseline, 6 &amp; 12 month results onto the X-PERT Audit Database.</p> <p>Forty-seven per cent of X-PERT centres (55/118) have submitted data for 16,031 people with diabetes.</p> <p>All outcomes improved at one year: glycated haemoglobin, body weight, waist circumference, systolic and diastolic blood pressure; total and LDL cholesterol; triglycerides, HDL cholesterol, requirement for prescribed diabetes medication (i.e. 23% less likely to increase medication.</p>	<p>Exploring insulin - onset, peak and duration, regimens and devices. Hypo / hyper-glycaemia. Goal setting: activity to address specific challenges.</p> <p><b>Week 3</b> Know your carbs Carbohydrate counting - estimation, calculation and reading food labels. Goal setting: lifestyle experiment – counting the carbs.</p> <p><b>Week 4</b> Inspiration for insulin Troubleshooting: strategies to take control. “Inspiration” the game to address special considerations when living with diabetes. Goal setting: what trouble shooters may work for me</p> <p><b>Week 5</b> MATCH IT: taking control A chance to document blood glucose, carbs and activity Share diaries, identify challenges and apply self-management trouble shooters. Goal setting: Apply trouble shooters to my MATCH IT challenges</p> <p><b>Week 6</b> Are you an Insulin X-PERT?</p>
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	<p>Meets the NICE key criteria for diabetes prevention [July 2012] and diabetes structured education [January 2006].</p> <p><a href="http://www.xperthealth.org.uk/educators">http://www.xperthealth.org.uk/educators</a></p> <p>Accessed 20/10/2014</p> <p>(Deakin 2011; Deakin 2011a; Deakin 2011b; Deakin 2013; Deakin in press)</p>	<p>The National implementation of the X-PERT Programme has met audit standards. X-PERT increases skills, knowledge and confidence for diabetes self-management, resulting in intensification of glycaemic control and reducing cardiovascular disease risk factors in people with newly diagnosed and existing diabetes.</p> <p>Structured education is a clinical and cost-effective approach that should be offered to all people with diabetes as an integral part of their diabetes treatment and management, potentially saving the NHS £367 million per annum.</p>	<p>Game MATCH IT 24/7 to challenge real "living with diabetes on insulin situations</p> <p>Have the self-management challenges been addressed?</p>
<p><b>Local provision of XPERT</b></p> <p>Blackburn, Warrington, Bury, Accrington, Clitheroe, Wirral, Stockport, Wythenshawe, Salford, Eccles, Hyde and Manchester</p> <p><a href="http://www.xperthealth.org.uk/contact/x-pert-centres/northwest">http://www.xperthealth.org.uk/contact/x-pert-centres/northwest</a></p>			

## Programme descriptions and brief appraisals

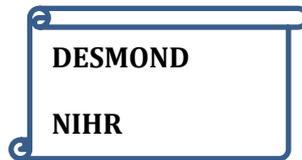
**Table 11. Existing structured adult educational programmes for BME**

NAME OF PROGRAMME	BASIS OF PROGRAMME	SESSION CONTENTS
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<p><b>DESMOND South Asian Newly Diagnosed &amp; Foundation Modules</b></p> <div data-bbox="300 384 474 520" style="border: 1px solid black; background-color: #fff9c4; padding: 5px; text-align: center;"> <p><b>Type 2 diabetes</b></p> </div> <p>Culturally appropriate for the South Asian community BME (Black Minority and Ethnic). Delivered in Gujarati, Punjabi, Urdu and Bengali</p>	<p>Culturally specific self-management education for South Asian communities</p> <ul style="list-style-type: none"> <li>• Deliverable in either Punjabi, Gujarati, Urdu &amp; Bengali with interpreters (4 x 3 hour sessions)</li> <li>• Or in Punjabi, Gujarati, Urdu &amp; Bengali in mother tongue (2 x 3 hour sessions or 1 x 6 hour session).</li> <li>• Or in English with appropriate resources (2 x 3 hour sessions or 1 x 6 hour sessions).</li> <li>• All with culturally-sensitive resources and images to avoid reliance on the written word</li> <li>• Delivered in local community venues.</li> <li>• Delivered by 2 trained health care professionals.</li> </ul> <p><b>APPRAISAL</b> Delivering this would require a close collaboration with the local BME community in terms of engagement, employing interpreters and training them to deliver this programme. However, it is a good beginning in that it is a simple introduction to, and outlines, the risks and potential complications associated with the condition. It moves towards self-management examining diet and exercise</p>	<ul style="list-style-type: none"> <li>• Thoughts and feeling of the participants around diabetes</li> <li>• Understanding diabetes and glucose: what happens in the body</li> <li>• Understanding the risk factors and complications associated with diabetes</li> <li>• Understanding more about monitoring and medication</li> <li>• How to take control -- Food choices -- Physical activity</li> <li>• Planning for the future</li> </ul>
<p><b>DESMOND 'A Safer Ramadan' Group Education In Leicester</b></p> <div data-bbox="486 1169 757 1251" style="border: 1px solid black; background-color: #fff9c4; padding: 5px; text-align: center;"> <p><b>Type 2 diabetes</b></p> </div> <p>For people planning to observe the holy month of Ramadan, they are welcomed to a 'A Safer Ramadan' group to learn how to manage their diabetes at this time.</p>	<p><b>Session content</b> Each session will explore how to fast safely and also medication adjustments needed during Ramadan. Each session is 2.5 hours in length</p> <p><b>Who runs them</b> These sessions will be led by diabetes specialist nurses helping people with diabetes who wish to fast during the Holy month.</p>	

<p>Available at local pharmacies</p> <p>Group session being held throughout May and June at <b>Moins Chemist and Wellbeing Centre, 137A East Park Road, Leicester. LE5 5AZ</b></p> <p>Contact: Saleha Patel on 0116 2584223</p>	<p><b>APPRAISAL</b></p> <p>It could be an idea to engage with local community pharmacists with a view to implanting initiatives such as BME education. Pharmacies have a high footfall and many customers are not attending for health services and some do not engage with primary care.</p> <p><b>CLAHRC for South Yorkshire</b> ran this module in 2010 for people with Type 2 Diabetes in Leicester, Preston, Harrow, Reading and Kirklees. This pilot project is the start for a full future programme.</p>
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## Let's Prevent



An RCT for the Prevention of Diabetes using an Educational Intervention and Continuous Support Programme in those with Pre-Diabetes in a Multi Ethnic Population.

University Hospitals of Leicester Diabetes Research

<http://www.desmond-project.org.uk/letsprevent-277.html>

Accessed 20/11/2014

Project Lead: Stephanie Goldby.

T: 0116 258 7249

E: [letspreventdiabetes@uhl-tr.nhs.uk](mailto:letspreventdiabetes@uhl-tr.nhs.uk)

Study protocol

<http://www.cardiab.com/content/11/1/56/abstract>

(Gray, Khunti et al. 2012)

## Aims

To establish whether the use of a structured lifestyle modification programme (based on the DESMOND curriculum of diet and exercise) prevents those with pre-diabetes going on to develop diabetes.

- A multi-disciplinary approach to reducing the progression to diabetes in high risk people.
- An appropriate structured education programme to target lifestyle modification and behaviour change and a culturally sensitive structured education for the Black Minority and Ethnic (BME) community.
- A support and motivational maintenance programme for the duration of the study.
- And to evaluate the programme to provide a low cost solution for practical health improvement.

## Participants

748 participants. Aged 40-75 of European origin or aged 25-75 of South Asian origin or those who have previous IFG or IGT.

## Intervention

A 6-hour self-management structured education programme focussing on understanding pre-diabetes, and Type 2 diabetes, how to prevent its development, understanding risks and complications of pre-diabetes, the benefits and practicalities of making positive lifestyle changes including physical activity, and food choices, followed by action planning.

All study participants' measurements and clinic visits are now complete.

## APPRAISAL

Early findings are that the Leicester Practice Risk Score (LPRS) is an inexpensive and simple way of targeting screening programmes at those with the highest risk. The study team is in the process of writing the final report to funders and completing their analysis which is anticipated for the Spring of 2015 (personal communication SG)

<p><b>IDF Educational modules for HCPs</b></p> <p>These have been developed to support the education and training of health care professionals with the latest evidence-based material. They are not intended for commercial use.</p> <p>© International Diabetes Federation. All rights reserved. All intellectual property relating to the Modules and the suite of tools they provide are IDF's.</p> <p>Please see end note i</p> <p><a href="http://www.idf.org/diabetes-education-modules">http://www.idf.org/diabetes-education-modules</a></p> <p>Accessed 22/9/2014</p>	<p><b>In Arabic, Chinese, French, Russian, Spanish and English</b></p> <p>IDF's Diabetes Education Modules are intended to be used by health professionals wishing to develop a high quality education programme.</p> <p>Each module contains slides, facilitators' notes and activities. Activities are used to increase participation during a programme and to allow some practical application of the discussion material.</p> <p>Also available on CD rom with a Facilitator's Guide containing information to assist in planning, implementing and evaluating the programme.</p> <p><b>APPRAISAL</b></p> <p>IDF uses the most up-to-date information and guidance on diabetes education in the Modules and carefully evaluates users' feedback.</p>	<p><b>CURRICULUM</b></p> <ul style="list-style-type: none"> <li>• Section 1 – Self-Management Education consists of two modules that cover the role of the diabetes educator, principles and practical application of teaching and learning and psychosocial issues and counselling for behaviour change.</li> <li>• Section 2 – Diabetes and Lifestyle Intervention consists of six modules covering the basics of diabetes management; pathophysiology, classification and prevention, the basics of nutrition and physical activity, and an overview of clinical monitoring.</li> <li>• Section 3 - Pharmacotherapy consists of three modules covering blood glucose-lowering medicines, insulin therapy and an overview of complementary therapies.</li> <li>• Section 4 – Glycaemic Excursions consists of modules devoted to hypoglycaemia, managing sick days, diabetic ketoacidosis and hyperosmolar hyperglycaemic state.</li> <li>• Section 5 – Diabetes-Related Complications consists of five modules focusing on the long-term complications of diabetes.</li> <li>• Section 6 – Special Situations contains one module on planning for disasters.</li> </ul>
<p><b>The Health Foundation. Inspiring Improvement in BME</b></p>		
<p><b><i>X-PERT for BME communities</i></b></p> <p>Part of the Year of Care programme. <a href="http://www.diabetes.nhs.uk/year_of_care">www.diabetes.nhs.uk/year_of_care</a>. Project completed.</p> <p>Tower Hamlets Project with South Asian communities Central London Community Health Care NHS</p>		

Education initiatives provided:

- X-PERT & X-POD structured education programmes
- X-PERT insulin and Arabic speaking programmes
- Diabetes awareness talks to community groups

<http://www.health.org.uk/public/cms/75/76/1194/2695/Year%20of%20Care%20report%20July%202011.pdf?realName=Fu99Cx.pdf>  
<http://www.health.org.uk/areas-of-work/programmes/year-of-care/related-projects/tower-hamlets/>

Accessed 22/10/2014

### **IN-HOUSE APPRAISAL**

Demonstrable improvements for both white Caucasians and non-English speaking BME groups are reported. Tower Hamlets had to tackle a wide range of issues and worked individually with practices in 'meet and greet' events, carried out an extensive patient participation exercise based at practices where lunchtime meetings sometimes attracted 100 or more participants. This was helped by the well-networked Patient and Public Involvement (PPI) lead who sat on the local Project Board. The team identified a range of approaches that would be needed to gain greater involvement with their diverse local population. They also recognised the difficulties of working in this way with people with extremely poor health and language literacy.

### **Oldham: The shared leadership for change project 'Don't lose sight of diabetes'**

<http://www.health.org.uk/areas-of-work/programmes/shared-leadership-for-change-BAME/related-projects/oldham/>

Multidisciplinary project October 2007 to November 2009.

- The increased risk of diabetes for people of South Asian origin is estimated to be four to five times higher than for people of European origin. NHS Oldham has been developing a new service model for diabetes having concerns about the level of screening for diabetes amongst the Pakistani and Bangladeshi communities in the Coppice and Glodwick areas of Oldham.
- The team identified a disproportionately high number of non-attendances at retinotherapy screening appointments for Pakistani and Bangladeshi people, and patchy records of ethnicity within practices in relation to the diabetic register. They also found that there are problems in the communication between health services and Pakistani and Bangladeshi people living with diabetes; many do not understand what diabetic retinotherapy screening is, why it is important to them and what they are meant to do about it.
- This project aimed to improve access to health services and the quality of care for people living with diabetes from these BME communities. The focus was on retinotherapy screening and the provision of education on lifestyle management for people living with diabetes.

The project included implementing drop-in sessions to increase awareness, and developing recommendations for practices, screening services and commissioners on what could be done to address the issue.

### **Conclusion**

Given PCFT's interest in extending BME provision for CYP, existing structured adult BME programmes are described. The Department of Health acknowledges that diabetes educational models can be adapted to suit local situations (Clark 2008) and age groups, thus there is the potential to adapt these for BME CYP. The numerous projects described above offer ample opportunities to contact organisations presently running these programmes with this in mind.

## Section 6. Written resources

### Comment

Access to specialist, expert information is key to complex and long-term conditions management. High quality age appropriate CYP health information can empower CYP and their families to learn to self-care and self-manage. However, little is known about which type and format of information given is most useful (Williams, Noyes et al. 2011), undertook a large multi method study including a systematic review of information and in-depth interviews with 98 CYP aged between 6-18, family members and HCP's and aimed to gather a greater understanding of their health information needs, with an emphasis on medicines-management and service delivery across various health conditions including diabetes. The study gathered a picture of the contribution of children's health information in current practice, explored levels of partnership and participation, active ingredients to successful translation, and the implementation and use of children's health information in service delivery and organisational contexts.

They found that content of policies, clinical guidelines and children's information resources are not consistently translated from policy into practice. Quality assurance processes are inconsistently applied and children's resources are less specific than the guidelines. CYP want realistic and meaningful information that fits with their age, circumstances and health needs. Information should be high quality, relevant, contemporary and shared at key information points, for example diagnosis, starting school, changing school, at significant developmental points, address lifestyle issues and transition to adult care. Written information should be up to date and match what CYPs are told by HCPs. It needs to be more detailed (although less scientific) and with more use of lay language.

Children's services reviewed varied widely in terms of how they conceptualised the child and family, delivered care and provided information. As discussed above this is important given variations in families nationwide and implications for health practices. There was little evidence of information for CYP being actively facilitated in child-centred ways in hospitals, with the provision of information being inconsistent in both primary and secondary care. Clinical nurse specialists appear best placed to facilitate information exchange with CYP. The cost of producing and accessing resources is a barrier to their use and whether it is effective and cost effective remains to be seen.

Teenagers especially, vary in their perception of the value of information and the same applies to their parents. That is, some actively seek information whilst others find it overwhelming. As we have already seen, the specific needs of CYP is a significant gap in key strategic, operational and organisational NHS policies, because adult diabetes which tend to conceptualise diabetic patients as adults with little referral to the needs of CYP. Whilst CYP specific policies and clinical guidance advocate the provision of high-quality, age-appropriate health information, it is not clear what is meant by this, where it can be obtained and the most effective ways to deliver information to CYP in clinical practice.

Notwithstanding there being a large and growing pool of available information, age-appropriate focus groups held with CYP revealed that information varies in quality, is not available everywhere and often does not match with their preferences for CYP centred, individually tailored, realistic information<sup>10</sup>. Children with diabetes have to try and make sense of multiple, incoherent and competing realities as they grow up and services vary in their approach to flexible child centred care.

There are more weaknesses and gaps that act as barriers to children's information translation than good use and provision of CYP information in the NHS. Information for CYP is an important but relatively under-realised resource, and sometimes not present at all in many complex interventions to promote choice, decision-making and self-care as CYP gain their autonomy. Service delivery and organisational issues need to be addressed before written materials for diabetes care of CYP can reach their full potential. These authors designed the EPIC resources described below and, notwithstanding undertaking a robust research study based on the above considerations, they found that their packs and diabetes diaries were no more effective than receiving diabetes information in an ad hoc way. They concluded that it may be necessary to understand how best to reorganise current diabetes services for children to optimise child-centred delivery of children's diabetes information (Williams, Noyes et al. 2011).

In addition to identifying resources belonging to programmes described above, the following three written resources were found. From a teacher's perspective, the Hannon Manual appears to be the most effective resource in terms of applying gold standard clinical guidelines, addressing current UK policy and practice recommendations and excellent lesson plans. However, HCPs may find them difficult to implement in groups without supportive skills in teaching practice. How to address this skill deficit is outlined in the recommendations section at the end of this document.

## Summary of written information resources

**Table 12. Summary of written information resources**

TITLE OF RESOURCE	SUMMARY OF EDUCATIONAL CONTENT
<p><b>TYPE 1 DIABETES AT SCHOOL PARENT PACK</b></p> <p><b>DIABETES UK CARE AND CONNECT CAMPAIGN See end note iii</b></p>	<p>This pack is designed to be given to a child's school and read by parents or carers, but equally as useful for parents, children, adolescents, family members and carers' other than teachers, for example those at after school clubs. It is attractively packaged with robust contents and contains:</p>

<sup>10</sup> Realistic equates to HCPs taking into account risk behaviour taken by CYP and working with this.



HCPs/parents/teachers/youth workers/employers

### **PACK PROVIDED FOR CLAHRC**

Diabetes UK's packs have been produced as part of its National Charity Partnership with Tesco

[www.diabetes.org.uk/schools](http://www.diabetes.org.uk/schools)

- One large card describing 'What care to expect at school' and which outlines a school's responsibilities towards a child with diabetes.
- A concertina card dispelling myths about diabetes which could be used to educate other children about diabetes.
- A credit sized card for a child to carry on them which gives information to others that they a) have diabetes, b) what the signs of a hypo are and c) what needs to be done to help them.
- One leaflet 'Meeting with your child's school' is mainly onerous homework for parents, advocating extensive reading of school, NHS and local authority, policies, guidance and legislation. It also advocates that the parents link with the local authority, and plan meetings at the school in order to planning their child's individual health plan and puts the onus on them to ensure that all appropriate persons are present. Given current legislation (see page 126) and that school staff should be trained in diabetes management, this booklet could be quite overwhelming for some parents. It is complex, with a middle class orientation and unsuitable for parents with other languages and/or reading difficulties. One leaflet for the school 'Looking after children with Type 1 diabetes' is designed for the person who is taking responsibility for CYP with diabetes. This is actually much simpler to understand than the one designed for parents!

### **APPRAISAL**

Some of this pack is extremely useful for the correct recipient:

- 1) It is useful given teenagers' misconceptions of diabetes even when they have a close relative or friend with the condition. Early education for all school children about diabetes could be given through the curriculum via educational visits by the Diabetes MDT team and talks by children or staff with T1DM (Prince, Alexander, 2014).
- 2) It does not have space for an ICE (in case of emergency) contact number or address.
- 3) The content of this could be considered very onerous for many parents and could be simplified by outlining the main points for them relating to policy documents. Much of this could be entered into the leaflet for the school because staff also need to know the details about national guidelines from a practical and legal perspective.

N.B. A new Care in School Helpline has recently been launched by Diabetes UK to help parents to work with their school and PDSN to create Individual Healthcare Plans. Call 0345 123 2399 or go to [www.diabetes.org.uk/care-in-school](http://www.diabetes.org.uk/care-in-school). Please see page 108 below.

**Diabetes Care for Children and Young People** (New National Journal). The journal for healthcare professionals caring for children and young people with diabetes' (communication, policy, education, research, voice of young people & parents, events)  
 Paediatric Diabetes  
 Nursing Children and Young People  
 British Journal of Community Nursing  
 Journal of Diabetes Nursing and Practical Diabetes International  
 Diabetes Digest.  
 Diabetes UK's Education and Care Section offer updates.  
 Email news alerts are available from the Juvenile Diabetes Research Foundation (JDRF)

**EPIC** (Evidence into Practice Information Counts)

For ages 6-18

These resources were developed for a RCT taking into account gold standard clinical guidelines, and addressing current UK policy and practice recommendations to identify the best types/formats of information most likely to assist decision-making and choices concerning blood glucose monitoring and insulin management. They also were the result of in depth consultations with CYP, parents, HCPs, Clinical Advisory groups, a medical illustrator and key stakeholders over time.

The EPIC project was conceived to address the lack of appropriate children's diabetes information and a diabetes diary in routine NHS care and to generate evidence of what works concerning delivery and use of diabetes information and diaries as a way of enabling children and young people to engage in

**Co-designed**

Given the lack of high quality, child-centred and effective health information to support development of self-care practices and expertise in children with acute and long-term conditions, EPIC packs fulfilled all NHS policy imperatives that children and young people should receive high-quality, accurate and age-appropriate information about their condition, self-management and wider lifestyle and well-being issues.

Diabetes guidelines recommend the use of a daily diabetes diary and the EPIC diaries filled a gap in current provision. In type 1 diabetes, clinical guidelines indicate that high-quality, child-centred information underpins achievement of optimal glycaemic control with the aim of minimising acute readmissions and reducing the risk of complications in later life.

With this in mind a range of age appropriate child centred information resources were developed by this study team aiming to improve children and young people's quality of life by increasing self-efficacy in managing their type 1 diabetes.

**THEY COMPRISE**

- Three age related diabetes diaries for children and young people using multiple insulin injections (6-10 years, 11-15 years and 16-18 years);
- One diabetes diary (6-18 years) for children and young people using insulin pumps;
- Child-friendly sheets for recording carbohydrate intake;
- Three age-appropriate information packs containing published diabetes information bound in age appropriate folders (6-10, 11-15 and 16-18 years)

<p>optimal self-care with a focus on insulin management.</p> <p>MCRN CRC CYMRU RES NET</p> <p>(Edwards, Noyes et al. 2014) (Noyes, Lowes et al. 2014) (Noyes, Williams et al. 2010)</p> <p>Please note: these resources have not been seen by the UoM.</p>	<ul style="list-style-type: none"> <li>• Stickers and pens for children and young people to personalise their folder</li> </ul> <p><b>Parents of CYP were provided with verbal and written guidance on supporting their child.</b></p> <p>The results of the RCT however, showed that the (EPIC) packs and diabetes diaries were no more effective than receiving diabetes information in an ad hoc way. The authors put forward reasons for this.</p> <ul style="list-style-type: none"> <li>• CYP participating had a range of recorded glycated haemoglobin (HbA1c) levels. Thus, their diabetes self-management would generally need to improve to achieve the HbA1c levels recommended in National Institute for Health and Care Excellence guidance.</li> <li>• A process evaluation showed that promotion of the EPIC packs and diaries by diabetes professionals at randomisation did not happen as the study leads intended.</li> <li>• The current dominant ‘normalisation’ theory underpinning children’s diabetes information may be counterproductive. Risk and long-term complications did not feature highly in children’s diabetes information</li> <li>• Children and young people engaged in risky behaviour and appeared not to care</li> <li>• Most did not use a diabetes diary or did not use the information to titrate their insulin as intended.</li> <li>• It is difficult to recruiting ‘hard to reach’ children and young people living away from their families.</li> </ul> <p>The findings indicate a need to rethink context and the hierarchical relationships between CYP diabetes HCP’s in terms of ‘partnership and participation’ in diabetes decision-making, self-care and self-management. However, these resources could work in a family context, although it may be necessary to understand how best to reorganise formal current diabetes services for CYP to optimise child-centred delivery of children’s diabetes information.</p>
<p><b>Providing Structured Diabetes Education for Children and Young People.</b> A Successful Diabetes Handbook (2011) Rebecca Hannan.</p>	<p>Rooted in <b>DAFNE</b> and Freedom 4 Life programmes.</p> <p>This manual is an attempt to offer diabetes on-going structured education in an appropriate learning environment for CYP from the age of two, and which encompasses the principles and practice of education of children as exemplified in the ISPAD Clinical Practice Consensus</p>



<http://www.successfuldiabetes.com/>

Accessed 21/10/2014

Book provided to Pennine Care NHS Foundation Trust

Guidelines (see below, page 112).

The book is divided into five age ranges from 2 to 16 years old. The sessions for 2 – 5 year olds include parents and siblings. There is a short section for each age range on evidence based child developmental theory, for example Piaget's stages for the 2 to 5 age range. Learning styles for each age group are also described and a very detailed programme of six sessions to be delivered twice a year (or as needed) for each age group with a rationale for each session if given. Age appropriate hour long structured lesson plans are broken into smaller sections and aims and objectives addressing emotional, educational and psychosocial needs are given. Lesson plans and activity details for each group are described. All handouts are included and the programme comprises an ongoing, rolling programme for those with diabetes and the newly diagnosed.

Educators suggested included PDSN's, dietician, other CYP with diabetes, school nurses, psychologists, sports physiologists, drugs and alcohol specialists, meter manufacturers and midwives. The book acknowledges programmes described in this document CASCADE, CHOICE, DEPICTED, FACTS, KICK-OFF and the SWEET PROJECT.

All lesson plans and resources can be photocopied for the purposes of diabetes education.

#### **APPRAISAL**

Successful Diabetes is an independent company run by health professionals who are also education specialists. They have also worked with specialist paediatric diabetes dieticians, an illustrator and consultant paediatricians. The resources have not had an official evaluation or assessment. An audit conducted after a year yielded encouraging results but these are not expanded upon. Some 'Quick Quotes' offer some reflections from users and professionals' on the Workshops.

[http://www.successfuldiabetes.com/images/stories/Quick\\_Quotes\\_-\\_reflections\\_from\\_Participants\\_of\\_SD\\_Workshops\\_2013.pdf](http://www.successfuldiabetes.com/images/stories/Quick_Quotes_-_reflections_from_Participants_of_SD_Workshops_2013.pdf)

Accessed 21/10/2014

The theory or child age related development and learning is simply and clearly outlined for each age group and is a useful element of this resource. Psychological issues appear not be

	fully addressed. However, risky situations are covered well. . The detailed lesson plans are extremely useful for trained teachers. However, these may be more difficult to interpret and deliver for someone without teaching experience. Ideally someone with teaching experience and/or be trained in diabetes knowledge could deliver sessions jointly successfully however.
<b>Juvenile Diabetes Research Forum (JDRF)</b>	The JDRF website for children of all ages. Support packs for primary and secondary schools which can be ordered free of charge.

## Section 7. Curriculum mapping exercise

### Comment

The mapping exercise below in Table 13 illustrates the current position of PCFT in terms of their proposed educational modules programme, other accredited curriculums and resources which meet ISPAD/NHS/ guidelines. Table 13 ‘maps’ these to show which are covered by PCFT and where there are gaps and how some of these can be filled by existing programmes and resources. Some suggestions by the UoM are made for additional modules to cover these gaps and suggested titles. Training programmes for HCPs are briefly alluded to with further details of these in

Table 7. The level to which any of the gaps can be filled with other modules would need inspection by PCFT because in some cases these are under review /development and in others, permission would need to be sought to use resources.

**Table 13. Curriculum mapping exercise**

NHS curriculum	SDE for CYP based on ISPAD guidelines	Pennine Modules UoM suggested module components/titles	PROGRAMME/ RESOURCE UoM suggestions	Training Programme for HCP's
Aetiology, epidemiology and diagnosis	<b>At diagnosis: Survival skills. Primary (Level 1) education</b>	<b>PARTIAL GAP</b>  OUR NEW LIFE	<b>CASCADE</b>  <b>KICK-OFF</b>	RCN guidance for newly-

<p>Phases of type 1 diabetes</p> <p>Defining the MDT and delivery of ambulatory services</p>	<ul style="list-style-type: none"> <li>• Explanation of how the diagnosis has been made and reasons for symptoms</li> <li>• Simple explanation of the uncertain cause of diabetes. No cause for blame</li> <li>• The need for immediate insulin and how it will work</li> <li>• What is glucose? normal BG levels and glucose targets</li> <li>• Practical skills - insulin injections - blood and/or urine testing and reasons for monitoring</li> <li>• Basic dietetic advice</li> <li>• Simple explanation of hypoglycaemia</li> <li>• Diabetes during illnesses</li> <li>• Advice not to omit insulin—prevent DKA</li> <li>• Diabetes at home or at school including the effects of exercise</li> <li>• Identity cards, necklets, bracelets and other equipment</li> <li>• Membership of a Diabetes Association and other available support services</li> <li>• Psychological adjustment to the diagnosis</li> </ul>	<p>For CYP, parents and carers</p> <p><b>Specific nutritional themes for babies, infants, preschool children, elementary school children and their parents.</b></p> <p>Mandatory support available in schools and colleges</p>	<ul style="list-style-type: none"> <li>• Simple, clear printed/E booklets, apps and guidelines</li> <li>• In other languages</li> <li>• MATHS worksheets</li> <li>• Free individual tuition</li> <li>• Free weekend groups sessions for families</li> </ul> <p><b>EPIC</b></p> <p><b>HANNAN</b></p> <p><b>IDF Section 2</b> <sup>11</sup></p> <p><b>IDF Section 4</b> <sup>12</sup> <b>Glycaemic Excursions</b></p>	<p>appointed nurse specialists<sup>13</sup></p> <p>CASCADE</p> <p>IDF</p> <p>KICK-OFF</p>
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<sup>11</sup> Section 2 consists of 6 modules; basics of diabetes management; pathophysiology, classification and prevention, the basics of nutrition, physical activity and an overview of clinical monitoring

<sup>12</sup> Section 4. Modules devoted to hypoglycaemia, managing sick days, diabetic ketoacidosis and hyperosmolar hyperglycaemic state.

<sup>13</sup> See page 51

	<ul style="list-style-type: none"> <li>Details of emergency telephone contacts.</li> </ul>		 Lange 2013.pdf	
<b>Aetiology, epidemiology &amp; diagnosis. Other types of diabetes.</b>	<b>ISPAD CONTINUING LEVEL (2)</b> Insulin secretion, action and physiology Pathophysiology epidemiology classification metabolism	What is Diabetes?  Physical and psychological impacts Dispelling myths	<b>BERTIE KICK-OFF</b>  <b>SCHOOL PARENT PACK</b>	<b>KICK-OFF</b>
<b>Insulin therapy</b>	<b>ISPAD CONTINUING LEVEL (2)</b> Insulin injections, types, absorption, action profiles, variability and adjustments	Insulin: Types, injections and pumps	<b>BERTIE CASCADE FACTS</b> IDF Section 3 Pharmacotherapy <sup>14</sup> <b>KICK-OFF</b>	IDF  <b>KICK-OFF</b>
	<b>ISPAD CONTINUING LEVEL (2)</b>  Problem solving and adjustments to treatment Goal setting	Insulin adjustment /BG monitoring	<b>BERTIE CASCADE EPIC Resources FACTS</b> <b>KICK-OFF HANNAN</b> IDF Section 3 <sup>14</sup>	IDF  <b>KICK-OFF</b>
	<b>ISPAD CONTINUING LEVEL (2)</b> Metabolism Monitoring, including glycated haemoglobin Clear (agreed) targets of control	<b>THE SCIENCE OF INSULIN</b>  Monitoring Blood Glucose  <b>EFFECTS OF CARBS ON BG</b>	<b>BERTIE CHOICE EPIC Resources FACTS</b> <b>HANNAN</b> IDF Section 3 <sup>14</sup>	IDF  <b>KICK-OFF</b>

<sup>14</sup> IDF Section 3 – Pharmacotherapy. Modules covering blood glucose-lowering medicines insulin therapy

			<b>KICK-OFF</b>	
<b>Nutrition</b>	<b>ISPAD CONTINUING LEVEL (2)</b> Metabolism. Nutrition—food plans advice on intake of carbohydrate, fat, proteins and fibre coping with special events and eating out 'diabetic foods'; sweeteners and drinks growth and weight gain	METABOLISM: (1) Food and me  Carb Counting to insulin ration Nutrition. Practical cooking and counting sessions  (2) LOOKING /FEELING GOOD  Eating Disorders, weight loss	<b>BERTIE</b> <b>CASCADE</b> <b>CHOICE</b> <b>FACTS</b> <b>HANNAN</b> <b>IDF Section 3</b> <sup>14</sup> <b>KICK-OFF</b>  (Lange 2013)	IDF  KICK-OFF
<b>Complications</b> <b>Acute: Hyper, Hypo, DKA</b> <b>Sick day rules</b>	<b>ISPAD CONTINUING LEVEL (2)</b> Hypoglycaemia and its prevention, recognition and management including glucagon	<b>SICK DAYS</b>  Hypo and Hyper glycaemia	<b>BERTIE</b> <b>HANNAN</b> <b>IDF Section 3</b> <sup>14</sup> <b>IDF Section 4</b> <sup>12</sup> <b>KICK-OFF</b>	IDF
<b>Managing physical activity and exercise</b>	<b>ISPAD CONTINUING LEVEL (2)</b>  Exercise	<b>FIT ME</b>  Exercise	<b>BERTIE</b> <b>CASCADE</b> <b>CHOICE</b> <b>FACTS</b> <b>HANNAN</b> <b>KICK-OFF</b>	CASCADE  KICK-OFF
<b>Psychological aspects</b>	<b>GAP</b>	<b>KEEPING A COOL HEAD</b>  <ul style="list-style-type: none"> <li>• Mental Health well being</li> <li>• Communication</li> <li>• Conflict resolution skills</li> <li>• Coping skills</li> <li>• Stress management bullying/exams/family conflict etc.</li> <li>• Growing up with diabetes</li> </ul>	<b>CASCADE</b>  <b>DOLPHIN (FOR CARERS)</b>  <b>FACTS</b>  <b>KICK-OFF</b>	CASCADE  DOLPHIN  KICK-OFF

		Physical and Psychological challenges in puberty and beyond		
	<b>ISPAD CONTINUING LEVEL (2)</b> Holiday planning and travel, including educational holidays and camps including going abroad.	INTERDEPENDENCE  SLEEPOVERS – PARENTS LETTING GO BUT STAYING INVOLVED	FACTS HANNAN	
Surgery, fasting and sick day rules	<b>ISPAD CONTINUING LEVEL (2)</b> <ul style="list-style-type: none"> <li>• Intercurrent illness</li> <li>• hyperglycaemia, ketosis and prevention of ketoacidosis</li> </ul>	<b>Difficult Situations</b> <ul style="list-style-type: none"> <li>• Managing stress</li> <li>• illness</li> <li>• Change of regimen</li> </ul>	<b>HANNAN KICK-OFF</b> IDF Section 4 <sup>12</sup> IDF Section 6 <sup>15</sup>	IDF  KICK-OFF
Vision of the future for CYP diabetes services	<b>ISPAD CONTINUING LEVEL (2)</b> Sexuality, contraception, pregnancy and childbirth Smoking, alcohol and drugs	<b>MY PRIVATE LIFE</b>  Sex/ drugs/alcohol/ living away from home	<b>FACTS HANNAN</b> IDF Section 6 <sup>15</sup> <b>KICK-OFF (not sexual issues)</b> <b>WICKED</b>	IDF  KICK-OFF  WICKED
	<b>ISPAD CONTINUING LEVEL (2)</b> School, college, employment and driving vehicles	<b>MY NEEDS AND RIGHTS AT SCHOOL AND WORK</b>		
Support & Education of CYP lay carers	<b>GAP</b>  Physiology/ pathophysiology, principles of differentiated insulin therapy (basal and prandial insulin), nutrition, metabolic self-control,	<b>PARENT/ FAMILY/OTHER SUPPORT</b> Lange (2013) based on the German SDEP system for CYP and their parents, advocates that around 30 teaching hours is needed for initial parental	<b>BERTIE CASCADE CHOICE EPIC resources DOLPHIN FACTS</b>	CASCADE  DOLPHIN  IDF Section

<sup>15</sup> IDF Section 6 – Special Situations and contains one module on planning for disasters

	<p>hypoglycaemia and hyperglycaemia, physical activity and sport, insulin therapy in acute diseases, therapeutic goals, secondary complications and psychological, didactic and social medical issues.</p> <p>How the boluses of insulin can be flexibly adapted to the child's nutrition and physical activity.</p> <p>Nutritional counselling includes food Science, planning meals suitable for Children, solving conflicts typical of this age group (Lange 2013)</p>	<p>education.</p> <p>This will vary depending on habits, life goals, family stress, cultural factors, knowledge, skills and understanding as well as emotional readiness to cope with diabetes and its consequences (Lange 2013)</p> <p><b>Assessment of knowledge and skills related to the following:</b></p> <p>Educating about CYP developmental stages learning and levels of understanding Behaviour change techniques including; Motivational Interviewing (MI)</p>	<p><b>IDF Section 1</b> <sup>17</sup> Psychosocial issues and counselling for behaviour change</p> <p><b>KICK-OFF</b></p> <p><b>DELFIN parenting program.</b> <sup>16</sup></p>	<p>1 <sup>17</sup></p> <p>KICK-OFF</p>
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<sup>16</sup> To assess initial efficacy and feasibility of a structured behavioural group training (DELFIN) for parents of children with diabetes type 1, in order to reduce parenting stress and to improve parenting skills. A German RCT parents of children with type 1 diabetes (2-10 yrs) (intervention group n = 37; control group n = 28). Parenting skills, parents' psychological burden, children's behavioural difficulties and quality of metabolic control were assessed before, 3 months after and 12 months after participating in the training program. Results: In the intervention group parenting behaviour in conflict situations improved significantly after 3 months and remained stable over 12 months. Depression and anxiety scores of parents decrease. Even though the outcome in the intervention group was more positive, the differences between both study arms failed to reach statistical significance. Unexpectedly parenting behaviour in the control group improved also and their anxiety and stress scores also decreased. In both groups the initial metabolic control was good and not significantly different. It remained stable in the DELFIN group and increased slightly in controls. This study has brought first evidence for the efficacy and feasibility of the program. A multicentre study with a larger sample is necessary to confirm these first results (Saßmann H, de Hair M, Danne T, Lange K, 2012). Reducing stress and supporting positive relations in families of young children with type 1 diabetes: A randomized controlled study for evaluating the effects of the DELFIN parenting program. BMC Pediatrics 12: 152

<sup>17</sup> IDF Section 1 – Self-Management Education consists of two modules that cover the role of the diabetes educator, principles and practical application of teaching and learning and psychosocial issues and counselling for behaviour change.

		Family dynamics		
Monitoring of diabetes and screening for associated conditions	ISPAD CONTINUING LEVEL (2) Micro and macro-vascular complications and their prevention The need for regular assessment	MY LIFELONG HEALTH  Long term conditions (eye, vascular dental disease) Leaving home and moving onto adult services	<b>FACTS HANNAN KICK-OFF IDF Section 5</b>	HANNAN KICK-OFF
	<b>GAP</b>	MOVING ONTO ADULT CARE  Specific nutritional themes for adolescents with diabetes and their parents.	<b>CLAHRC S/Y DIABETES INITIATIVES Self-Management of Diabetes</b> <a href="http://clahrc-sy.nihr.ac.uk/theme-diabetes-adolescent.html">http://clahrc-sy.nihr.ac.uk/theme-diabetes-adolescent.html</a>  <b>FACTS</b>  (Lange 2013) <b>WICKED</b>	WICKED
	<b>GAP</b>	COMPLEMENTARY THERAPIES	<b>IDF Section 3</b> <sup>14</sup> .	IDF Section 3
Vision of the future for CYP diabetes care.	CYP, FAMILY, SCHOOL, COMMUNITY DIABETES EVENTS	CO WORKING AND CO DESIGN  Gain continual feedback on programme and teaching methods	<b>CASCADE CHOICE FACTS KICK-OFF</b>	CASCADE KICK-OFF
<b>ADDITIONAL GAPS</b>				
<b>TYPE 2 DIABETES</b> Enhancing health literacy and behavioural change in people with Type 2 diabetes.  This two-year, prospective, observational study, using questionnaires and in-depth interviews with 319 patients initially recruited from a deprived urban area in north-west England.			<b>DESMOND</b>  CLARHC L N R. Self-management and Education. 3 NIHR projects currently being	

<p>The intervention comprised dedicated tele-carer education and support, tailored to each individual's circumstances.</p> <p>Outcome measures looked for included, perceptions of confidence, levels of empowerment, learning for self-care and the most helpful aspects of the intervention.</p> <p>Over 90% of participants expressed confidence in keeping their blood sugar controlled. High levels of perceived empowerment were noted. Changes in the depth and detail of diabetes-related knowledge and confidence, from the specific to the more general, were observed along with enhanced competence in translating knowledge into practice.</p> <p>The intervention, built a working partnership between tele-carer and patient and operated two levels:</p> <ul style="list-style-type: none"> <li>• health literacy, enhancing knowledge, developing personal skills and enabling self-control</li> <li>• socio-psychological behavioural change, tailored to individuals within their socio-economic environments, both enabling increased motivation and supportive problem solving (Long and Gambling 2012)</li> </ul> <p>Contact. <a href="mailto:a.f.long@leeds.ac.uk">a.f.long@leeds.ac.uk</a></p>	<p>piloted.</p> <p>The intervention study opposite is also worthy of note (It uses the PACCTS tele-care stepped call approach</p> <p>Patients receive 20 minute duration telephone calls, prearranged date and time, in relation to their level of blood glucose control: between one call per month to one call every 3 months with follow up calls if requested</p> <p>A supervisory diabetes specialist nurse is on hand for urgent issues (for example, unexplained hypoglycaemia) or for supplementary counselling and medication change.)</p>
<p><b>BLACK, ASIAN, MINORITY, ETHNIC</b></p> <p>See <b>Error! Reference source not found.</b> Page <b>Error! Bookmark not defined.</b> for all adult BME programmes</p> <p><a href="#">IDF</a></p>	<p>DESMOND</p> <p>IDF – HCP training</p> <p>LET'S PREVENT</p> <p>X-PERT</p>
<p><b>LESBIAN, GAY, BISEXUAL, TRANSEXUAL</b></p>	

## Best Practice Tariff

The 'Best Practice Tariff' (BPT) may encourage and facilitate PCFT to develop a bespoke, evidence based SDEP for CYPs. This is the first new initiative in paediatric diabetes for some time and hopes are high that it will impact on care in the future and improve children's diabetes service in line with service re-design proposals (Kime 2013). The BPT was introduced by the Department of Health in 2012. This is paid to any CYP provider service that can evidence to their commissioners that the diabetes services they are delivering fulfil the stringent criteria for providing a high quality service clearly stated in the Payment by Results Guidance 2012. <https://www.gov.uk/government/collections/payment-by-results-2013-14>.

The BPT will outline *minimum* standards of care for paediatric diabetes services. The BPT standards will provide a mechanism for raising standards and, in so doing, ensure consistent high-quality care for all CYP with T1DM although it will take time for standards to improve and have a long-term impact (Kime 2013). QISMET offers a national accreditation framework for organisations that supply SDEP's (see Table 14).

**Table 14. QISMET**

<p><b>QISMET</b></p> <p><b>(Quality institute for self-management education and training) 2011</b> <a href="http://www.qismet.org.uk">www.qismet.org.uk</a></p> <p>An independent body which sets standards and procedures and provides a national accreditation framework for organisations that supply diabetes self-management care programmes.</p> <p><a href="http://www.qismet.org.uk/certification/dsme-certification/">http://www.qismet.org.uk/certification/dsme-certification/</a></p> <p>accessed 10/11/2014</p> <p>For providers or commissioners of Diabetes self-management education. QISMET have developed the DSME- the Diabetes Self -Management Education Quality Standard, launched in 2011 as a way for providers to demonstrate they meet NICE Criteria.</p> <p>The NICE Standard for the treatment of Diabetes in adults was published in March 2011 and states: 'People with diabetes and/or their carers receive a structured educational programme that fulfils the nationally agreed criteria from the time of diagnosis, with annual review and access to on-going education.'</p>	 <p>SWEET</p>
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QISMET has taken this high level statement and developed a usable 'tool' which, when applied via the auditing process, shows how providers measure up to this NICE quality statement. The two corner-stone documents the DSME Standard has been developed upon are:  
'Structured Patient Education in Diabetes – Report from the Patient Education Working Group'  
'How to Assess Structured Diabetes Education: An improvement toolkit for commissioners and local diabetes communities'  
These are the documents which NICE recognises as giving 'best practice' for providing structured patient education programmes. They detail the 'nationally agreed criteria' for diabetes education programmes which NICE refers to in the quality statement above.

The benefits of DSME Certification for providers:

- Clear, observable and measurable requirements
- Demonstrate you are serious about the quality of your diabetes education provision
- Benchmark your service
- Demonstrate you meet the requirements in the NICE Diabetes in Adults Quality Standard
- offering structured educational programmes that fulfil nationally agreed criteria
- Offer the very best service to people who attend your programmes
- Demonstrate to commissioners that you have been independently audited and verified on the
- quality of your diabetes self-management education provision

[http://www.qismet.org.uk/files/1313/8511/2281/QISMET\\_DSME\\_Standard\\_14\\_11\\_11.pdf](http://www.qismet.org.uk/files/1313/8511/2281/QISMET_DSME_Standard_14_11_11.pdf)

accessed 10/11/2014

## Conclusion

The mapping exercise largely speaks for itself and is available as an A1 poster. A paper has also been attached to this report (Lange 2013) as a useful resource in that it outlines, very clearly and simply exactly what is needed for successful SDEP at all ages and their parents in terms of nutritional themes for babies, infants, preschool children, elementary school children and adolescents with diabetes and their parents (Lange 2013). Parents of young children with diabetes need to be shown how to eat normally in spite of diabetes and this is based on the German model previously described (Lange, Swift et al. 2014). Parenting skills also play a part in diabetes management and the German DELFIN has shown promise and worth examining given Germany's success with CYP diabetes management and outcomes (Saßmann, de Hair et al. 2012).

## Section 8. Bringing Science Home - Diabetes related awards

This section is intended to illustrate how diabetes initiatives have been used across the UK and won awards and how best practice can be shared across groups developing education and skills for CYP and their carers. Details of various local, regional and national award winners for their work in CYP diabetes care are briefly described. Some of these have the potential for PCFT to apply for and/or to collaborate with those which are proceeding. Additional Bring Science Home Technology Research Awards are described in the m-Health section below page 104.

### Bringing Science Home awards

Bringing Science Home is committed to research that focuses on living well with chronic disease. Projects focus on positive psychology, the science of optimism, social support and daily living with disease. The project teams include psychologists, anthropologists, diabetologists and paediatricians. Many of these are related to families and family functioning. Those particularly for families, parents and adolescents are marked thus.



Table 15. Diabetes related award winners

<p><b>2013 RESEARCH AWARDS FROM BRINGING SCIENCE HOME (BSH)</b></p> <p><b>“Just For Parents” assessment tool: Implementation, Intervention, Testing and Evaluation.</b> With a view to creating an intervention program for families living with diabetes. This project builds off previous BSH research.</p> <p><b>Development of the Youth Health Resiliency Scale.</b> This project is working to develop an assessment scale to help professionals and caregivers better understand the current knowledge and resiliency factors for youth and young adults with chronic illness. Information gathered will be used to empower youth and young adults with chronic health conditions to develop health skills as well as promote positive outcomes such as social connectedness and optimism.</p>	
<p><b>2012 RESEARCH AWARDS</b></p> <p><b>Just for Spouses and Partners: Development of an Online Program to Understand and Address Emotional Distress in the Spouses and Partners of Adults with Type 1 Diabetes.</b> BSH with The Behavioural Diabetes Institute.</p> <p><b>Development of a Health Understanding Tool for Teens with Chronic Health Conditions.</b> This project will develop a survey and questionnaire designed to promote positive outcomes for youth and young adults with chronic illness. The domains of the questionnaire and survey will include health literacy, social support, problem solving and overall quality of life. Psychologists will</p>	

<p>guide the process and create tools that will be usable for both patients and professionals.</p> <p><b>Qualitative Research to Understand Distress in Families Touched by Diabetes</b> Continuing a focus on distress and family dynamics, focus groups and interviews will be conducted in order to understand how the family unit functions in life with diabetes. The emphasis this year is on partners. Last year the team focused on caregivers.</p> <p><b>Cultivating Healthy Eating, Exercise and Relaxation</b> This study will evaluate the efficacy of mindfulness based cognitive behavioural therapy in reducing BMI and improving hyperglycaemia, blood pressure, cholesterol, anxiety, depression, self-esteem, sleep and quality of life. This study is based in a Healthy Weight Clinic.</p>	
<p><b>2011 RESEARCH AWARDS</b> The following projects focus on the lived experiences and needs of people with chronic conditions.</p> <p><b>Helping Parents</b> <b>“Parent Perspectives on Life with a Child with Diabetes”</b> This research study is designed to gain feedback from parents of youth and young adults with Type 1 Diabetes to understand their perceptions of living with diabetes and their needs as parents. Information from this research will guide product and program development. Recruitment Flyer</p> <p><b>Measuring Distress: Family Centred Therapeutic Relationships</b> BSH has entered into a consulting relationship with world-renowned psychologists and the Behavioural Diabetes Institute to investigate the needs of families coping with life with chronic conditions. It is a look into the experience of caregivers and a journey toward creating a system of care that embraces the family experience with disease. Part of the effort will include building distress in diabetes instruments to assess family coping.</p> <p><b>Creating New Care Teams</b> <b>“Diabetes Change for Life”</b> A clinical study that uses Cognitive Behavioural Therapy, along with intensive behaviour based education, and a creative team approach to prevent the progression of pre-diabetes, type 2 diabetes, and obesity.</p>	 <div data-bbox="1899 1070 2056 1206" style="background-color: yellow; border: 1px solid black; padding: 5px; text-align: center;">       Type 2 diabetes     </div>
<p><b>2010 RESEARCH AWARDS</b> The studies below focus on how people with chronic conditions live their lives and the needs they have and are sponsored by BSH.</p>	



## Section 9. Technology and m-Health

### Comment

Just as health informatics has evolved into e-Health its technology now being thoroughly embedded in all aspects of health care, this has in turn generated the concept of E-nursing and differences in nursing practice impacting on the work of nurses, system requirement, governance, education and research. The rapid development of technology in the field of mobile technology such as smartphones, tablets, apps, clouds and social media initiated a shift from e-Health into mobile Health (m-Health). M-Health is bringing the new world of technology within the reach of all patients and practitioners of all ages, around the planet. HCPs are considering how these can potentially contribute to health goals including, quality of care, service provision, patient empowerment and continuity of care. There are a wide range of digital solutions that are essential for health care innovations and nurses are exploring how they can take advantage of this growing environment to give better care to patients (ACENDIO 2013).

The use of diabetes technology by people with type 1 (and type 2) diabetes is becoming increasingly widespread. These include devices that monitor glucose and deliver insulin, cell phone-based text messaging, applications (apps) on smart phones, and internet-enabled education and support programs (Goyal and Cafazzo 2013). An Australian study with 150, 18–35 years old with T1D found that 80.7% of them referred to diabetes organisation websites for further education; and 30.0% used online chat rooms and blogs for education thus the usefulness of m-health is indisputable for all age groups (Wiley, Westbrook et al. 2014). Whilst some APPS are very technical and expensive, others are more user-friendly and free. CYP then, have the potential to be educated, motivated and supported by diabetes related technology in a world where this is a common mode of learning, playing and communicating generally across the lifespan. Programs range from; simple text messages reminding CYP or their caregiver to perform various diabetes tasks; review educational and motivational online videos; utilise programs that track and analyse multiple data obtained manually or via other devices, like pedometers, scales etc. Glucose values, insulin doses, carbohydrate and calorie intake, physical activity levels and weight can be tracked and analysed with some offering additional treatment and behavioural suggestions and encouragement. Applications have been linked to games and on-line communities to increase engagement and motivation in CYP. Advanced technologies such as the soon-to-be-available artificial pancreas hold promise, but will only be adopted by richer countries, whilst on line programmes and cell phone applications have greater potential to be used by more patients across the world (Kaufman 2013). However, precisely how this technology can be fully exploited in order to alter the face of diabetes education, care and outcomes is under discussion and has yet to be realised (Goyal and Cafazzo 2013).

A review of 137 m-health apps, all of which promised help for people to manage their diabetes was undertaken by Goyal & Cafazzo. Evidence suggests that m-Health apps may be used to effectively deliver health services and self-management tools, overcoming some barriers to provider access. Mobile phone apps allows access into hard to reach populations (especially CYP), creating opportunities for health care providers to help them manage their diabetes remotely by communicating with them, capturing data and making decisions together in real time and thus improving their outcomes. m-Health apps may be targeted for patients, their carers or both so that they share management. For CYP's, struggling with complex diabetes care guidance, they offer the potential to supplement traditional care, especially between clinic visits, offering in-situ feedback and personalised education, the lack of which can lead to complications and poor quality of life. Traditionally paper tools allowed a logging of various measures but often do not offer accurate data due to faulty entry, their inability to capture enough data for a HCP to make clinical decisions and the lack of real time feedback and motivation for behaviour change. On the other hand, to be able to transfer blood glucose data wirelessly to a mobile phone could eliminate errors, making this task easier, potentially improving self-monitoring adherence.

Unfortunately, all commercially available apps require manual data entry, with only 64% using wireless data transfer. Wireless medical devices are increasingly available but general use of them is restricted by regulatory issues. A similar discrepancy is seen with the integration of personal health records (PHRs) in research-based apps compared to those commercially available. Although PHRs allow for secure and portable storage of personal health information between informal and formal caregivers, most of the apps found on the market only allow for Excel data export. Given that personalised feedback is the key to self-care behaviour, only 20% of apps assessed in Goyal and Cafazzo's review had an educational component. Of this 20% only one fifth delivered personal feedback. With a lack of embedded behaviour change strategies, mobile apps risk could be just an electronic replacement of existing paper based tools, failing to empower patients with knowledge they can respond to (Goyal and Cafazzo 2013).

### **Addressing the gap between research and the APPS**

Most commercially available apps are not evidence based and tend not to differentiate between T1DM and T2DM. Of the 137 apps identified by (Goyal and Cafazzo 2013) top features included manual data recording, insulin and medication tracking, followed by data export and communication. By focusing on simple logging of blood glucose readings, the significant and fundamental differences between self-management of both conditions remain ignored. Although the role of SMBG amongst T2DM patients on oral medications remains a controversial issue, there is some agreement that these patients could benefit from monitoring blood glucose when viewed in the context of their lifestyle behaviours. Although there exist individual apps that allow users to objectively track physical activity, nutrition, weight and medications, few offer an integrated behavioural self-management tool targeted towards non-insulin requiring type 2 diabetes and the potential of harnessing fully the capabilities of smartphones to deliver real-time feedback, diabetes education, and secure data sharing is still underexplored. More importantly, the potential for them to shape individuals' behaviours towards optimal, self-management and mental,

emotional and physical health and wellbeing is exciting. The "*bant*" app, piloted by this author and described below explored the use of automated algorithms and external incentives to influence behaviour change. It effectively engaged with patients, influenced their behaviour positively and has the potential to impact positively on their health (Goyal and Cafazzo 2013).

## Existing evaluations of research based APPS in development/co-designed with CYP

in this section contains evaluations of three APPS/apps in development which were tested with CYP using rigorous research methods. Table 18 illustrates some current ideas from the NHS for health providers to develop on-line training.

**Table 16. Three research based apps in development**

APP DETAILS	CONCLUSIONS
<p>Patient and Parent Views on a <b>Web 2.0 Diabetes Portal</b>—the Management Tool, the Generator, and the Gatekeeper: Qualitative Study</p> <p>(Eysenbach 2010)</p>	<p><b>User verified</b></p> <p>A small study examined CYP and parents' views towards a local Web 2.0 portal tailored to CYP (ages 11-18 years with type 1 diabetes, their mothers and fathers. The portal incorporates message boards and blogs, locally produced self-care and treatment information, and interactive pedagogic devices. It provides access to continuous support and learning opportunities.</p> <p>Three main user attitudes were identified:</p> <ol style="list-style-type: none"> <li>1) "the management tool" or the functionality of the portal. Being able to search when necessary and find reliable information provided by local clinicians was advantageous, facilitating a feeling of security and being in control. Finding answers to difficult-to-ask questions, some that had not occurred to users previously and questions focusing on sensitive areas such as anxiety and fear was also an important feature.</li> <li>2) "the generator," function. Visiting the portal could generate more information than expected, which could lead to increased use. Active message boards and chat rooms were found to have great value for enhancing mediation of third party peer-to-peer information. A certain level of active users from peer families and visible signs of their activity were considered necessary to attract returning users.</li> <li>3) "the gatekeeper" function of the password requirement created various access problems. This and other unsuccessful experiences caused users to drop the portal. A largely open portal was suggested to enhance use by those associated with the child with diabetes, such as school personnel, relatives, friends and others, and also by young users somewhat unwilling to self-identify with the disease.</li> </ol>

	<p>Web 2.0 services hold great potential for supporting parents and patients with type 1 diabetes by enhancing their information retrieval and disease management. It is a well-developed service, generates continued use and needs to be carefully maintained and updated by health care professionals who are alert and active in providing new information and updates. Login procedures were problematic and should be simplified. Clinicians need education of clinical practices regarding the use of Web 2.0 resources. A largely open portal would make access easier for all patients, families, HCPs and, potentially, school personnel. An open portal would facilitate it being used by others related to the child with diabetes, such as relatives and friends.</p>
<p><b>WellDoc system</b> Cluster- Randomized Trial of a Mobile Phone Personalized Behavioural Intervention for Blood Glucose Control.  (Quinn, Clough et al. 2008)</p>	<p><b>Patient-coaching and provider clinical decision support system</b> The involvement of HCPs in offering feedback is vital but costly and this multimodal tool enables patients to wirelessly upload BG readings and other diabetes related information, and receive real time feedback either via the HCP, caregiver or WellDoc research team. The effectiveness of WellDoc was evaluated in a cluster RCT. HbA1c decreased by 1.9% in the WellDoc group compared to those not using it (i.e. only 0.7%). The solution's dependency on the HCP or coach is difficult to measure however, and also does not fully explore the advanced capability of personal devices and mobile applications to promote more autonomous patient self-management.</p>
<p><b>Bant app</b>  Design of an m-Health App for the Self-management of Adolescent Type 1 Diabetes: A Pilot Study  (Cafazzo, Casselman et al. 2012)</p>	<p><b>Co-designed</b> Despite their keenness on technology, this has not resulted in improved management outcomes for adolescents with type 1 diabetes. A Canadian study hypothesized that a more tailored approach and a strong adherence mechanism was necessary for this group. With 20 adolescents (aged 12-16), they co-designed, developed and piloted an m-Health intervention for the management of type 1 diabetes. <i>Bant</i> allowed users to wirelessly transfer blood glucose readings, review trends, receive automated feedback, and share information through Microsoft HealthVault.  The app was evaluated over 12-weeks with CYP with a glycated haemoglobin (HbA1c) of between 8% and 10%. Each CYP ran their bant app on an iPhone or iPod Touch and a LifeScan glucometer with a Bluetooth adapter for automated transfers to the app. The outcome measure used was the average daily frequency of blood glucose measurement during the pilot compared with the preceding 12 weeks. The pilot study found the role of data collecting important rather than decision making; there was a need for; fast, discrete transactions; overcoming decision inertia; and ad hoc information sharing. In terms of design, simple, automated transfer of glucometer readings; the use of a social community; and the concept of gamification, (whereby routine behaviours and actions are rewarded in the form of iTunes music and apps). Blood glucose trend analysis was provided with immediate prompting of the participant to suggest both the cause and remedy of the adverse trend.</p>

	Results showed a 49.6% increase in the frequency of blood glucose measurements and an average of 8 rewards were distributed to each participant. CYP were happy with the app stating that they would continue to use it. A properly powered study is necessary to ensure that this translates into improved health outcomes, incentives will need to be tied not only to frequency of blood glucose monitoring but also to patient actions and decision making based on those readings such that glycaemic control can be improved.
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**Error! Not a valid bookmark self-reference.** contains descriptions of user verified existing apps/on line resources. Please note that these are descriptions only of what the apps can offer. They have not been appraised by VF and do not, therefore, incorporate the flag system. Finally, technology related awards are described from, Bring Science Home Technology Research Awards.

**Table 17. User verified existing apps/on line resources**

NAME	Description
<p><b>DAFNE on line.</b></p> <p>Developer: Keith Clarke; Simon Fisher (Simfish) [UK based app developers]</p> <p><a href="http://hscweb3.hsc.usf.edu/bringingsciencehome/2010-research-awards-from-bringing-science-home/">http://hscweb3.hsc.usf.edu/bringingsciencehome/2010-research-awards-from-bringing-science-home/</a></p> <p>English language only.</p>	<p><b>User verified</b></p> <p>Allows the user to remain connected with the DAFNE online support network for people with type-1 diabetes who have attended the ‘Dose Adjustment For Normal Eating’ (DAFNE) course.</p> <p>The app has a blood glucose diary that allows blood-glucose levels, and carbohydrate and insulin intake to be recorded and uploaded to the user’s DAFNE online account. Blood-glucose targets can be specified for different times of day.</p> <p>Diary results are colour coded, to show below or above target. The app will auto-calculate insulin dosage. Backup of data can be set to manual or automatic. Also contains information about the carbohydrate content of portions (accessible without an Internet connection).</p> <p>For android: <a href="http://bit.ly/Qmmtt">http://bit.ly/Qmmtt</a>  Apple: <a href="http://bit.ly/Op8TO8">http://bit.ly/Op8TO8</a>  Blackberry  Nokia  Windows Phone  Other weblinks. Free</p>

<p><b>Diabetes UK tracker app for teens</b></p> <p><a href="http://www.diabetes.org.uk/How_we_help/Diabetes-UK-apps/Tracker-app/">http://www.diabetes.org.uk/How_we_help/Diabetes-UK-apps/Tracker-app/</a></p> <div data-bbox="315 443 495 580" style="border: 1px solid black; background-color: #fff9c4; padding: 5px; width: fit-content; margin: 10px auto;"> <p>Type 2 diabetes</p> </div>	<p><b>User verified.</b></p> <p>Third Sector Excellence Award winner for Use of Digital Media 2012. This prestigious award recognises innovation by charities in digital media.</p> <p>For Type 1 or Type 2 diabetes, and for carers. The app is designed to be quick and simple to use, taking the daily chore out of logging levels such as blood glucose, carbohydrates and calories</p> <p>Designed by a team that included user experience professionals, clinical specialists and people with diabetes, to help manage the condition.</p> <p>For Apple or Android smartphone. Free.</p>
<p><b>Diabetes UK tracker app</b></p> <p><a href="http://www.diabetes.org.uk/How_we_help/Diabetes-UK-apps/Tracker-app/">http://www.diabetes.org.uk/How_we_help/Diabetes-UK-apps/Tracker-app/</a></p>	<p><b>User verified.</b></p> <p>For Type 1 or Type 2 diabetes, or for carers.</p> <p>Designed to be quick and simple to use, taking the daily chore out of logging levels such as blood glucose, carbohydrates and calories.</p> <p>Designed by a team that included user experience professionals, clinical specialists and people with diabetes, to help manage the condition</p> <p>For Apple or Android smartphone. Free</p>
<p><b>Diabetes forum app</b></p> <p><a href="http://www.diabetes.co.uk/app/">http://www.diabetes.co.uk/app/</a></p>	<p>.Provides support and sharing of experiences</p> <p>A survey undertaken in 2013 indicated that, 71.4% of forum members users had a better understanding of their diabetes and 35.2% had improved HbA1C.</p> <p>This app would require an assessment of safety for CYP in terms of confidentiality on the Web.</p> <p>Free</p>

<p><b>NHS Decision Aid for Diabetes</b></p> <p>This App is a Patient Decision Aid designed to help people with Diabetes make a decision as to the best treatment choice for them.</p> <p>Totally Health</p> <p>March 20 2013.</p> <p>Medica</p> <p><a href="https://play.google.com/store/apps/details?id=uk.co.activata.TotallyHealth.condition330">https://play.google.com/store/apps/details?id=uk.co.activata.TotallyHealth.condition330</a></p>	<p>This patient decision aid assists patients to progress through it in an ordered fashion, having a number of distinct elements to the decision making process which support the patient in reaching a provisional decision which they can then discuss with their Healthcare Professional.</p> <ol style="list-style-type: none"> <li>1) The aid provides information about Diabetes in order to facilitate better understanding of what is happening in the body as a result of this condition. The description is supported by an animation which demonstrates how the disease or condition progresses.</li> <li>2) Treatment options for Diabetes are then displayed providing the patient with an explanation of each of the available treatment options which can be easily compared.</li> <li>3) The decision aid then invites the patient to answer some questions which require him/her to consider what his or her values and preferences are regarding the treatment of their Diabetes, when considered alongside the consequences of each of the treatment options, for example are they happy to have an operation in order to treat the condition, and how much are the symptoms they experience upsetting them or interfering with their everyday activities?</li> </ol> <p>Once the patient has considered these questions the preferences they have entered are displayed back to them in the order they have input and information regarding each of the preferences is displayed alongside it so that the patient can fully understand which of the treatment options is most likely to fulfil their preferences.</p> <p>Finally they are presented with the information they have said is their preferred treatment option and they are encouraged to then discuss that with their Healthcare Professional so that an agreement can be reached and treatment plans made.</p>
<p><b>CLAHRC for South Yorkshire diabetes initiatives</b></p> <p><b>Self-Management of Diabetes</b></p> <p><b>Adolescent Programme of Research</b></p>	<p><b>WITHCARE</b></p> <p>Development of a telemedicine intervention which will allow the remote monitoring of blood glucose by the clinical care through real-time automated transmission of results from the patients monitor. It is hoped that this may allow more timely support to young people to assist them in managing their diabetes.</p> <p><a href="http://clahrc-sy.nihr.ac.uk/theme-diabetes-adolescent.html">http://clahrc-sy.nihr.ac.uk/theme-diabetes-adolescent.html</a></p>
<p><b>Useful web sites</b></p>	<p><a href="http://www.nhs.uk">www.nhs.uk</a></p> <p><a href="http://www.yorkshirediabetes.com">www.yorkshirediabetes.com</a></p>

	<a href="http://www.ispad.org">www.ispad.org</a> <a href="http://www.jdrf.org.uk">www.jdrf.org.uk</a> <a href="http://www.childrenwithdiabetes.com">www.childrenwithdiabetes.com</a> <a href="http://www.sign.ac.uk">www.sign.ac.uk</a> Juvenile research foundation	
<b>European Directory of Health Apps 2012-2013: A review by patient groups and empowered consumers.</b>  <a href="http://www.patient-view.com/uploads/6/5/7/9/6579846/pv_appdirectory_final_web_300812.pdf">http://www.patient-view.com/uploads/6/5/7/9/6579846/pv_appdirectory_final_web_300812.pdf</a>  Accessed 25/11/2014	<b>DIABETES RELATED APPS</b> CarbFinder Carbs & Cals DAFNE Online Diabetes UK Tracker Glucose Buddy—Diabetes Helper Glucose Companion Free HelpDiabetes iBGStar Diabetes Manager App (mmol/L or mg/dL) Journals of the American Diabetes Association OnTrack Diabetes	<b>PAGE NUMBER</b> 42 43 50 52 78 79 88 94 102 136
<b>Bring Science Home Technology Research Awards</b>		
<p><b>2011</b>  <b>People Centred Technology</b>          “The Design and Development of a Patient Centric Diabetes Management System”          This project will design a comprehensive patient-centric tool, completely customizable and tailored around the individual’s condition, needs, goals, and desires.</p> <p><b>2013</b>  <b>Participatory Medicine using Social Media.</b> This project intersects psychology, clinical care and engineering to provide a modern approach to many delicate issues involving family functioning in life with chronic disease.</p> <p>Starting a New Dialogue in Diabetes Education. This project looks at reframing diabetes education with an eLearning, patient engagement platform. This system is being built in partnership with a Healthy Living Centre.</p> <p><a href="http://hscweb3.hsc.usf.edu/bringingsciencehome/2010-research-awards-from-bringing-science-home/">http://hscweb3.hsc.usf.edu/bringingsciencehome/2010-research-awards-from-bringing-science-home/</a></p>		

There is also potential for health providers to develop modules for on line training of both lay and professional carers. Table 18 describes some suggestions from the NHS.

**Table 18. Potential of the development of on-line training by health providers**

On-line training in some elements of the CYP curriculum. For example, the development of on-line modules for training of school staff/other volunteers including how to do blood glucose testing, insulin injections/boluses, hypoglycaemia etc. would be beneficial (NHS 2013)
The 'Pump school online'- basic pump training module for parents/children/MDT/ward staff and schools (NHS 2013)
E-learning teaching courses in addition to /face-to-face teaching for Continuous Glucose Monitoring (CGM) for professionals and families (NHS 2013)
An e-learning foundation package based on the first level of the NHS curriculum. This should be mandatory for all HCPs working with CYP with diabetes (NHS 2013)
Replacing routine follow-up outpatient with web-based consultation attending the transitional and young adult services
Newham University Hospital NHS Trust: Web based outpatient consultations in diabetes <a href="http://www.health.org.uk/areas-of-work/programmes/shine-eleven/related-projects/newham-university-hospital/">http://www.health.org.uk/areas-of-work/programmes/shine-eleven/related-projects/newham-university-hospital/</a>

## Conclusion

The position of m-Health in CYP diabetes care has been outlined above, along with a description of m-Health apps tested with rigorous research methods and opportunities for PCFT to develop NHS recommended resources. Existing diabetes apps have also been described along with some on-line resources. Notwithstanding the growing body of research supporting the use of specific m-Health applications for diabetes self-management, (along with the difficult task of identifying those with clinical relevance), the impact of m-Health on clinical outcomes compared to 'usual care' is unknown (Goyal and Cafazzo 2013). Apps developed on various nutritional themes constitute practical aids. They cannot, however, replace person-centred and motivational counselling given by a HCP (Lange 2013). The main take home message from this section is that apps which are co-designed and have undergone a rigorous research process appear to be the ones with the potential to affect care and the APPS in

which are in the process of being developed via a research process are worth watching out for in the context of CYP SDEPs.

## Section 10. Mandatory support in schools for children with diabetes

### Diabetes UK's Type 1 diabetes: Make the grade. NATIONAL CAMPAIGN FOR SUPPORT IN SCHOOLS

#### Comment

Theoretically informed systematic review examined intervention effectiveness and synthesised child/parent/professional views of barriers and facilitators to achieving optimal diabetes self-care and management for children and young people age 3–25 years in educational settings (Edwards, Noyes et al. 2014). This is the first to integrate intervention effectiveness with views of children/parents/professionals mapped against school diabetes guidelines. In terms of school support they found the following:

- Health plans, and school nurse support (various types) were effective.
- Telemedicine in school was effective for individual case management.
- Most educational interventions to increase knowledge and confidence of children or school staff had significant short-term effects but longer follow-up is required.
- Children, parents and staff said they struggled with many common structural, organisational, educational and attitudinal school barriers.
- Aspects of school guidance had not been generally implemented (e.g. individual health plans).
- Children recognised and appreciated school staffs that were trained and confident in supporting diabetes management.

The review concluded that diabetes management could be generally improved by fully implementing and auditing the impact of guidelines (Edwards, Noyes et al. 2014).

Schools in England now have a legal duty to support children with long-term health conditions. The Children and Families Act means that all parents of children with Type 1 diabetes should now be able to send their children to school with procedures in place to help keep them safe and ensure that they are able to participate fully in school activities.

<http://www.diabetes.org.uk/Guide-to-diabetes/Schools/Diabetes-in-schools-legal-information/>

Accessed 3/12/2014

Schools are now required to have a medical conditions policy in place, along with individual healthcare plans, tailored to meet each child's needs, for any child with Type 1 diabetes. Schools must also work with parents and diabetes specialist nurses to make sure children get the individual support they need and ensuring that relevant staff are trained to provide the right support is also a new requirement. Free resources

are available (see Section 6. Written resources ) to help parents and schools get the right care in place. There is also a new webpage offering detailed information on care in schools.

There is a plethora of information for school staff on the website and it would be pertinent to have whole school training sessions on main issues with paediatric diabetes with more advanced ones for particular involved staff. Topics available are:

- Treating diabetes
- Managing diabetes
- Complications of diabetes
- Exams
- School trips
- Responsibilities of head teachers and school governors
- Responsibilities of teachers
- Responsibilities of trained staff
- Responsibilities of SENCOs, Additional Needs Coordinators, Inclusion Managers
- Responsibilities of school nurses

<http://www.diabetes.org.uk/Guide-to-diabetes/Schools/School-staff/>

<http://www.diabetes.org.uk/Guide-to-diabetes/Schools/Children/>

<http://www.diabetes.org.uk/Guide-to-diabetes/Schools/Diabetes-healthcare-team/>

The NHS would like to implement legislation which would make appropriate management of diabetes in schools compulsory, including carbohydrate related insulin dose adjustment, via pens or pumps. The Department for Education is also looking at potentially including diabetes management in OFSTED criteria. The NSF for CYP also explains how someone who knows how to use insulin pumps should be available in order to help with blood glucose tests, add up mealtime insulin needs, adjust pump settings, and troubleshoot any problems. Standard 2 (supporting parents or carers) advocates attendance on a two-day outpatient programme in order to be able to do this (NSF 2010).

Thus, although parents will continue to have the main responsibility for a child's health at school, they should not have to go into school to inject or test blood. They need to keep the school up to date with the child's diabetes management, making sure they've got the equipment they need and giving consent for any medical treatment to be given at school. Tasks for parents are detailed in Table 19 below.

## Parental responsibilities

**Table 19. Parental responsibilities**

- Letting the child's school know about their condition
- Prepare for, and attend, a school meeting with all relevant staff including breakfast club/after school club staff
- Play a part in drawing up their child's Individual Healthcare Plan (IHP) and fulfil their role in this Individual Healthcare Plans
- Provide written permission for insulin to be given by the head teacher, school staff, or to be self-administered by your child
- Help train and support school staff
- Make sure school staff have the right medication and equipment to look after your child as detailed in their IHP
- Provide specific advice/training for school staff regarding school trips, exams etc.

<http://www.diabetes.org.uk/Guide-to-diabetes/Schools/Parents/What-are-my-responsibilities/>

## Care in School Helpline

This is provided by specially selected and trained volunteers who will give rights-based information and support. They can support with drafting letters to schools and can direct parents to other useful organisations. Many of the volunteers are parents who have knowledge and experience of the issues parents may face. This is helpful because the information, policy documents parents are expected to read and understand are many and complex.

**Call 0345 123 2399 or go to [www.diabetes.org.uk/care-in-school](http://www.diabetes.org.uk/care-in-school)**

Diabetes UK has dedicated information for children in primary and secondary schools, to provide support for them to manage their diabetes at school – including: telling friends and teachers; tips on food, PE, school trips and exams; and how to deal with any problems.

The Lobbying of Members of Parliament is proposed, to legislate to make appropriate management of diabetes in schools compulsory, including carbohydrate - related insulin dose adjustment via pens or pumps and the Department for Education for the potential to include diabetes management in OFSTED criteria.

In addition to the apps already in existence (table 16) which CYP and their carers can utilize, the NHS advocates on-line training in some elements of the CYP curriculum. For example, the development of on-line modules for training of school staff/other volunteers generally including how to do blood glucose testing, insulin injections/boluses, hypoglycaemia etc. would be beneficial

## **Conclusion**

Mandatory support, both existing and recently put into force, in schools for CYP and their parents is detailed in the appendices of this document. Parents should be aware of some of the above legislation, acts and guidance. However, they may require support and education in this particularly if reading/ understanding of the English language is a challenge for them in whatever context. An educational module on this may be beneficial for them because of the plethora of complex information. Details of all relevant guidelines and policies are in the Appendix.

## Section 11. Recommendations for SDEP's for CYP and their lay and professional carers – a good start

This final section takes into account all the above and offers detailed recommendations for setting up and running a SDEP for CYP. Based on German models of structured diabetes self-management education and care described above, a “**good start**” is advised which should reduce the burden of diabetes and maintain optimum quality of life and constitutes the following:

- Diagnosis is an ‘**ideal moment**’ to instigate an intensive personalised healthcare package which includes a family focused diabetes education package, self-management education and on-going support should be initiated (this can result in a prompt reduction of HbA1c and maintaining optimal glycaemic control).
- The education of CYP and their families to self-manage diabetes should use nationally standardised and evaluated programmes of education that are age and maturity appropriate; tailored for the individual child and family and which can measure and benchmark clinical and psychosocial outcomes.

The following recommendations are based on recent NHS, ISPAD guidelines relating to CYP diabetes structured education and training of HCPs (Swift 2009)

### Main premise

Education of CYP and their families to self-manage diabetes should rely on nationally standardised and evaluated programmes of education that are age and maturity appropriate; tailored for the individual child and family and which can measure and benchmark clinical and psychosocial outcomes.

### Universal Principles to be adhered to are that:

- Every young person has a right to comprehensive expert structured education which should empower them and their families to take control of their diabetes
- Children and adolescents, their parents and other care providers should all have easy access to and be included in the educational process
- Diabetes education should be delivered by health care professionals with a clear understanding of the special and changing needs of young people and their families as they grow through the different stages of life
- Diabetes education needs to be adaptable and personalised so that it is appropriate to each individual's age, stage of diabetes, maturity and lifestyle, culturally sensitive and at a pace to suit individual needs

- Diabetes education should be based on a thorough assessment of the person's attitudes, beliefs, learning style, ability and readiness to learn, existing knowledge and goals
- Educators (doctors, nurses, dieticians and other health care providers) should have access to continuing specialised training in diabetes education and educational methods
- Diabetes education needs to be a continuous process and repeated for it to be effective

#### **The educational program should:**

- utilise appropriate patient-centred, interactive teaching methods for all people involved in the management of diabetes, particularly the affected child or adolescent
- be grounded in a realistic understanding of self-management
- use technology which may be attractive to young people
- enable young people to use knowledge and practical skills in problem solving and self-care, to be in control of goal setting for better care and to have influence over their own lives in making informed decisions about their diabetes

#### **ISPAD Clinical Practice Consensus Guidelines:**

- Motivation – The learner needs to have a desire to learn
- Context – Personal - where is the CYP now and where do they want to be later?
- Environment – Learner centred, comfortable, trusting, enjoyable, entertaining, interesting, open
- Significance – Meaningful, important, links/joins up. Rewards and gains incorporated.
- Concepts – Simple to complex in gentle steps allowing for attention time spans
- Activity – Constant interaction, practical, real life oriented, goal setting, problem solving
- Reinforcement – Repetition, review, summarise
- Reassess – Evaluate, audit
- Move forward – Continuing, on-going education

## ISPAD age related content for structured diabetes education programmes

Changing insulin regimens per se does not improve metabolic control. However, by addressing the total management package utilising comprehensive structured education there is more likelihood of success. Diabetes education needs to be adaptable and appropriate to each individual's age and maturity, beginning with infants and toddlers, school age children and finally adolescents. Table 20 below outlines ISPAD guidelines in relation to age appropriate training and content (Swift 2009).

**Table 20. ISPAD age related content for structured diabetes education programmes**

Age group	Education
<p><b>Below 5 years Infants and toddlers</b></p>	<ul style="list-style-type: none"> <li>• Total dependence on parents and care providers for injections, food and monitoring and the requirement of a trusting attachment between infant and caregivers</li> <li>• Mothers may feel increased stress, diminished bonding and depressive feelings. This can be the case with many chronic diseases however,</li> <li>• Unpredictable erratic eating and activity levels</li> <li>• Difficulties in distinguishing normal infant behaviour from diabetes-related mood swings</li> <li>• Injections and BG checks seen as pain inflicted by caregivers</li> <li>• Hypoglycaemia is more common. Severe hypoglycaemia may be more harmful. Education on prevention, recognition and management is therefore a priority. Age specific targets for BG should be discussed.</li> </ul> <p>There is conflicting evidence on the behavioural characteristics of preschool children with diabetes and whether diabetes outcomes depend on education per se.</p> <p>Parents report the importance of education and non-judgmental support from a team.</p> <p>Children's NSF model of children's acute and chronic disease management focuses on educating children/young people in age-appropriate ways to deliver aspects of their own healthcare, and specifically identifies parents as experts (Noyes, Williams et al. 2010). Parental education should include advising parents on the gradual development of the child's independence with progressive stepwise hand-over of appropriate responsibilities.</p>
<p><b>Primary level School age children</b></p>	<ul style="list-style-type: none"> <li>• Adjusting to the change from home to school developing self-esteem and peer relationships</li> <li>• Learning to help with and developing skills in injections and monitoring</li> <li>• Progressive recognition and awareness of hypoglycaemic symptoms</li> <li>• Increasing understanding and self-management</li> </ul>

	<ul style="list-style-type: none"> <li>• Adapting diabetes to school programs, school meals, exercise and sport</li> <li>• Including monitoring of BG levels and injections in the school setting</li> </ul>
<b>Teenagers Adolescents</b>	<ul style="list-style-type: none"> <li>• Accepting the critical role of continued parental involvement and yet promoting independent, responsible self-management appropriate to the level of maturity and understanding</li> <li>• Understanding that knowledge about diabetes in adolescence is predictive of better self-care and (metabolic) control but the association is modest</li> <li>• Discussing emotional and peer group conflicts</li> <li>• Teaching problem solving strategies for dealing with dietary indiscretions, illness, hypoglycaemia, sports, smoking, alcohol, drugs and sexual health</li> <li>• Negotiating targets, goals and priorities and ensuring that the tasks taken on by the adolescent are understood, accepted and achievable</li> <li>• Understanding that omission of insulin is not uncommon. The opportunity should be grasped for non-judgemental discussion about this</li> <li>• Developing strategies to manage transition to adult services.</li> </ul>
<b>Transition (16 – 18 years).</b>	<p><b>Transition from paediatric to Adult care</b></p> <p>The period between CYP and adult care is difficult and there is an increased risk of deterioration in glycaemic control. CYP SDEP's are vital to equip individual with the knowledge, skills, understanding and tools by which they can successfully manage their condition as adults (Lotstein, Kuo et al. 2010).</p> <ul style="list-style-type: none"> <li>• Lengths of sessions need to be kept to under 45 minutes</li> <li>• Management of group dynamics is a necessary skill</li> <li>• Individual 5 minute slots/consultations with CYP if necessary</li> <li>• Practical activities</li> <li>• Session length, position within the day and the overall structure of the whole course needs to be considered in order to maximise engagement</li> </ul> <p>(Beer, Eiser et al. 2014).</p>

## **Levels of training**

### **Level 1. Primary education.**

At diagnosis: Survival skills (detailed in the mapping exercise above, page 84)

- Methods of delivering this level of education and the use of educational resources will depend on local experience and facilities.
- It will be dominated initially by individual (family) teaching.
- Health professionals should learn to incorporate and deliver the education using behavioural approaches which are learner centred and not didactic.
- Initial learning should be reinforced by written guidelines and booklets which should be appropriate to the child's age and maturity
- Written materials for parents should use appropriate language and a style that is easily comprehensible

### **Level 2. Secondary.**

Continuing educational curriculum (Detailed previously in the mapping , page 84). Ideally this should be carried out in outpatient, domiciliary, community settings. If this is untenable, it can be delivered in a hospital environment, individually or in groups and whenever possible in a protected environment conducive to learning.

### **The “Ideal moment” - optimal times for learning**

As recommended, SDEP immediately following a diagnosis of type 1 diabetes and during follow-up care is considered as ‘an integral and essential part of long-term paediatric diabetes management’ (Lange 2013)(p96). Offering education at this time may increase future uptake and attendance of group education. Delivery of SDE at an early stage will negate the difficulties associated with trying to change established behaviour at 1 year post diagnosis. Both group and individual structured diabetes education should be available according to preference and need. Groups are cost-effective and efficient and facilitate the sharing of knowledge and experiences through interaction and peer support. Relationships between people with diabetes and healthcare professionals also are of benefit (Bleakly and McKee 2010). Although group education may be more cost effective and enhanced by peer group or school friendships, there is evidence that education directed at individual needs is equally effective as group education (Swift 2009).

## **Optimum learning and structured education**

### **Other suggestions for optimum learning from existing CYP programmes include:**

- Scheduling the most demanding sessions to prime learning times in the morning. Focus on practical considerations in the afternoons
- Simplifying worksheets on using [insulin] ratios and sick day rules
- Providing individual support for CYP and parents who have difficulty with mathematical calculation
- Maintaining a routine of explaining after each session what has been covered in a particular day, showing where information is located in any theory booklets and encouraging participants to share this with other members of their family
- An initial preparatory session for CYP and parents
- Running sessions for adults can be held alongside those for their children
- Establishing firm ground rules for dealing with problematic behaviours during the course
- It should be available to all people with diabetes at the time of initial diagnosis, or when it is appropriate for them, and then as required on an on-going basis, based on a formal, regular individual assessment of need
- It should be provided by an appropriately trained interdisciplinary team who, between them, have a sound understanding of the principles governing teaching and learning
- It should be provided by interdisciplinary teams including, as a minimum, a diabetes specialist nurse and a dietician. HCP's with psychological skills can add value to a programme.
- It should be held in a location accessible to individuals and families
- It should use a variety of teaching techniques, adapted wherever possible to meet the different needs, personal choices, learning styles of young people with diabetes and parents, as well as local models of care.

## **Parental involvement**

SDEPs for CYPs should actively involve parents. Ethically, all family members should be informed about diabetes treatment and risks in order for them to live successfully with a person with this condition. Parents should, therefore, have knowledge of diabetes therapy and be offered advice as to how they can integrate this into their parenting skills. CYP and their parents need to know age appropriate physical, cognitive, mental and social development (Lange 2013). It is important to reduce misunderstandings between adolescents and their parents and/or carers in order to reach a consensus between them for taking future personal responsibility for their treatment regimens group (Larsman, Eklöf et al. 2012). It appears that multicomponent interventions, that is, those that targeted emotional, social, or family processes that will facilitate diabetes management, were more potent than interventions that neglect these variables and simply target a direct, behavioural process (such as

monitoring increase in blood glucose monitoring frequency). Such multicomponent interventions showed more robust effects on A1C and it is important to refine these interventions and examine their effect on CYP with diabetes health outcomes (Hood, Rohan et al. 2010)

## **Logistical issues**

### **Venues for SDEPS**

These should be chosen carefully to suit the audience they are intended for and be culturally and socially appropriate and should have provision for:

- Inside and outside space
- Easy access by public transport and parking provision
- CYP and educators to be able to relax at break and lunch times
- Preparing cooked snacks, lunches and drinks
- Being able to create displays and leave them
- Reliable web access

### **Recruitment and attendance**

Feedback suggests timetabling, childcare difficulties and other commitments interfered with a programme running on weekdays and recruitment rates can be higher when session times and dates are fixed in advance and without family consultation.

## **Outcomes to consider**

Regulating agencies and consumers hold healthcare accountable for providing high-quality, safe patient care. Educational activities should, have an outcome based approach and learning objectives should focus on the best practice outcomes in order to maintain organisational change. HCPs delivering this education should have the skills and knowledge to meet this goal (Loyola 2010).

Evaluation of educational programmes is essential and this will be addressed at the end of the completed EBS. However, SDEP for CYPs should focus on outcomes such as:

- the patient's achievement of self-selected diabetes care goals
- improved psychosocial adaptation
- enhanced self-efficacy
- glycaemic control

## Conclusion

The information and evidence presented above offers PCFT the tools and knowledge to successfully consider what the development of a SDEP for CYP would require in all domains. Current guidelines, suggested curricula, and many potentially suitable co-designed programmes already in existence or in development, have been described and appraised above. Many of the programmes described meet all or some of the appropriate guidelines. Some have been successfully implemented; others less so for varying reasons and reasons for this have been noted. Contacts for programmes are available.

To run a successful and efficacious programme would involve several components being considered beginning with HCPs in MDTs being trained in an approved curriculum for CYP. Their skills, knowledge and training needs would need to be ascertained before delivery of such a programme could take place. They may require specialised training in the principles and practice of teaching and education in order to successfully deliver a programme of work which involves behaviour change strategies. Parents and lay carers also have the potential to be trained in the theory and practice which underpins positive behaviour change. An introduction to theories of change techniques and methods has been offered which is beneficial to both parents and HCPs and for which training already exists.

Additional services such as transition, Type 2 and BME programmes would require adaptation from the successful adult programmes already up and running across the UK. BME communities can be challenging to engage in health care. In the US, lay-led, community based peer support sessions for minority ethnic groups are popular and well attended but have yet to be fully evaluated. In view of PCFT's current engagement with some BME groups in their geographical area, this may be a start to involving them in self-management of their diabetes. There also exist a number of excellent initiatives for Type 2 diabetes; again, these are adult programmes which can be adapted to suit CYP and their carers. LGBT programmes have not been devised thus far and would require considerable thought and co-design.

The question of evaluating structured educational programmes in general will be covered in more depth at the end of the completed evidence scan. Should PCFT design a programme or part of a programme for CYP with Type 1 and/or 2 diabetes, this could be, potentially, a contender for the BEST PRACTICE INITIATIVE. Accreditation by QISMET of a programme could then be considered (page 92). It is advised that PCFT use the services of a consultant to aid them in devising a coherent quality SDEP for CYPs, their parents and carers'.

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## Appendix

### Best practice for schools to meet the requirements of the 2014 Children & Families Act (2014) in England

#### Head teachers, school governors and responsible bodies (HT, SG & RBs)

All schools should look after and support children with medical conditions, like diabetes, so they remain safe and healthy and help them get the most out of their time at school. If the responsibility of making arrangements for children with medical conditions is delegated to a senior member of the school's management team, the HT, SG & RBs must ensure that the responsibilities set out below are met.

#### Medical conditions policy

- HT, SG & RBs should make sure their school has a medical conditions policy.
- The policy should recognise medical conditions can be life threatening, understand the impact it can have on a child's ability to learn and make clear every child with a medical condition is different and should be treated as an individual.
- The medical conditions policy must make clear who is responsible for the policy. If it is not the head teacher it must be a senior member of the school's management team and they should be named in the policy.
- How the medical conditions policy will be implemented must be explained, while schools must regularly review and audit their policy to make sure the arrangements for children with medical conditions are working.
- The policy must also be readily available for parents and staff to view and the school's complaints procedure must be part of the medical conditions policy.

#### What do staff need to know?

##### [Information for school staff](#)

HT, SG & RBs must make clear the plans and procedures they have in place when they are made aware a child has been diagnosed with diabetes. It is good practice that every member of staff is made aware of the child's condition. The following should also be undertaken:

- Train key members of staff and making sure all relevant staff are aware of the child's condition.
- Ensure that every teacher who takes the child for a lesson is made aware of their condition and have a basic understanding of diabetes.
- All staff must understand their role in helping the school look after children with medical conditions.

- The policy must set out what members of staff should do in an emergency. An emergency is an incident that requires immediate attention, not simply treatment that requires an ambulance.

### [Sample Medical Conditions Policy](#)

#### **Individual Healthcare Plans (IHP)**

- Every child with diabetes will need an IHP. HT, SG & RBs should make sure each child has an IHP and that it is being carried out.
- When a school is informed that a child has been diagnosed with diabetes or will be joining the school the HT should organise the initial meeting to agree the IHP. They will need to make sure the child's parents, the child's diabetes specialist nurse and all relevant members of staff are present. If it is appropriate, the child should also be present. The policy should state how quickly this is expected to happen.
- A school should make sure it informs the school nurse of the child's diabetes.

#### **Who should see the IHP?**

- The child's IHP should state who needs to see it. Some parents may have issues with privacy. However, in reality every teacher who teaches the child will need to know about their diabetes, have read and understood the IHP and have a basic knowledge of diabetes.
- Exactly what a child is able to do themselves should be clearly stated along with precautionary measures in case they are unable to look after themselves. Every child's ability to manage their own diabetes will differ and progress, and potentially regress, at different speeds.

### [Read more about developing an Individual Healthcare Plan and what should be in it.](#)

#### **Training and insurance**

- The medical conditions policy should state that staff must receive suitable training and make clear how these members of staff will be supported in carrying out their role in supporting a child. The policy should make clear how training needs are assessed (by a specialist diabetes nurse for diabetes) and how training will be provided.
- Staff need to be trained to care confidently for children with diabetes. If the school has a child with diabetes, at least two members of staff will have to be trained, normally by the child's diabetes specialist nurse.
- Staff should receive suitable training and be signed off as competent before they support a child with diabetes. If there are staff members who are already trained about one child's diabetes they will still need to be signed off as competent to care for another child, because their diabetes care may differ.
- All trained staff members should have their training reviewed regularly and kept up to date. If a child's diabetes care changes – e.g.,

they may move from injections to an insulin pump, the staff member will need new training.

- If no members of staff volunteer to be trained it is necessary to employ members of staff who are prepared to be trained.

### **Contingency plans and absence**

- HT, SG & RBs should also make contingency plans so the school always has someone who is trained and available for staff absence and turnover. It should be made clear how supply teachers will be informed about children with diabetes.

### **Insurance**

- The school should be properly insured. It should be made clear in the medical conditions policy any requirements of the insurance, such as staff members supporting children being trained properly.

### **Exams**

- When a child is taking exams, schools should have an agreed exam protocol in place, which is clearly stated in their IHP. It will vary from child to child. Some may like to take the exam away from other children in case they need to treat themselves, while others will want to be with their classmates.
- This should be agreed well before the exams take place. Invigilators must be made aware of the agreed protocol.

[More information on exams.](#)

### **Inclusion**

- HT, SG & RBs should make sure that no child is excluded from any part of school life because of their diabetes. This includes making sure they are able to take part in PE, extra-curricular activities, school trips and residential trips.
- All relevant staff organising these activities should be aware of children with diabetes and make necessary plans to make sure the child can take part. This can be included as part of a normal risk assessment plan.
- For residential, overnight trips, the lead member of staff should meet with the child (if appropriate), the child's parents, your school's trained members of staff and, at the very least, speak to the child's diabetes specialist nurse to agree the support and care needed for them to take part.

### **Unacceptable practice**

Only allowing a child with diabetes to take part in an extra-curricular activity or trip if one of their parents or carers accompanies them is not acceptable practice. There are other unacceptable practices heads and governors must make sure do not take place in their school:

- No child should be prevented from treating themselves or managing their diabetes when and where necessary.
- No school should assume a child's diabetes is the same as another child's and requires the same treatment.
- The views of children with diabetes and their parents should not be ignored.
- Children with diabetes should not be sent home unnecessarily.
- If a child with diabetes requires treatment they should never be left unaccompanied or sent off to the medical room alone.
- A child should never have their attendance penalised for attending medical appointments to do with their diabetes. Their IHP should make clear how these are entered in the register so they are not penalised.
- Schools must not require parents to provide support in school for their child or make them feel obliged to do so.

### **Medicine – insulin and equipment**

- Heads, school governors and responsible bodies should make sure their medical conditions policy includes clear procedures around medicine.
- As part of the child's IHP, parents must give consent for trained members of staff to administer insulin.
- The school should check insulin provided to the school is in date.
- It will generally be made available to the school inside an insulin pen or a pump, rather than in its original container.
- All children with diabetes and trained staff should know where their insulin and equipment (such as their insulin pens and blood glucose meters) are kept. It should always be to be easily accessible. Some children with diabetes will look after it themselves and this should be allowed. For those who don't, who will look after it or where it is stored should be made clear. These details will form part of a child's IHP.
- A child's IHP must also make clear what equipment and treatment they will need for PE and who should look after this when the child is taking part.
- A child's diabetes pen, their pump, or blood glucose meter must never be locked away from them.
- If a trained member of staff is administering insulin, whether through a pen or a pump, each dose must be recorded. One way of doing this is by using a communications book.
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[Read what a school will need to do to meet this duty for a child with diabetes.](#)

Accessed 3/12/2014

## **England – legal duties of schools.**

### **Supporting pupils at school with medical conditions Children and Families Act 2014.**

The Children and Families Act 2014 includes a duty on schools to support children with medical conditions. This is inclusive of children with diabetes. Schools must make arrangements for supporting pupils at schools with medical conditions and in meeting that duty they must have regard to the statutory guidance issued by the Secretary of State (SEE BELOW).

Schools that must meet the duty in the Children and Families Act are:

- a maintained school
- an Academy school
- an alternative provision Academy
- a pupil referral unit
- Independent schools
- Six form colleges

The legal duty in the Children and Families Act is on “the appropriate authority”. “The appropriate authority” means:

- The governing body of a maintained school
- The proprietor of an academy
- The managing committee of a pupil referral unit.

<http://www.diabetes.org.uk/Guide-to-diabetes/Schools/Diabetes-in-schools-legal-information/>

Accessed 3/12/2014

## **Statutory guidance for supporting pupils at school with medical conditions**

**Department for Education.**

The statutory guidance below is issued under the legislation in Section 100 of the Children and Families Act 2014 which places a duty on governing bodies of maintained schools, proprietors of academies and management committees of PRUs to make arrangements for supporting pupils at their school with medical conditions. Schools must take account of the guidance issued by the Secretary of State, carefully consider it and have good reasons for not complying with it. This guidance is now in force as of 1 December 2014 and due to be revised in 2015.

The statutory guidance is stated in detail in the link below. Briefly however, the following has to be addressed:

- The role of governing bodies, proprietors and management committees
- Developing the school's policy
- Policy implementation
- Procedure to be followed when notification is received that a pupil has a medical condition
- Individual healthcare plans
- Roles and responsibilities
- Staff training and support
- The child's role in managing their own medical needs
- Managing medicines on school premises
- Record keeping
- Emergency procedures
- Day trips, residential visits and sporting activities

Other issues for consideration

- Unacceptable practice
- Liability and indemnity
- Complaints

There is also non-statutory advice is provided to assist and guide:

- schools, academies (including alternative provision academies) and PRUs
- local authorities

- clinical commissioning groups (CCGs), NHS England
- anyone who has an interest in promoting the wellbeing and academic attainment of children with medical conditions, including alternative provision, e.g. independent schools, parents/carers and pupils, health service providers

The statutory guidance, Supporting pupils at school with medical conditions, is available to read on the Government website, Gov.uk.

### **The Equality Act 2010 (England, Scotland and Wales)**

Children with diabetes are legally defined as being disabled.

The NHS, local authorities and all schools in England, Scotland and Wales all have duties towards these children. This includes fee paying schools. They must meet the duties in the Equality Act 2010.

Governing bodies or proprietors must make reasonable adjustments to ensure that children and young people with a disability are not put at a substantial disadvantage compared with their peers.

This duty is anticipatory, which means adjustments must be put in place in advance to prevent disadvantage from occurring.

Schools must ensure that they have enough staff trained at all times so that a child with diabetes can take part in all aspects of school life.

The Equality Act also states children with disability must not be discriminated against, harassed or victimised

Equality and Human Rights Commission website

### **The Education Act 2002**

Sections 21 and 175 detail how governing bodies of maintained schools must promote the wellbeing of pupils and take a view to the safeguarding of children at the school.

### **Legal duties on local authorities**

Local authorities have legal responsibilities to help make sure schools can meet the duties relating to children with diabetes. These duties both refer to all children in the local authority and they do not depend on the kind of school the child attends.

### **Section 10 of the Children Act 2004**

This is a particularly important piece of legislation if schools are struggling to get the support and training they need to allow them to look after a child with diabetes properly.

Section 10 essentially means the local authority must make arrangements to promote cooperation between the authority and relevant partners. Relevant partners include the governing body of a maintained school, the proprietor of an academy, clinical commissioning groups and the NHS Commissioning Board. They must make arrangements with a view to improving the wellbeing of children, including their physical and mental health, protection from harm and neglect, and education.

If a school cannot get the support it needs to look after a child with diabetes then they must approach their local authority.

### **Section of 17 of the Children's Act**

This gives local authorities a general duty to safeguard and promote the welfare of children in need in their area. If a school is looking after a child with diabetes so poorly that the child is put in danger, the local authority must step in.

### **Legal duties on the NHS: Section 3 of the NHS Act 2006**

This gives Clinical Commissioning Groups (CCGs) a duty to arrange for the provision of health services to the extent the CCG considers it necessary to meet the reasonable needs of the persons for whom it's responsible. What this means is that CCGs should provide the healthcare the people in its area need, if these needs are reasonable.

This section also provides for CCGs to arrange such services as it considers appropriate to secure improvements in physical and mental health of, and in the prevention, diagnosis and treatment of illness, in the persons for whom it's responsible.

In relation to children with diabetes, this means that a CCG should, within reason, make sure support and health care is in place to improve their health or at least keep them healthy. Poor management of diabetes at school will obviously affect the health of a child. If a school is unable to get the support it needs to help manage a child's diabetes successfully then both the local authority and the local CCG have a responsibility to the child's health and welfare

### **Section 3 of the Children Act 1989**

This places a duty on a person with the care of a child to do all that is reasonable in the circumstances for the purposes of safeguarding and

promoting the child. With relation to a child with diabetes, this will mean knowing what to do in the event of an emergency.

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## **IDF Education Programmes**

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If IDF Modules are being used by a third-party organisation in a programme from which the organisers will gain commercially, the organisers must contact IDF and negotiate a funding contract.

When the Modules are used in a programme the IDF logo is not to be used on any certificates or programme material. However the programme can be described as “Based on the IDF Diabetes Education Modules”.

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