



DIABETES

**National Clinical Programmes
for
Diabetes and Paediatrics**



PAEDIATRICS



**Model of Care for All Children and Young People
with Type 1 Diabetes**

November 2015



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Clinical Strategy and Programmes Division



**FACULTY OF
PAEDIATRICS**

ROYAL COLLEGE OF
PHYSICIANS OF IRELAND

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Foreword – Dr Stephen MP O’Riordan

Type 1 diabetes is complex in childhood and remains so throughout adolescence. Intensive diabetes care is provided by specialist teams that are there to serve the patient. One cannot underestimate, however, the burden on parents, grandparents and other siblings. This quotation from a young person with diabetes sums up many of those aspects:

“Young people with diabetes are no different to those free of diabetes. They have to be more disciplined in what they eat and when. As for sugary treats, having diabetes does not stop me from enjoying these either, as long as I eat enough “good food” to put in the foundation. Some of my friends just eat too much rubbish. Sometimes I envy them. In our family, we have each other and so we are lucky. I am also lucky my Mammy is always around, she worries so much about us, I think she could do with a break for herself and Daddy.”

This model of care has been developed by the Paediatric Diabetes Working Group along with specific expertise and input from Professor Peter Hindmarsh, consultant paediatric endocrinologist at Great Ormond Street Hospital and University College London. Additional advice and input on the development of this model of care (MoC) was sought from our European colleagues in Sweden and the UK. I would like to thank Ragnar Hanas and Fiona Campbell for their support in developing this document. The contribution of both the Diabetes and Paediatric National Clinical Programmes was invaluable, a special thanks to Dr. Ronan Canavan, Dr. Kevin Moore and Professor Alf Nicholson.

The needs of the patient have been considered through the involvement of Diabetes Ireland, and this document includes both parent and young person questionnaires addressing the essential themes and comments to optimise quality and excellence in diabetes care for children. It is representative of the focus of this document with children with diabetes and their parents at the core of service development for paediatric diabetes in Ireland in the future.

This will involve a departure from routine diabetes care and organisation of care into integrated practice units (IPUs) with centres of reference at the core of each IPU. These IPUs will require clear communication, and new governance structures that must cross geographic boundaries to be successful. This MoC may not be immediately achievable; however with new resources approved in the 2015 service plan I would hope to aspire to this model in the next 5-10 years. The next step will be to support the development of an implementation plan as soon as possible.

I would like to thank all of those who have provided their support and assistance in the development of this model, especially my colleagues in the Paediatric Diabetes Working Group. A special thanks to my colleague Dr. Susan O’Connell and all my paediatric colleagues in the Paediatric Unit in Cork University Hospital. Finally, Grace Turner and Claire Browne have been outstanding programme managers for Paediatric Diabetes over the last three to four years, I could not have completed this MoC, the Transition document or the MoC for the under five pump programme without their time, patience and editing; a sincere thank you.



Dr. Stephen MP O’Riordan MD, FRCPI, Clinical Lead in Paediatric Diabetes, CUH, Cork

Foreword – Professor Peter Hindmarsh

Type 1 diabetes is increasing in incidence year on year with a worldwide average annual increase of 2.8% per year and the greatest increase in children under five years of age (4%). Paediatric diabetes is essentially a hospital-based service with opportunities for care delivery in settings such as the home, school and community-based organisations. The delivery of care (as defined in part by glycosylated haemoglobin, HbA1c) varies throughout the Republic of Ireland and is behind benchmark nations such as Germany. Factors influencing this include varying staffing levels and skill sets along with social deprivation and ethnic diversity and attaining a standard of equitable care is a major challenge. The fundamental issue is not whether care is delivered centrally or not but whether that care is of value to the patient.

This means moving from a supply-driven health care system, organised around what physicians do, to a patient-centred system, organised around what patients need. To achieve this, organisation into Integrated Practice Units (IPUs) is a proven way to improve outcomes. An IPU is patient-centric and results driven, focused on the best way to deliver care using interdisciplinary groups, manages information, integrates decisions and ensures continuity, is responsible for the whole cycle of care even if other entities are involved, and the staff work exclusively in diabetes.

The benefits for the patient are a partnership of excellence serving them, care delivered using state-of-art facilities and technologies, expertise always available when needed by the patient or their family, continuity of care and scale that allows development of dedicated teams rather than part time practitioners with shorter wait times and convenient booked appointments. For the clinical service, common management allows for a unified process of care, shared staff training develops skilled teams, strong governance, efficient division of labour, more rapid evolution and deployment of effective techniques and care plans. The scale allows for richer feedback and support, better flexibility and efficiencies in scheduling.

This report takes these concepts and translates them into a system for the delivery of diabetes care across Ireland. The report has been generated after consultation with parent support groups and health care professionals. It represents a radical departure from the classic model of delivering care. It puts the patient and family at the centre of the process which is exactly where they should be.



Professor Peter Hindmarsh

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Executive Summary

This document outlines a model of care (MoC) for paediatric diabetes aimed at improving the care of, and outcomes for, children with type 1 Diabetes (T1DM). It examines the current situation in Ireland, and proposes what needs to change in order to support quality, access and value in diabetes care for all children with T1DM in Ireland and their families.

The primary **aim** of this model of care is to define excellent diabetes care, and improve access, quality and value for all children with Type 1 Diabetes in Ireland.

The key **objectives** are to:

- Define how quality diabetes care will be provided to all children and young people in Ireland based on Integrated Practice Units (IPUs). Each IPU will have a centre of reference (CoR) at the core, according to SWEET criteria, and a number of additional units under the umbrella of the IPU.
- Provide a pathway to improved health-related quality of life of children and their families living with T1DM, and reduce acute and chronic complications of T1DM.
- Identify the structured education programmes to be used by multidisciplinary teams to optimise diabetes education, carbohydrate counting and insulin pump initiation.
- Define the goals to be achieved for HbA1c.

This model of care was developed in line with ISPAD, BSPED and ADA recommendations and in accordance with European SWEET criteria.

Key Recommendations for Implementation of this Model of Care:

1. Services should be organised within integrated practice units (IPUs) comprising a centre of reference and a number of additional units.
2. IPUs should be equipped with the core staffing requirements detailed in this document. A reduction in general paediatric workload may be required for the lead paediatric endocrinologist in each IPU. Adequate staffing should facilitate the availability of 24-hour telephone support within each IPU.
3. Referral pathways need to be determined for each IPU taking into account the seven hospital groups.
4. Each IPU will need to develop governance arrangements which cross current geographic boundaries.
5. Ongoing training and structured education of paediatric diabetes teams is required annually.
6. National, quality assured, educational programmes for children with type 1 diabetes and their families and carers should be developed.
7. Ongoing patient and parental engagement is required, for example with links with Diabetes Ireland.
8. Appropriate national information and communication technology infrastructure and support is needed.
9. Accurate baseline data is required in the form of an active electronic database for longitudinal data, this will allow ongoing audit and appropriate service development.
10. This MoC will require a formal commissioning process and a dedicated finance source needs to be identified based on a unit cost per child with Type 1 Diabetes to address current and future staffing deficits.
11. An implementation teams and an implementation strategy will need to be developed involving all stakeholders to realise this model of care and all the recommendations above.

Glossary of Acronyms, Abbreviations, Terms and Definitions

| | |
|------------|---|
| ADA | American Diabetes Association |
| BMI | body mass index |
| BSPED | British Society for Paediatric Endocrinology and Diabetes |
| CGM | continuous glucose monitoring |
| CI | confidence interval |
| CSII | continuous subcutaneous insulin infusion |
| DCCT | Diabetes Control and Complications Trial |
| DKA | diabetic ketoacidosis |
| DNS | diabetes nurse specialist |
| EAG | expert advisory group |
| EDIC | Epidemiology of Diabetes Interventions and Complications |
| HbA1c | glycated haemoglobin |
| HRQOL | health-related quality of life |
| HSE | Health Service Executive |
| IPU | integrated practice unit |
| ISPAD | International Society for Paediatric and Adolescent Diabetes |
| MoC | model of care |
| MDI | multiple daily injections |
| NICE | National Institute for Health and Clinical Excellence |
| NPDA | National Paediatric Diabetes Audit |
| PCT | primary care trust |
| PDNS | paediatric diabetes nurse specialist |
| QALY | quality adjusted life year |
| QALE | quality adjusted life expectancy |
| QISMET | Quality Institute for Self-Management Education |
| RDPI | regional director for performance improvement |
| SWEET | 'Better control in paediatric and adolescent diabetes: Working to create Centres of Reference' (see Appendix 3) |
| T1DM | type 1 diabetes |
| TDABC | time driven activity based costing |
| WHO | World Health Organisation |
| WTE | whole time equivalent |
| “Diabetes” | In this document, refers to type 1 diabetes only |
| “Under 5” | Refers to children aged <5.99 years old |
| “Under 18” | Refers to children and young people <17.99 years old |

Introduction

This document outlines a model of care (MoC) for paediatric diabetes aimed at improving the care of, and outcomes for, all children with type 1 diabetes (T1DM). Diabetes care is delivered by teams led by consultants trained in diabetes and endocrinology and the subspecialties are intimately linked. Children with T1DM may also develop additional endocrinology co-morbidities. The document examines the current situation in Ireland, and proposes what needs to change in order to support quality, access and value in diabetes care for all children with T1DM in Ireland and their families. A model of care for endocrinology has been detailed in the National Model of Care for Paediatrics and Neonatology, and is due to be published in late 2015.

Background

In 2008, the Diabetes Expert Advisory Group (EAG) report, led by Dr. Colm Costigan, was published outlining significant deficits in paediatric diabetes care in Ireland, with over half of patients having no access to a proper multidisciplinary team and many of the rest travelling long distances for care (Costigan, 2008). This report recommended that care provided to the child/adolescent with diabetes be of an internationally accepted standard, from a multidisciplinary team of professionals sensitive to the needs of the child or young person and those of the family. This document highlights that many of the staffing and resources deficits remain.

In 2010, the Health Service Executive (HSE) introduced a procurement process led by Professor Richard Firth and Dr Kevin Moore in relation to insulin pump therapy, which led to a reduction in the price of insulin pumps and their consumables and a limited cost saving to the health service. This cost saving was identified by the Diabetes and Paediatrics National Clinical Programmes, and used to develop a business case to develop new regional pump centres nationally. The aim was to increase clinical personnel in existing pump centres and develop new regional pump centres, in order to improve access for all children with T1DM to insulin pump therapy. At the time, it was only possible to provide this service to a finite number of patients (children under 5.99 years of age) because of financial constraints.

In 2011, Dr. Barry White appointed Dr. Stephen O’Riordan as the Clinical Lead for Paediatric Diabetes and the insulin pump programme. A programme manager was also appointed to this important initiative, Ms. Grace Turner. Dr. O’Riordan, Ms. Turner and the Paediatric Diabetes Working Group led the development of a model of care for the provision of continuous subcutaneous insulin infusion (CSII) in children under five. Implementation of the CSII model commenced in 2012 with the identification of realistic referral pathways for all appropriate children under five years to be offered insulin pump therapy. This was the first step in the evolution of a national paediatric diabetes model of care for all children with type 1 diabetes (this document).

Rationale for Document

Children with type 1 diabetes (T1DM) are a priority because of the high incidence of this condition, and effective interventions can reduce long term complications. To date, services have been configured and resourced for low disease incidence (Roche et al., 2002, Patterson et al., 2009), but there are now robust data confirming that Ireland is a country of high incidence (Patterson et al., 2009). Ireland underperforms relative to other European countries in outcomes such as higher HbA1cs and this must be addressed. It is strongly felt among professionals, children and young people with T1DM, and their families, that action is needed to address the long term service deficits and improve outcomes.

Prevalence

The number of people with all types of diabetes is predicted to increase rapidly over the coming years. T1DM is increasing in all age groups internationally, and in Ireland this is especially so in the 10-15 year old age group. The crude incidence of T1DM was 27.2 (95% CI 23.9, 30.7) / 100,000 children in 2008, and 25.7 (22.6, 29.2) / 100,000 children in 2009, in those under 15 years of age in Ireland (Roche et al, 2014). The total child and adolescent population with T1DM in Ireland was estimated in a recent HSE audit of 19 centres in at approximately 2,700. Diagnosis peaks between 10 and 15 years of age. Patterson et al. (2009) reported, as part of the EURODIAB study group, that if present trends continue a doubling of new cases of T1DM in European children under five is predicted between 2005 and 2020 and prevalent cases younger than 15 years will rise by 70% (Patterson et al., 2009). Adequate healthcare resources need to be available to meet the needs of these children.

Although there is a recognised increase in complex diabetes, type 2 diabetes and rarer forms of diabetes, this document will focus primarily on type 1 diabetes in childhood.

Effectiveness of Interventions

Improved diabetes control from diagnosis onwards can reduce the incidence of microvascular complications, and delay their progression. The 'Diabetes Control and Complications Trial' (DCCT) and the 'Epidemiology of Diabetes Interventions and Complications' (EDIC) studies provide us with conclusive evidence that intensive management and psychosocial support improves glycaemic control and diabetes outcomes in children and young people with T1DM (Shamoon et al., 1993, 2000, 1999). Intensive management should commence at diagnosis, with an extensive family-focused education package together with continued support (Swift et al., 2010). The converse is also true - poor control of childhood diabetes is definitely associated with poorer outcomes and a higher mortality rate in early adult life (Cooper et al., 2014).

The DCCT supports tracking of HbA1c in the paediatric population, in which a "good start", based on intensive diabetes education and multidisciplinary support, reduces HbA1c and maintains optimal glycaemic control. This approach highlights the importance of achieving optimal control of diabetes from the day of diagnosis, and can reduce the burden of diabetes and maintain quality of life (Edge et al., 2010, Hofer et al., 2014). These studies have shown

that when T1DM is effectively controlled, it can reduce the risks of developing complications as follows:

- New eye disease: 76% reduction
- Worsening of existing eye disease: 54% reduction
- Early kidney disease: 54% reduction
- Serious kidney disease problems: 39% reduction
- Nerve damage: 60% reduction

There are unique challenges in replacing the insulin deficiency as the child develops from very young to adolescent. These include the differences in the size of the patients, the unpredictability of a toddler's intake and activity level, oppositional food behaviour, the increased vulnerability of the developing brain to low blood glucose levels, and the risk of more rapid development of DKA where glycaemic control is poor. An additional challenge is that young children are unable to provide their own diabetes care, so the extended family will require education on how to care for the child with diabetes. Education needs to emphasise age- and developmentally-appropriate self-care and integrate this into the child's diabetes management in partnership between the child, extended family and multidisciplinary team. Structured education in the early period following diagnosis is recognised as critical in determining both clinical outcomes and quality of life (Edge et al., 2010, Hofer et al., 2014). Early diabetes education and intensive management can provide the following benefits:

- Reduction in frequency of daytime and nocturnal hypoglycaemia, thereby increasing the ability of the child and family to recognise and treat hypoglycaemia appropriately
- Protection of the developing brain of children with diabetes as there is concern over the impact of hypoglycaemia on cognitive function and seizure risk
- Improvement in HbA1c
- Reduction of daily glycaemic excursions
- Smoother blood glucose profiles at times of unpredictable exercise and eating patterns
- Negation of the need for injections during pre-school or school by insulin pump use

Paediatric Diabetes in Schools

Primary school children with diabetes are dependant on parental support for blood glucose monitoring, insulin administration and management of out-of-range blood glucose values. This support is not available while the child is attending school, a time when significant fluctuations in blood glucose can occur. Suboptimal glycaemic control increases the risk of long-term micro- and macrovascular complications. Furthermore, glycaemic variability can impact significantly on a child's education, with concentration difficulties and alterations in mood and behaviour linked to high glucose levels in addition to the well known acute cognitive effects of hypoglycaemia.

Insulin regimens currently selected by clinicians for most young children do not require the administration of insulin during school hours, but do not mimic normal physiology. Over the past decade, initiatives to facilitate greater supports for children with diabetes in schools have been successfully introduced in areas of the UK. Such supports, in addition to providing greater diabetes education for school staff and individualised diabetes care plans for children, have facilitated the use of more physiological insulin regimens. These school initiatives have not

occurred in Ireland to date; however Dr. Michael O’Grady & Ms. Anna Clarke have commenced a schools initiative to address this on behalf of the Paediatric Diabetes Working Group.

To optimise diabetes management for primary school children, the experiences of children regarding diabetes management in schools must first be identified and then engagement with the Departments of Education and Health must take place. It is intended that education of school staff on diabetes could be increased along with developing individualised care plans for children with T1DM. In this way, the barriers to insulin administration in schools could be overcome, thus paving the way for more intensive and effective diabetes management. A CNS in diabetes from community nursing services could contribute education and support for the primary school and primary school child with diabetes.

Adult Complications

Macrovascular disease, e.g. heart attack or stroke, may not affect children with diabetes during childhood but is very likely in adulthood because of the length of time children live with diabetes. Effective preventative education and motivation about diet, activity, smoking and weight management should be provided. Early identification and treatment of cardiovascular disease in young adults with diabetes is essential (Polak et al., 2011). The Wanless Report (Moore, 2002) stated that, based on best available evidence, the interventions known to be cost effective using a €24,000 cost per quality adjusted life year (QALY) threshold are:

- Tight control of blood glucose and blood pressure
- ACE (angiotensin converting enzyme) inhibitors for those with diabetes and one other risk factor not otherwise quantified, and for multiple risk factor management
- Retinopathy screening for all with diabetes
- Foot screening for those at high risk
- Self-care, including patient education

Cost per Child with Type 1 Diabetes

It has been suggested that the cost of achieving blood glucose control per event-free life year gained was approximately €1,445 (Diabetes Care 2007). DCCT researchers estimated that intensive management doubles the cost of managing diabetes because of increased healthcare professional contacts and the need for more frequent blood testing. However, this cost is offset by the reduction in costs related to long-term complications and by the improved quality of life of people with diabetes. Therefore, over a lifetime, DCCT-defined intensive therapy reduces complications, improves quality of life, and can be expected to increase life expectancy (Shamoon et al., 1993, 2000). In a modelling analysis using a validated CORE Diabetes Model, a UK group projected the long-term costs and outcomes of CSII compared to MDI in the United Kingdom. This study revealed that treatment with CSII is associated with a significant improvement in mean quality adjusted life expectancy (QALE) of 0.76 ± 0.19 years compared with MDI and concluded that CSII produced an incremental cost-effectiveness ratio of £25,648 per quality-adjusted life-years (QALY) than MDI (Roze et al., 2005). From a HSE perspective, intensive therapy in Paediatric Diabetes is well within the range of cost-effectiveness considered to represent good value.

Cost analysis for a child with T1DM is £4,000 annually for a multidisciplinary team including annual review (UK Department of Health estimate for Best Practice Tariff, 2002 submission from UCLH). A cost analysis from Greece estimated €5,000 per child on a pump, €3,500 for multiple daily injections (MDI), and €1,950 for conventional therapy annually (ESPE 2014, Hormone Res 2014). The required funding for provision of paediatric diabetes care provides value for money in terms of the long term savings made through reduction of complications in adult life. The unit cost per child is important for those commissioning and financing paediatric diabetes services in the future. At present, there are almost 2,700 children diagnosed with diabetes nationally, representing a national cost of approximately €10 million per annum if all treated with MDI. The more likely scenario is that centres will have a mix of patients on CSII and MDI, e.g. larger centres may have 21-40% using CSII therapy while the vast majority of smaller centres would have up to 80-90% on MDI.

Aims, Objectives and Scope of Model of Care

The **aim** of this model of care (MoC) is to define excellent diabetes care, and improve access, quality and value for all children with type 1 diabetes mellitus (T1DM) in Ireland.

The key **objectives** are to:

1. Define how quality diabetes care will be provided to all children and young people in Ireland based on integrated practice units (IPUs). Each IPU will have a centre of reference (CoR) at the core, according to SWEET criteria, and a number of additional units under the umbrella of the IPU.
2. Provide a pathway to improved health-related quality of life of children and their families living with T1DM, and reduce acute and chronic complications of T1DM.
3. Identify the structured education programmes to be used by multidisciplinary teams to optimise diabetes education, carbohydrate counting and insulin pump initiation.
4. Define the goals to be achieved for HbA1c in different age groups.

The **scope** of this model of care is limited to children and young people under the age of 18 (≤ 17.99 years old) with type 1 diabetes. While the national policy for treating children is under sixteen years, the complications of diabetes may be life-long; therefore transition from paediatric to adult services and continuity of care must be undertaken with great care.

Mission, Vision and Core Values

Mission

To develop and deliver a high quality, responsive diabetes service that maximises health and wellbeing for children, young people and their families

Vision

A high performing, innovative national paediatric diabetes service that is patient-centred and provides value for money

Core Values

- Focus on the service needs of the paediatric and adolescent diabetes population, and the skills and resources necessary to meet these needs.
- Provide a comprehensive interdisciplinary integrated service based on good clinical practice and a holistic approach to healthcare.
- Ensure that service developments and changes are thoroughly evaluated, have a sound evidence base, and are implemented in a safe and timely manner.

Paediatric Diabetes: Current services in Ireland

Service provision has improved in Ireland, but it still lags behind that available in most of Europe and includes wide variations in care delivery, outcomes and resources. A number of initiatives have taken place in Ireland in recent years:

National Diabetes Audit Data

2006 Data:

In 2006, Savage and Loftus undertook a survey of the 19 centres identified at the time as providing care for children and adolescents with Type 1 Diabetes Mellitus (T1DM) with 100% response rate. The key findings were:

- 29 consultants provided care for a reported 2,040 patients in the 19 centres
- 16 (55%) paediatricians surveyed expressed a special interest in diabetes, while 27 (93%) saw patients in a designated diabetes clinic
- The mean caseload per whole time equivalent (WTE) diabetes nurse specialist (DNS) was 162 patients
- The mean caseload per WTE dietitian was 416 patients
- 13 centres (68%) had no access to psychology services

This report clearly outlined significant deficits in paediatric diabetes in Ireland (Savage et al., 2008). The reports by Savage et al. 2006, the DEAG (2008) and the National Diabetes Audit (2012) all highlight the deficiencies, particularly in relation to support staff, with respect to international recommendations (ADA & ISPAD guidelines, 2014). A recent survey (October 2014, appendix 7) of the 19 centres undertaking diabetes care in Ireland confirms there are still deficits in staffing and resources in paediatric diabetes in Ireland.

Previously, all tertiary paediatric diabetes care was delivered from Dublin, however recent consultant appointments outside Dublin have allowed the establishment of new regional paediatric diabetes centres, bringing the best care for children closer to home.

2012 Data:

In 2012, an audit was undertaken to describe what services were available to children with T1DM in Ireland (Hawkes and Murphy, 2014). Clinicians in 17 out of 19 paediatric diabetes units responded to an online questionnaire, which gathered data on patient numbers, demographics, diagnostics, outpatient management, multidisciplinary team resources, comorbidity screening, transition policies, clinical guidelines and use of insulin pumps. This study reported 2,518 children attending, with considerable variations seen among centres. Eight centres initiated pump therapy, with insulin pump usage ranging from 0-42%. Self-reported mean HbA1c ranged from 8.2-9.4% (66.1-79.2mmol/l) and frequency of clinic appointments varied between three-monthly (12 centres), four-monthly (three centres) and five-monthly (two centres). Larger centres were less likely to meet international recommendations for three-monthly appointments due to large patient numbers. Written protocols existed for the following: management of DKA (100%), hypoglycaemia management (94%), education plan for new diagnosis (94%), sick day rules (94%), and perioperative management (77%). Timing of transition from paediatric to adult care also varied considerably from 16 years to completion of school. This study recommended a standardised approach to improve paediatric diabetes care for all patients nationally. Driskell et al. reported that the optimal testing frequency required to maximize the downward trajectory in HbA1c was four times per year, particularly in those with an initial HbA1c of $\geq 7\%$ (≥ 53 mmol/mol), supporting the ISPAD and ADA international guidance. Testing three-monthly was associated with a 3.8% reduction in HbA1C compared with a 1.5% increase observed with annual testing; while testing more frequently provided no additional benefit (Driskell et al., 2014).

National Childhood Diabetes Register

The incidence of T1DM is increasing in most populations in Europe at a rate of 0.6-9.3% (Patterson et al., 2009). A study of T1DM in children under the age of 15 years in Ireland demonstrated a high national incidence of T1DM in the under 15 age group, which was moderately high in comparison to the UK and within the top 25% incidence levels in Europe (Roche et al., 2002). Previous studies that included Irish data had suggested a low incidence of T1DM. This research highlighted the need for a national diabetes register to monitor important epidemiological changes, and the robust methodology of this early study was employed in the development of the register in January 2008 generously supported by the National Children's Hospital Foundation.

The functions of the National Childhood Diabetes Register are to:

- Act as a basic health indicator
- Provide complete and accurate data regarding the annual incidence of T1DM in children and adolescents in Ireland
- Provide complete and accurate demographic and attendance data for Irish children and adolescents from 2008 onwards
- Monitor changes in disease epidemiology over time
- Monitor the occurrence of serious disease complications at diagnosis
- Provide robust data for health planning and appropriate resource allocation, thereby optimising service delivery and enhancing patient care
- Permit accurate determination of the prevalence of T1DM in children under five years of age
- Enable the assessment of completeness of audit through provision of reliable and accurate denominator data
- Participate with the EURODIAB collaboration to aid further insight into the causation of this complex disease

Participation rates in the national diabetes register have been excellent to date, with all centres that care for children with diabetes nationally submitting data. Five year data regarding the epidemiology of T1DM in Ireland reported a standardised incidence of 27.5 and 26/100,000 per year in 2008 and 2009 respectively (Roche et al., 2014). These data provide insight into the development of this condition, and also the resources required to address the needs of this large patient group. It can now be confidently stated that Ireland has a high incidence of T1DM in the child and adolescent population, with almost doubling of incidence since 1997 (Roche, 2014, Roche et al., 2014).

Insulin Pump Programme for Children Under Five Years

The Paediatric Diabetes Working Group (PDWG) developed a model of care for the provision of insulin pump therapy for children aged 5 and under with T1DM which is available here:

<http://www.hse.ie/eng/about/Who/clinical/natclinprog/paediatricsandneonatologyprogramme/paediabetes/modelofcaredocument.pdf>

This was initially developed in 2012, and updated in March 2015 in consultation with the PDWG. The key objectives of this model of care are to provide continuous subcutaneous insulin infusion (CSII) therapy to children five years of age and under where appropriate, ensure that diabetes services and staffing levels are equitable in the pump centres nationwide, reduce acute and chronic complications of T1DM and improve the quality of life of children living with T1DM and their families.

The centres providing insulin pump therapy are:

1. Childrens University Hospital, Temple Street (Dublin)
2. Cork University Hospital (Cork)

3. National Childrens Hospital, Tallaght (Dublin)
4. Our Lady of Lourdes Hospital, Drogheda
5. Our Lady's Childrens Hospital Crumlin (Dublin)
6. Sligo Regional Hospital (Sligo)
7. University Hospital Limerick (Limerick)
8. University Hospital Galway (Galway)

Each centre must have a paediatric endocrinologist trained in diabetes, a minimum of 150 children with T1DM attending, and be staffed with the appropriate support services – paediatric DNSs, dietitians and psychological support. The units in Our Lady of Lourdes Hospital, Drogheda and Sligo Regional Hospital have recently started providing insulin pump therapy. The units receive referrals from the surrounding areas. Additionally Sligo provides an outreach service to Letterkenny General Hospital.

Screening for Microvascular Complications of Type 1 Diabetes in Childhood

International guidelines (ISPAD and ADA) mandate routine screening for microvascular complications. It is recommended for all children who have had type 1 diabetes for more than five years or are over 12 years of age (Donaghue et al., 2014). Screening happens routinely in adult care. The National Diabetic Retinal Screening Programme is a new, government-funded screening programme that offers free, regular diabetic retinopathy screening to people with diabetes aged 12 years and older. This screening programme was established in June 2014 and has been a highly successful initiative to date. Foot screening has also improved nationally with the appointment of 11 new podiatrists. It is important that renal, foot and eye screening are undertaken routinely in all paediatric diabetes clinics nationwide, according to international guidelines (Donaghue et al., 2014, Kordonouri et al., 2014).

National Model for Transition of Care

The transition from childhood to adulthood for patients with T1DM can be challenging, and compounded by the differences between paediatric and adult diabetes services. The familiar team and surroundings are left behind and there is more focus on the patient managing their own condition, rather than in conjunction with their parent/carer. It is important that the transition to adult services is done in a structured and supported way. Guidelines have been developed to support regional diabetes teams in ensuring young adults are safely and effectively integrated into adult diabetes services. The guidelines recommend the availability of a transition nurse and a clinical psychologist to aid this process. This document is due to be published early in 2016.

Psychosocial Risk Screening in Children with Type 1 Diabetes: Implications for Health Outcomes

A study has just commenced, including twelve centres nationally, to assess the psychosocial risk of children with T1DM. This will be a 2-3 year prospective study. The study will examine the utility of incorporating psychosocial screening (including a broad assessment of psychosocial risk, as well as an assessment of psychological distress) into routine clinical care of children with T1DM in terms of its ability to predict poor glycaemic control, quality of life and higher rates of

acute diabetes-related complications. Despite many advances in insulin types, administration systems and glucose monitoring, multinational studies have demonstrated suboptimal HbA1c levels in children. Psychological and social factors may be key to explaining why many young people fail to adequately control their diabetes. The American Diabetes Association and ISPAD both recommend that a psychosocial assessment is carried out on all children with T1DM (ADA, 2014, Delamater et al., 2014).

Study Aims:

- To prospectively evaluate the utility of psychosocial risk assessment, in an Irish cohort of children and adolescents with T1DM, in terms of its ability to predict poor glycaemic control, greater incidence of DKA and Emergency Department admissions, and HRQOL
- To evaluate the RI-PGC in terms of its association with early indications of psychopathology
- To estimate the national prevalence of anxiety and depression in paediatric patients with T1DM
- To examine the association between emotional distress in paediatric patients with T1DM and diabetes-related health outcomes including poor glycaemic control and acute diabetes-related complications.

This study hopes to report accurately the clinical psychology staff deficit in paediatric diabetes units in Ireland, all data will be collated and used to support this MoC.

Paediatric Diabetes Service in the UK and Europe

Service Provision in the United Kingdom (UK)

The DiabetesUK report *Your Local Care – a Survey of Diabetes Services* (2005) found that provision of services in England by primary care trusts (PCTs) was stretched, with an average caseload of more than 100 children for every PDNS. For many existing models of care the Royal College of Nursing recommends a maximum ratio of 70 patients per WTE paediatric diabetes nurse and 50 children with diabetes on CSII therapy (Nursing, 2006, Diabetes Policy Team, 2007).

Despite evidence that 85% of children were not achieving recommended blood glucose concentrations, *Your Local Care* found that only a quarter of PCTs had made improving paediatric diabetes a priority in their local plans. Half of PCTs did not have adequate systems in place to transfer young people to adult care. In 2006, DiabetesE reported that not all children and young people were able to access specialist advice: only 87% had access to a specialist nurse, 75% to a dietitian, and 48% to a paediatric psychologist / counsellor (DiabetesE, 2006). This report also noted that only 54% of PCTs had management guidelines for children and young people with diabetes, 53% of paediatric specialist teams did not have guidelines for optimising glycaemic control, and 34% of PCTs did not require that all over 12s with diabetes have annual retinal screening (DiabetesE, 2006).

The UK National Paediatric Diabetes Audit (NPDA), established in 2001, has recently published data from 2011-12 (Warner, 2013) - see Appendix 2 for details on incidence and prevalence of T1DM, and recording of key age specific care processes. These data showed only 19% of 12-15 year olds with diabetes were recorded as receiving eye examinations as recommended by the National Institute for Health and Clinical Excellence (NICE, 2004).

SWEET Centres of Reference

The SWEET Project was initiated in 2008 to improve standards of care across Europe and create centres of reference (Danne et al., 2012). The criteria for a SWEET centre of reference are detailed in Appendix 3. Recommendations on standards, education for children and young people and their families, education for healthcare professionals, and a toolbox of resources were delivered to the European Commission in April 2011. A key element of the SWEET report was the need to have a written national diabetes plan that includes reference to children and young people. This plan should also identify quality standards embedded in a quality assurance programme that includes external peer review of diabetes services.

Comparison of HbA1c in Ireland with other European Countries

HbA1c is the most recognised key performance indicator internationally, and Table 1 (below) highlights Ireland’s performance. Compared to other European countries, paediatric diabetes in Ireland is not meeting the same targets. It also highlights the lack of data that is available on a national basis, however it is intended that the national diabetes register and the national diabetes audit will help address the deficit in data.

| Targets (ISPAD and ADA Guidelines) | Ireland | UK (2011-12 data) | Germany and Austria |
|---|---|---|--|
| HbA1c <7.5% (59mmol/l) | Mean of all children under 16 is 8.2-9.4% (66.1-79.2mmol/l). Proportion reaching targets <7.5% unknown . | 18.1% of girls and 16.7% of males reached targets of <7.5%. | 50-55% reached targets. Median all centres HbA1c 7.7% (61mmol/l) in all patients under 21. |
| HbA1c >9.5% (80mmol/l) | Unknown | 25.1% | 10% |

Table 1: Comparison of HbA1c levels in children and young people with T1DM

International Clinical Guidelines

This document draws on standards of care and clinical guidelines from the International Society for Paediatric and Adolescent Diabetes (ISPAD) (Acerini et al., 2014)), the American Diabetes Association (ADA) (ADA, 2014)) and the British Society for Paediatric Endocrinology and Diabetes (BSPED) in accordance with SWEET EU criteria(Danne et al., 2012) (see Appendix 3).

Patient and Family Experience of Services

Through Diabetes Ireland, a questionnaire was sent to more than 30 parents of children with T1DM. This feedback was collated under a number of themes: travel, care at diagnosis, style of practice, support systems, staff and knowledge, school support, centre design components (see Appendix 4 for summary of results). These factors are important in setting up a patient-focused and family-oriented paediatric diabetes service.

A second questionnaire using the same themes was sent families with teenagers and young people with T1DM through an online questionnaire. Sixty-nine responses were received, and the results are results summarised in Appendix 5. Quotations from this survey are featured below.

The feedback from the survey was borne in mind when drafting this model of care. Details are shown in the following table.

| Feedback received | How this has been addressed in the Model of Care |
|--|---|
| Shorter distance to clinic | Through local units with the support of the IPU structure, quality care can be provided |
| Availability of 24 hour phone line | This service has been recommended for each IPU |
| Psychological support is essential | Because of the increased comorbidity associated with T1DM, dedicated access to a psychologist and a social worker for each IPU is recommended. |
| Listen to patient's / families' views | The responses from the survey sent to parents have been considered when drafting this model of care. |
| Quality of life should be considered important | Improved quality of life and reduced burden of disease for children and young people with T1DM and their families is recognised as an important key performance indicator and therefore it should be included for measurement as well as HbA1c. |
| Transition to adult clinics should be determined by the young person and not by an arbitrary age cut off | This is reflected in the 'Transition' document – age cut off should be between 16 and 18, however there is flexibility depending on the individual. |
| There should be greater emphasis on schools receiving expert training in diabetes. | Initiatives to facilitate greater supports for children with diabetes attending school including education of school staff on diabetes is required. A project has commenced to address this matter. |
| Respondents reported they would like to have 4 appointments per year in the first few years following diagnosis. | This model of care states that children with T1DM will be carefully monitored with regular review (three to four monthly) |
| Refresher courses and presentations about getting the most out of pump | A structured educational programme, e.g. 'Pump school' is required for all children and young people |

| Feedback received | How this has been addressed in the Model of Care |
|---|--|
| therapy or injection regimens were seen as vital by all those surveyed. | receiving pump therapy. Education and re-education for all patients is provided by the multidisciplinary team. |

Quotes received from children and their families in relation to Type 1 Diabetes

Parent of child with T1DM commenting on shared care

As a mother it is very important for the child to receive all services, eyes, feet, psychologist etc. It's very hard to get through life without all the proper services.

Parent of child with T1DM commenting on improving diabetes services

Just that the team focus on the positive things that the child is doing to control their diabetes and not the negative

Parent with child with T1DM commenting on care at

It is very important that the school where the newly diabetic go to are well informed by a diabetic nurse. A kid spends a lot of time at school.

Child with T1DM commenting on improving diabetes services

I hate doing the HbA1c test squeezing out blood especially when I know that there is a machine similar to my BG monitor that could have the reading done at my clinic appointment, while I'm waiting to see my consultant! It can be very stressful especially when you are new to T1 diabetes.

Parent with child with T1DM commenting on improving diabetes services

I think it is very important to have follow up meetings after a kid is diagnosed a diabetic. It affects all the family and hard on the kid and everybody to understand everything. Also everybody is afraid because it is new. It affects everything, moods, hormones, sickness and sport. For a chronic illness there is no reassurance.

Teenager with T1DM commenting on improving diabetes services

I think young people should be given a choice of pumps. I think that Ireland needs to let other companies into the market. I think that there should be one national list for pumps and no one should skip the queue. There should be a maximum waiting time...max 2 years. Someone needs to be in schools teaching staff how to handle T1. It shouldn't be up to my Mom and Dad to be seeking out services...it should just happen. I'm a teenager and I'm scared of going into the Adult Services which I'm told will happen when I'm 16. It shouldn't happen until I'm 18 when I'm legally an adult.

Teenager with T1DM commenting on improving diabetes services

I think it's important to have the information nights or days. Maybe if we had a local diabetes club for teenagers so we could all talk about our problems and worries etc. Another suggestion is to have a hotline and we could ring if ill or need help with our diabetes.

Teenager with T1DM commenting on improving diabetes services

For people to look at me as a person and not just the diabetes. It would be great to learn from others and maybe for the hospital and the diabetes federation to work together to plan days out so we can learn and have fun. Huge gap seems to be there at the moment.

Parent of child with T1DM commenting on shared care

Shared care doesn't really work because not all professionals are on the same page, not all professionals are trained in pump services and people can get mixed up information.

Teenager with T1DM commenting on improving diabetes services

I really feel that they should look at the bigger picture and not just look at the HbA1c result. Teenage life is hard enough without having diabetes and I as a teenager wish that they could keep that in mind.

Teenager with T1DM commenting on improving diabetes

Should definitely have clinic appointments more than twice a year, should at least be four times a year no matter how long you're diagnosed.

Teenager with T1DM commenting on staff & knowledge

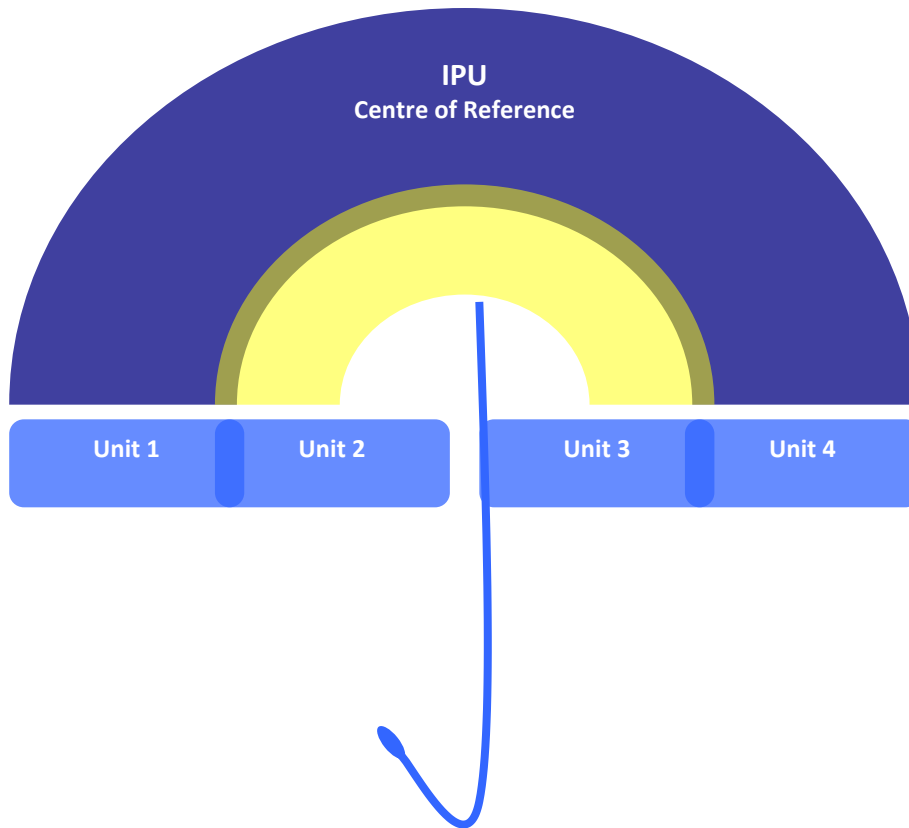
"My head gets wrecked with a lot of things to think about, I started 1st year and it's hard to remember everything to do. I get upset and need to talk at times I feel so sad. My parents try to help me but it's not easy."

Parent of child with T1DM commenting on supports

Technology is moving very fast. Devices need to be reviewed by the hospital. There are lots of things that are not covered and I think the hospitals need to keep up with moving technology.

Proposed Model of Care

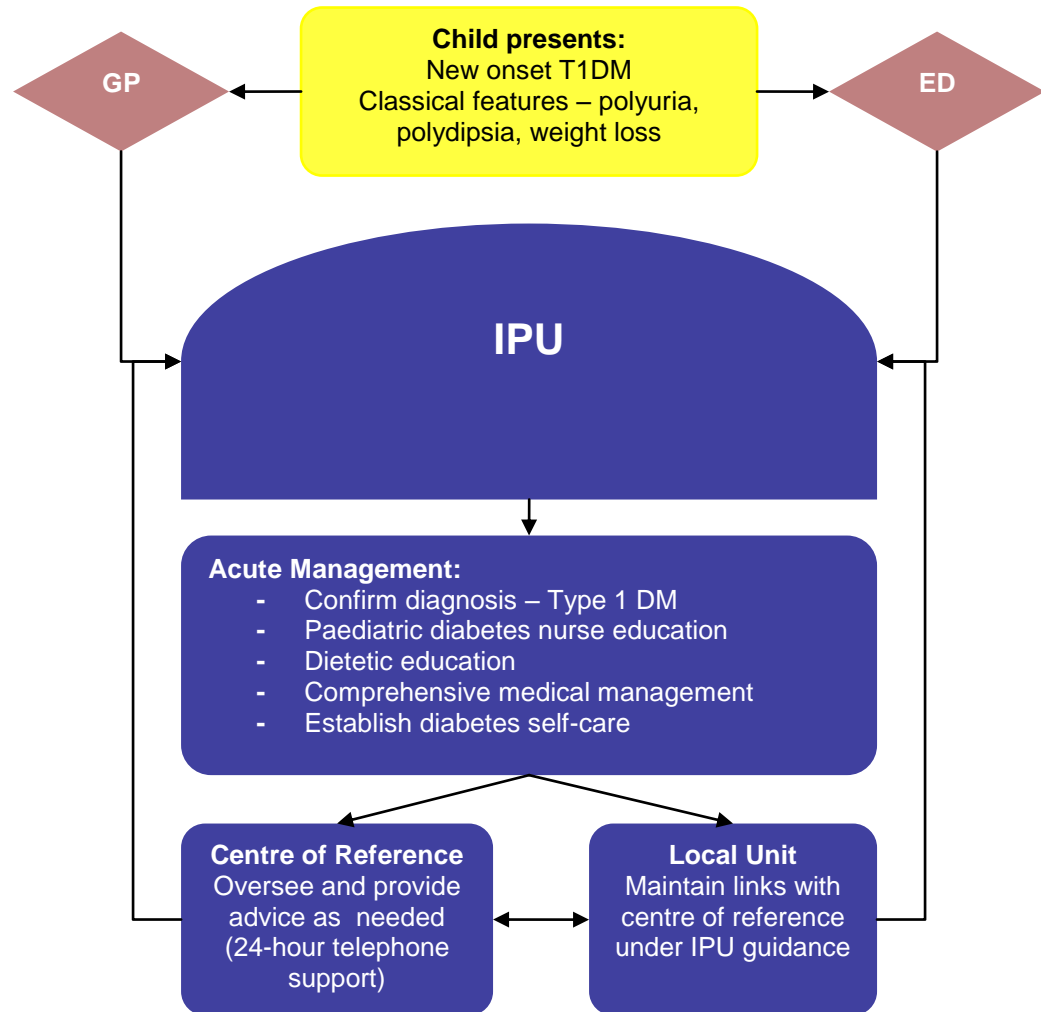
The proposed model of care for paediatric diabetes is via integrated practice units (IPUs) which focus on the needs of children and young people (Porter, 2013). This is based on the “value agenda” (see Appendix 6 for more details). An IPU consists of one centre of reference and a number of additional units:



The IPU will undertake all forms of diabetes care, operating through a variety of means to provide paediatric diabetes services as much as possible at a local level. The centre of reference will provide tertiary care and insulin pump therapy to children of all ages led by a consultant paediatric endocrinologist. The centre must be staffed by a full complement of multidisciplinary staff including paediatric diabetes nurse specialists (DNS), dietitians, psychologist and social worker (Porter, 2013). Additional units will support the delivery of services locally, acting under the ‘umbrella’ of the IPU. It is recommended that a centre of reference will have between 150 and 300 patients, while local units have less than 150 patients attending and will be linked to a larger centre of reference for provision of more complex care.

From initial diagnosis of diabetes, children and their families should be encouraged to link with patient groups such as Diabetes Ireland. These groups are helpful for children and families in the initial stages of diagnosis when they need peer support.

Patient Journey



Education

Research in EU countries has highlighted education as a major component of improving care and outcomes. A cohesive, integrated, highly skilled paediatric diabetes multidisciplinary team of healthcare professionals that delivers structured diabetes self-management education has been identified as a key component of care to deliver optimal outcomes (Danne et al., 2012). All education programmes delivered to children and young people, and their families, needs to be quality assured, and their delivery also needs to be independently quality assured, e.g. the Quality Institute for Self-Management Education (QISMET).

Education programmes should be available to the child, their family and ideally staff members from the child's school. Examples of educational programmes would include carbohydrate counting and structured pump schools, e.g. FABB, CHOICE. This model of care recommends that

national, quality assured, educational programmes for children with type 1 diabetes and their families and carers are developed.

Diabetes Education

Self-management of diabetes is the ultimate goal for all patients with diabetes. In order to do this, the carers of a young child need to be able to balance insulin replacement with dietary intake and exercise levels in order to maintain blood glucose control and prevent/recognise the occurrence of complications. The success of self-management is measured by blood glucose testing and the incidence of acute and chronic complications.

Education is essential at diagnosis. Basic education should include:

- What is diabetes?
- The role of insulin and delivery methods, administration and storage/disposal.
- Diabetes and food – relation of food to blood glucose levels
- Diabetes and exercise
- Blood glucose monitoring – targets, technique and actions based on results
 - Low blood glucose management
 - High blood glucose management
- Who and how to access help
- Support and entitlements for daily living with diabetes

Once basic skills are mastered, a more intensive educational programme can be initiated based on the families stage of engagement, including;

- Causes, symptoms, treatment, prevention of hypoglycaemia, glucagon/glucogel administration
- Causes, symptoms, treatment, prevention of hyperglycaemia- DKA and sick day management
- HbA1c – what it is, relationship to home blood glucose monitoring (HBGM) and benefits of attaining target levels
- Exercise – how to manage/insulin adjustment/practical tips and importance of regular activity
- How to manage diabetes in crèche/school/holidays
- Long term complications – what they are and how to avoid their development
- Injection sites
- The diabetes team roles
- Regular review – importance and necessity of attending
- Recognising patterns through review of food intake, blood glucose levels, insulin dosage and activity
- Adjusting insulin dosage to meet targets

Dietetic Education

Dietetic education can help people to balance and adjust their food choices according to their activity and insulin levels, avoid and treat high blood glucoses and low blood glucoses and adjust meal patterns when feeling unwell.

Initially the education given should focus on recognising food types and how they influence blood glucose levels. Topics should include;

- Healthy eating and food groups
- Effects of different food groups on blood glucose levels
- Carbohydrate sources and tools to calculate carbohydrate content per serving
- Options for meals, snacks and drinks.

Once basic skills are mastered, a more intensive educational programme should be initiated based on the treatment being provided to the patient;

- Reading food labels and quantifying carbohydrates accurately
- Measuring accurately carbohydrates in food portion sizes by using weighing scales
- Carbohydrate adjustment when exercising or eating out
- Fats and their effect on absorption
- Estimating carbohydrates in recipes and complex meals
- Insulin /Carbohydrate ratio and correction doses.

Refresher Education

It is important that people with long term illnesses keep up to date with developments in relation to the care of their disease. It is therefore recommended that units would provide children with T1DM and their families the opportunity to attend refresher educational programmes periodically.

HbA1c

Based on international evidence (ISPAD & ADA), HbA1c should be measured 3 to 4 monthly in the outpatient clinic. It is recommended that all centres should have access to point-of-care HbA1c and blood ketone testing (Acerini et al., 2014). The target HbA1c for all children and young people is <7.5% (59mmol/l) (ADA, 2014).

Outpatient Follow-up

As standard care, it is recommended that children with type 1 diabetes are followed up three to four monthly in a dedicated paediatric diabetes outpatient clinic. All children with type 1 diabetes should have an annual review. The annual review should start when a child is diagnosed with T1DM for greater than five years or the child is older than 12 years of age (ISPAD & ADA). An annual review should consist of eyes, feet and cardiovascular review along with routine annual bloods for thyroid, coeliac and fasting lipids (see p16 **Screening for Microvascular Complications of Type 1 Diabetes in Childhood**).

Resources Required to Implement Model of Care

The required resources fall into four main categories:

- Equipment
- Infrastructure
- Information Technology
- Staffing

Equipment

Adequate access for all multidisciplinary team staff to computers is essential for the successful implementation of this model of care. All patient records should be stored electronically to facilitate audit and database upkeep. A range of software packages are required to access information stored on glucometers, blood ketone meters and insulin pumps, but these are usually supplied free of charge by the companies providing them. Once this information is downloaded it can be reviewed and interpreted by the diabetes team, showing insight into each patient's behaviours and enabling appropriate recommendations made to insulin rate or ratio adjustments. A supply of pumps, infusion sets, cannulae, and continuous glucose monitoring (CGM) equipment are required to deliver insulin pump therapy. Centres will also need point-of-care HbA1c analysers and blood ketone testing equipment. The provision of 24-hour telephone support for clinicians and patients within the IPU is essential.

Infrastructure

Dedicated diabetes education space is required for the delivery of group structured education programmes. Adequate outpatient clinic space is also essential for the efficient running of multidisciplinary diabetes clinics.

Information Technology

The availability of data on patient numbers and outcomes are central to the planning and provision and continuous audit of appropriately resourced centres, and the highest quality of care. Data collection is a time consuming process. Ideally data should be collected prospectively using a national data management system that would be integrated to daily clinical practice across all centres. Data management would contribute positively to workflow, benchmarking and outcomes in paediatric diabetes.

Staffing

Staffing recommendations for the IPU can be determined on a pro rata basis from the following:

| | Centre of Reference (per 300 patients) (WTE) | Additional Unit (per 150 patients) (WTE) |
|---|---|---|
| Paediatric Endocrinologist | 2 (1.2WTE dedicated to paediatric diabetes) | 1 (0.6WTE dedicated to paediatric diabetes*) |
| Paediatric Diabetic Nurse Specialist (PDNS) | 4 (including dedicated pump and transition nurses) | 2 |

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| | Centre of Reference | Additional Unit |
|---------------------------|----------------------------|------------------------|
| Paediatric Dietitian | 2 | 1 |
| Psychologist | 1 | 0.5 |
| Social Worker | 1 | 0.5 |
| Access to Play Specialist | ✓ | |

*This is dedicated time to Paediatric Diabetes, so in the case of a 1WTE consultant paediatrician time would be allocated as follows 0.6WTE Paediatric Diabetes (0.2WTE outpatient clinics, 0.2WTE inpatient paediatric diabetes, 0.1WTE continuous professional development and 0.1WTE paediatric diabetes pump and service development and 0.4WTE general paediatrics

Additional general paediatricians may be required so that at least one dedicated paediatric endocrinologist can lead the IPU. A reduction in general paediatric ‘on call’ and/or ‘take’ may be essential for the lead paediatric endocrinologist in each IPU. For each team within the IPU with 150 patients, patients will be reviewed quarterly. These recommendations conform with those of the Royal College of Nursing (1 PDNS per 75 patients) (Nursing, 2006). PDNS and dietitian support is a critical factor in the delivery of intensive diabetes care. This includes structured education for newly diagnosed patients, carbohydrate counting and insulin pump commencement, i.e. ‘pump school’. The vast majority of initial education and follow-on support for multiple daily injections or commencement of CSII is delivered by the PDNS either face to face, by telephone or by email. The use of CSII involves inputting the carbohydrate content of foods and snacks 5-6 times per day, and inaccurate bolusing for meals significantly reduces the efficacy of CSII (Smart et al., 2013, Smart et al., 2010). Therefore, intensive education in carbohydrate counting is imperative prior to CSII initiation.

The burden of dealing with a chronic disease such as T1DM on a daily basis leads to an increased risk of psychological disorders, mainly depression and anxiety, especially among the adolescent population (McGrady and Hood, 2010, Herzer and Hood, 2010, Hassan et al., 2006). The focus on food and weight leads to greater risk of eating disorders, two to three times that of the background population (Rodin et al., 1986). The metabolic outcomes of individuals with psychological comorbidities are also significantly poorer. The involvement of a psychologist with any diabetes service is universally recommended, and screening for psychological morbidity at diagnosis has also been recently suggested (Cameron et al., 2007).

Because of the increased comorbidity associated with T1DM, dedicated access to a psychologist and a social worker for each IPU is recommended. In addition, when young patients are required to administer five to six insulin injections per day, there can be a reluctance to deal with needles or ‘needle phobia’ may present. Play specialists and occupational therapists are recommended to deal with children in this scenario.

Gap Analysis

A staffing survey undertaken in October 2014 across all paediatric diabetes units nationally allowed comparison of current staffing to the above recommendations based on actual numbers of patients attending each centre (shared care patients were not double counted). Two years after data collection for the national diabetes audit (Hawkes and Murphy, 2014),

PAEDIATRIC DIABETES: MODEL OF CARE FOR ALL CHILDREN AND YOUNG PEOPLE WITH TYPE 1 DIABETES

clear deficits still exist in the numbers of consultant, DNS, dietitian and psychology posts. These are most evident in the large centres of reference (Our Lady's Children's Hospital Crumlin, Childrens University Hospital Temple Street, the National Children's Hospital Tallaght and Cork University Hospital). This deficit in consultant numbers is in line with the HSE, Medical Education Training, entitled Medical Workforce Planning document (MET, 2014). See Appendix 7 for further details.

| | Consultant | DNS | Dietitian | Psychologist |
|--|------------|-------|-----------|--------------|
| Total approximate national deficit (WTE) | 13.95 | 18.11 | 11.97 | 8.18 |

Commissioning and Financing of Paediatric Diabetes Services

“The biggest problem with health care isn't with insurance or politics. It's that we're measuring the wrong things the wrong way!” (Kaplan, 2011)

As a minimum, the commissioning process should involve an assessment of local needs, design of a local specification to meet those needs, procurement of services to deliver the local specification, and proactive monitoring.

Whichever approach is adopted, commissioning should be specific to the needs of children and young people with diabetes and should also link to wider children and young people's initiatives. These include:

- Local needs assessment
- Involving children and young people, and their parents and carers, in planning and commissioning services
- Involving the 7 hospital groups
- Pooled budgets and resources
- Improvement and performance management cycle
- Children's services inspection

Based on the joint planning and commissioning framework in the UK, the following nine-step cycle for children, young people and maternity services should be considered:



Commissioning Levers

Commissioners have a number of levers, which allow them to support the process of service redesign and development. 'Payment by results' provides commissioners with national currencies, enabling providers to be paid a set price (or tariff) for the services they supply or targets they achieve (e.g. HbA1c <53mmol/mol (7%)), rather than being reliant on historic budgets and the negotiating skills of individual managers.

In order to improve paediatric diabetes care in Ireland, the service needs to be redesigned, and a potential financial solution to support this change would be to introduce a 'best practice tariff reimbursement' scheme, a form of payment by results. Only paediatric diabetes centres reaching their targets and providing a high quality service by clearly defined criteria (HbA1c targets and attaining percentage of children on pumps) would receive additional financial support (UK Department of Health, 2012). This requires further discussion and consultation with relevant stakeholders.

In order to facilitate these activities, commissioners would need to commission jointly an appropriate IPU infrastructure, which might include:

- an IPU / network coordinator;
- an IPU data manager and data entry facilities; and
- support services provided by the IPU network

Another way of financing the IPU would be via an accurate cost measurement system, this is referenced in Harvard Business Reviews from 2011-date (Kaplan, 2011, Porter, 2013). With

good estimates of the typical path a child with type 1 diabetes takes from diagnosis at the emergency department, to local centre, through basic diabetes education and via contact with a centre of excellence, providers can use the time driven activity based costing (TDABC) system to assign costs accurately and easily to each process step along the patient pathway. Time driven activity based costing (TDABC) includes 7 steps listed below:

1. Select medical condition to be examined (e.g. paediatric diabetes)
2. Define a care delivery chain
3. Develop process mapping for each activity in patient care delivery (identify resources involved and any supplies used for the patient at each process)
4. Obtain accurate time estimates for each process step
5. Estimate the cost of each patient care resource
6. Estimate the practical capacity of each resource provider – calculate the capacity cost ratio
7. Compute the total costs over each patients cycle of care i.e. TDABC (Kaplan, 2011, Porter, 2013)

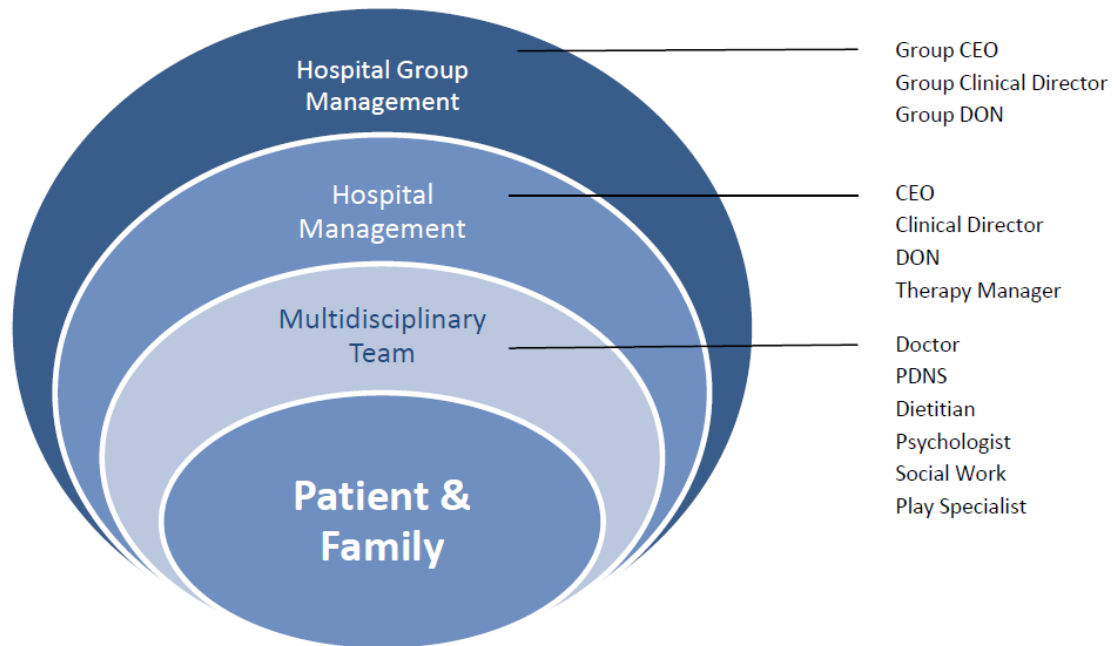
Continuous Professional Development

This model of care recommends that all health care professionals working with children and young people with T1DM attend regular continuing professional development updates, and structured educational training programmes where available and quality assured, e.g. CHOICE, SWEET, efficiency team workshops, etc. This would include paediatric endocrine consultants, paediatric diabetes nurse specialists, dietitians, psychologists, social workers and play specialists, and focus on a unified team approach.

Governance

The Paediatric Diabetes Clinical Programme adopts the clinical governance structures set out in 'The Code of Governance Framework for the Corporate and Financial Governance of the Health Service Executive Version 4, 2011' and 'National Clinical Programmes: Checklist for Clinical Governance (National) 2011'. The clinical governance structure of the paediatric diabetes service is 'nested' in the clinical governance structure of the hospital and, in turn, of its hospital group.

The Paediatric Diabetes Working Group has embedded the principles of clinical governance by adopting a leadership and accountability framework that envisages every clinician and administrator working in the programme having clear roles and responsibilities. The patient is pivotal to clinical and corporate governance strategy development. Clinical governance embraces clinical effectiveness, clinical audit, research and development, clinical indicators, integrated pathways, risk management, and organisational development. This governance structure should apply to all units providing paediatric diabetes care.



Governance Structure of the Model of Care

This model of care has been drafted by the Paediatric Diabetes Working Group. The group has been set up under the auspices of the National Clinical Programme for Paediatrics and Neonatology and the National Clinical Programme for Diabetes.

This document has gone through an approval process through the following groups:

- Paediatric Clinical Advisory Group and Working Group
- Diabetes Clinical Advisory Group and Working Group
- Patient Reference Group
- HSE Clinical Strategy and Programmes Division Senior Management Team

Governance within Paediatric Diabetes Units

Good governance is essential for the delivery of high quality paediatric diabetes care. Diabetes is a highly specialised area constantly evolving and dependent on a multidisciplinary team. The unit should have a lead clinician and a business manager. The paediatric diabetes unit needs to be accountable for safe quality patient care. Monthly, minuted departmental meeting should be held. The standing items on the agenda should be quality and risk issues, the number of new referrals within the IPU and the specific unit, the number of patients transitioning to adult care, the number of complex cases that need to be readmitted for education and/or stabilisation, manpower and research. It is important that each unit has a set of guidelines, ISPAD guidelines are recommended (Acerini et al., 2014). The unit should produce an annual report. The report should be circulated to all staff members, the hospital executive and the board of management and to those units within the same IPU. This report can highlight any staff deficits or concerns and plan on how best to address them. The quality of patient care can be reported at monthly meetings and in the annual report.

Risk Management and Patient Safety

The Paediatric and Diabetes National Clinical Programmes are committed to risk management and patient safety. Paediatric diabetes teams will adhere to the HSE risk management handbook and the processes contained within. Patients will be carefully monitored with regular review (three to four monthly) and appropriate education to effectively manage treatment. Patients who are not reaching HbA1c targets may need admission for stabilisation and education.

Programme Metrics and Evaluation

One of the objectives of this national model of care for children and young people with type 1 diabetes (T1DM) is to significantly improve outcomes of care over the next five to ten years provided the recommended investments in paediatric diabetes services are made. Critical to evaluating quality improvement of children's diabetes services is the development of a system of audit. This would be best done through a national web based diabetes data management system.

Primary quantitative outcomes are:

- Establish accurate baseline data on national HbA1c, clinic frequency, admission rates, DKA rates, severe hypoglycaemia rates
- HbA1c target of <7.5% (<59mmol/mol) for T1DM (ADA Criteria, Standards of Diabetic Care (2014))
- Improve Health-Related Quality of Life (HRQOL) and reduce family burden
- Set standards for the process of care delivery with regular 3-4 monthly review of patients.
- Reduce admission rates of known children with T1DM with diabetes-related acute complications (DKA and severe hypoglycaemia)
- Having established baseline data, set targets for planned improvement of HbA1C. A median HbA1c reduction nationally of 0.5% (5.5mmol/l) within 5 years and 1% (11mmol/l) in 10 years

Secondary quantitative and qualitative outcomes are:

- Evidence of listening, communicating and collaborating with children and young people with T1DM, families, carers and healthcare professionals in all disciplines
- Reduced variations between services and clinical outcomes
- Improved quality of life and reduced burden of disease for children and young people with T1DM and their families
- Improved patient experience of the service
- Standardisation and accreditation of training for all healthcare professionals who work with paediatric diabetic children and young people
- Educating children to self-manage their diabetes using nationally standardised and evaluated programmes of education
- Clinically led service improvements

- Screening for standardised complications as per ISPAD guidelines (Donaghue et al., 2014).

Key Recommendations for Implementation of this MoC:

1. Services should be organised within integrated practice units (IPUs) comprising a centre of reference and a number of additional units.
2. IPUs should be equipped with the core staffing requirements detailed in this document. A reduction in general paediatric workload may be required for the lead paediatric endocrinologist in each IPU. Adequate staffing should facilitate the availability of 24-hour telephone support within each IPU.
3. Referral pathways need to be determined for each IPU taking into account the seven hospital groups.
4. Each IPU will need to develop governance arrangements which cross current geographic boundaries.
5. Ongoing training and structured education of paediatric diabetes teams is required annually.
6. National, quality assured, educational programmes for children with type 1 diabetes and their families and carers should be developed.
7. Ongoing patient and parental engagement is required, for example with links with Diabetes Ireland.
8. Appropriate national information and communication technology infrastructure and support is needed.
9. Accurate baseline data is required in the form of an active electronic database for longitudinal data, this will allow ongoing audit and appropriate service development.
10. This MoC will require a formal commissioning process and a dedicated finance source needs to be identified based on a unit cost per child with Type 1 Diabetes to address current and future staffing deficits.
11. An implementation team and implementation strategy will need to be developed involving all stakeholders to realise this model of care and all the recommendations above.

Appendix 1: Membership of National Paediatric Diabetes Working Group

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Dr. Ronan Canavan, Clinical Lead Diabetes National Clinical Programme, Consultant Endocrinologist

Prof. Alf Nicholson, Clinical Lead Paediatrics National Clinical Programme, Consultant Paediatrician

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Dr. Kevin Moore, Consultant Endocrinologist, Naas General Hospital and Tallaght Hospital

Dr. Declan Cody, Consultant Paediatric Endocrinologist, Our Lady’s Childrens Hospital Crumlin

Dr. Juliet Jennings, Consultant Paediatrician, Our Lady of Lourdes Hospital Drogheda

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Prof. Edna Roche, Consultant Paediatric Endocrinologist, National Childrens Hospital

Dr. Orla Neylon, Consultant Paediatrician, Sligo General Hospital

Ms. Grainne Mallon, Paediatric Dietitian, AMNCH

Ms. Helen Fitzgerald, Diabetes Nurse Specialist, AMNCH

Ms. Adrienne Brennan, Diabetes Nurse Specialist, AMNCH

Ms. Grace Turner, Programme Manager, National Clinical Programme for Paediatrics and Neonatology, RCPI / HSE Clinical Programmes and Strategy Division

Ms. Claire Browne, Programme Manager, National Clinical Programme for Paediatrics and Neonatology, HSE Clinical Programmes and Strategy Division

Appendix 2:UK National Paediatric Diabetes Audit Findings (December 2013)

Number of Children with Diabetes in England and Wales 2011-12

| Age Group: | 0-4 | 5-9 | 10-14 | 15-19 | 20-24 | Total <25 |
|--------------|--------------|--------------|---------------|--------------|------------|---------------|
| Boys | 704 | 2,587 | 5,674 | 4,097 | 113 | 13,175 |
| Girls | 650 | 2,274 | 5,313 | 3,667 | 120 | 12,024 |
| Total | 1,354 | 4,861 | 10,987 | 7,764 | 233 | 25,199 |

Type 1 Diabetes Incidence Rates per 100,000 Persons 2011-12

| Age Group: | England | | Wales | | England & Wales | |
|---------------------|-------------|-------------|-------------|-------------|-----------------|-------------|
| | Boys | Girls | Boys | Girls | Boys | Girls |
| 0-4 | 12.5 | 13.8 | 9.8 | 11.5 | 12.4 | 13.6 |
| 5-9 | 24.8 | 20.6 | 17.9 | 31.5 | 24.5 | 23.5 |
| 10-14 | 35.5 | 28.3 | 40.6 | 40.4 | 35.8 | 29.0 |
| 15-19 | 6.6 | 5.4 | 5.9 | 4.1 | 6.5 | 5.4 |
| 20-24 | 0.1 | 0.0 | 0.9 | 0.0 | 0.2 | 0.0 |
| Total <25 | 15.2 | 13.4 | 14.3 | 16.3 | 15.2 | 13.6 |

Percentage of Children and Young People Aged 12-24 Having Key Age-Specific Care Processes Recorded from 2004-05 to 2011-12

| | 2004-05 | 2005-06 | 2006-07 | 2007-08 | 2008-09 | 2009-10 | 2010-11 | 2011-12 |
|------------------------------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|
| HbA1c* | 73.2% | 77.6% | 84.7% | 89.1% | 89.6% | 90.1% | 92.8% | 89.3% |
| BMI | 50.5% | 53.0% | 60.5% | 73.2% | 66.0% | 70.2% | 75.3% | 64.7% |
| Blood Pressure | 44.1% | 40.6% | 53.3% | 60.1% | 57.1% | 58.8% | 62.7% | 67.7% |
| Urinary Albumin | 18.7% | 23.3% | 30.3% | 34.1% | 32.2% | 36.5% | 40.3% | 40.7% |
| Cholesterol | 18.2% | 17.5% | 22.6% | 32.1% | 30.5% | 29.9% | 34.9% | 44.4% |
| Eye Screening | 17.7% | 15.3% | 25.2% | 25.7% | 26.9% | 25.8% | 35.8% | 36.9% |
| Foot Examination | 17.4% | 15.4% | 21.3% | 23.5% | 23.1% | 24.5% | 31.9% | 34.4% |
| All Care Processes Recorded | 2.0% | 2.6% | 3.6% | 5.0% | 5.2% | 4.1% | 5.8% | 6.7% |

* HbA1c is for all ages

Appendix 3: SWEET Criteria for Paediatric Diabetes Centres of Reference



CRITERIA FOR SWEET CENTRES OF REFERENCE (CoR)

- Provide a multidisciplinary approach with paediatric diabetes expertise
- Possess sufficient activity and capacity to provide relevant services at a sustained level of quality
- Possess sufficient capacity to provide expert advice, diagnosis or confirmation of diagnosis, to produce and adhere to good practice guidelines and to implement outcome measures and quality control
- Possess appropriate capacities for diagnosis, follow-up and management of patients with evidence of good outcome where applicable
- Provide appropriate arrangements for patient referrals from other EU countries
- Possess a high level of expertise and experience, as documented through teaching and training activities, publications, grants or honorific positions
- Provide a strong contribution to research
- Show involvement in epidemiological surveillance such as registries
- Show close links and collaboration with other national and international expert centres and show the capacity to network
- Show close links and collaboration with patient associations where they exist

REQUIREMENTS FOR SWEET COLLABORATIVE CENTRES (CC)

- Presence of at least 150 patients \leq 18 years
- Presence of at least a paediatrician with diabetes expertise and a nurse with paediatric diabetes expertise
- Presence of at least a knowledgeable and skilled dietitian, psychologist and/or social worker
- Presence of at least one ISPAD-member
- Presence of an electronic health record with longitudinal data documentation, indicating at least: age, diabetes duration, gender, diabetes type, HbA1c
- Participation in quality circle, including in data analysis
- Follow the ISPAD-guidelines
- Fulfil the national requirements for specialist education
- Offer outpatient diabetes services with confirmed inpatient access

Appendix 4: Parent Survey on Paediatric Diabetes Services (Diabetes Ireland)

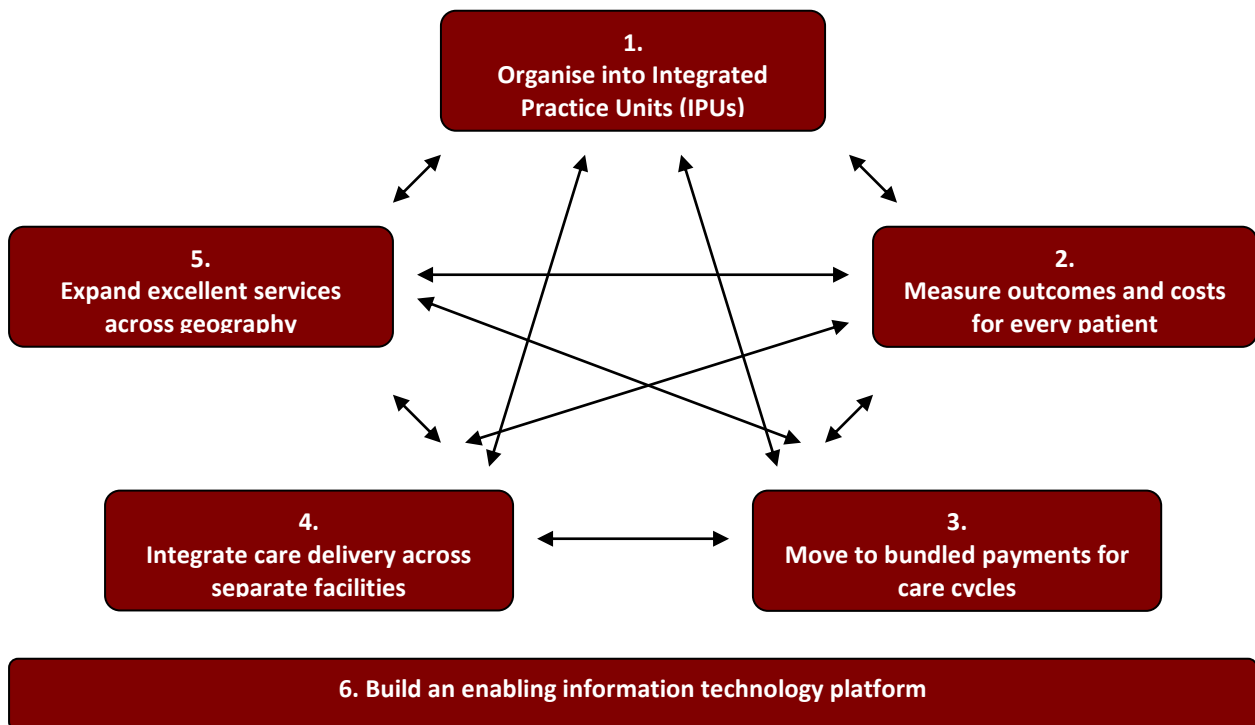
| | |
|--------------------------|---|
| Travel | 95.7% of individuals surveyed agree that a shorter distance to the outpatient clinic is important but the same number (95.8%) would choose a better standard of care over distance to the clinic. |
| Care at Diagnosis | <p>Over 95% of individuals surveyed would like more face to face appointments with a diabetes specialist, including dietitians, at the early stage of diagnosis.</p> <p>All participants surveyed agreed that the availability of a 24/7 diabetes-specific emergency contact service would be ideal in the early years of diagnosis.</p> <p>Furthermore, psychological support for dealing with the challenge of living with diabetes, as well as the provision of knowledge and training for extended family members were deemed 'essential' by 100% of those surveyed.</p> <p>Almost 70% agreed that they would have preferred to have access to an insulin pump from the time of diagnosis.</p> |
| Style of Practice | <p>All individuals surveyed agreed that it was important that their views and options were valued, and that they were seen as central in the decision making process.</p> <p>100% agreed that quality of life should be considered an important outcome measure when evaluating treatment effectiveness.</p> <p>Over 95% said that they would like access to a variety of mediums through which consultations could be delivered (e.g. Skype as well as face to face), and some degree of flexibility regarding when consultations took place.</p> <p>All individuals surveyed stated that transition to adult clinics should be determined by the young person and not by an arbitrary age cut off, with the possibility to revert to paediatric care for a period of time if adult care was not effective.</p> <p>Over 95% of individuals agreed that sensitive issues such as puberty and alcohol/drug use should be approached discretely by the diabetes team.</p> |
| Support Systems | All those surveyed agreed that peer support and interaction with other families living with diabetes would be desirable for both the parents themselves and the child with diabetes. |
| Staff and Knowledge | <p>100% of parents surveyed agreed that the availability of out of hours support, and support and advice from diabetes specialists when children are admitted to hospital with a non-diabetes related procedure or illness were important.</p> <p>Furthermore, refresher courses and presentations about getting the most out of pump therapy or injection regimens were seen as vital by all those surveyed.</p> |
| School Support | <p>All respondents agreed that there should be greater emphasis on schools receiving expert training in diabetes.</p> <p>64% agreed that school staff should attend diabetes training and education programmes designed for children and families affected by diabetes.</p> |
| Centre Design Components | <p>All those surveyed agreed that clinics should provide advice on relevant diabetes literature, new technologies available, and about support groups in the area.</p> <p>All agreed that having access to pumps and blood glucose monitoring equipment in the waiting room, together with an expert available to explain the benefits of these devices, would be beneficial.</p> <p>All parents surveyed agreed that having an attractive and bright space designed with children and teenagers in mind is required, with toys and other distractions available in the waiting areas for children.</p> <p>Finally, clinics where children of similar ages are seen together are seen as most desirable by 100% of parents surveyed.</p> |

Appendix 5: Survey of Young People with Type 1 Diabetes

| | |
|-----------------------------------|---|
| <p>Travel</p> | <p>The average distance travelled to the diabetes clinic was 54km, with 70% of respondents travelling less than 1 hour each way. While 91% agreed that they would love to travel not more than 1 hour each way to get to clinic appointments, almost three quarters felt they would travel further if it meant a better standard of care. 67.7% reported that they would be happy to have their diabetes care shared between their local hospital and a larger centre with more services available.</p> |
| <p>Care at Diagnosis</p> | <p>86% reported they would like to have 4 appointments per year in the first few years following diagnosis. 97% feel it is important to see the DNS as soon as diagnosed, while 81% and 78% felt it was important to see the diabetes doctor and diabetes dietitian respectively. 95% of respondents would love to be able to have an emergency number to call at any time in the early years after diagnosis, and speak to someone at the other end who knows more than them. 90.6% want more frequent contact in the first year, even by phone or email, and 95% agreed that it is important that the wider family (e.g. grandparents, older brothers and sisters, stepparents) learn about Type 1 Diabetes and how to manage it.</p> |
| <p>Style of Practice</p> | <p>97% of respondents would like to be included as part of the team, be asked for their opinions, and have their thoughts and ideas listened to. Almost the same number would like to be able to choose when their next appointment will be, especially around big events like exams or the debs. 46 patients thought that younger children and teenagers should be seen in different clinics, and 58% thought that talking about puberty, alcohol or drugs should be done discretely, separate to their parents.</p> |
| <p>Technology</p> | <p>95% would like email contact with diabetes services; almost 60% would like telephone reviews but only 26% would like reviews via skype. 66% of respondents would like online appointment scheduling, and 63% would like digital displays at clinics informing them about wait times.</p> |
| <p>Staff and Knowledge</p> | <p>95% agreed that transitioning to adult diabetes services should be discussed and agreed with them in advance. 81% of respondents felt that diabetes teams always focus on physical health at the clinic, and would like to have the opportunity to discuss how diabetes is impacting on life in general (for example: friendships, family/school life and emotional wellbeing or happiness).</p> |

Appendix 6: How Integrated Practice Units (IPUs) form part of the Value Agenda for Healthcare (Porter, 2013)

Maximising value for patients means achieving the best outcomes at the lowest cost, moving away from a supply-driven healthcare system towards a patient-centred system. Services for particular conditions are concentrated in the right locations to deliver high value care. The strategy to achieve this change is contained within “the value agenda”, which has six interdependent and mutually reinforcing components:



Step 1 - organising services into IPUs - is at the core of value transformation, with the patient’s medical condition the central focus. An IPU is a dedicated multidisciplinary team made up of both clinical and non-clinical personnel providing the full care cycle for a particular medical condition. IPUs not only provide treatment but also assume responsibility for engaging patients and their families in care, e.g. by providing education and counselling, encouraging adherence to treatment and prevention protocols, and supporting necessary behavioural changes. The IPU staff work together regularly as a team to achieve the common goal of maximising the patients’ outcomes as efficiently as possible. IPUs measure outcomes, processes and costs for each patient, and meet frequently to review their own data, and use this to establish new protocols, and devise better or more efficient ways to engage patients. IPUs work as a team even when not co-located.

Appendix 7: Paediatric Diabetes Staffing – Data Provided October 2014

| Hospitals | No. of Patients | Consultant | DNS | Dietitian | Psychologist |
|--|-----------------|------------|------|-----------|--------------|
| Cavan General Hospital | 39 | 0.05 | 0.05 | 0.1 | 0 |
| Childrens University Hospital Temple St. | 330 | 0.5 | 2.2 | 0.5 | 0.2 |
| Cork University Hospital | 375 | 0.66 | 2.8 | 1 | 0 |
| Galway University Hospital | 140 | 0.2 | 0 | 0.06 | 0 |
| Kerry General Hospital, Tralee | 39 | 0 | 0 | 0 | 0 |
| Letterkenny General Hospital | 51 | 0.05 | 0.5 | 0.2 | 0 |
| Mayo General Hospital, Castlebar | 76 | 0.2 | 0 | 0.04 | 0 |
| Midland Regional Hospital, Mullingar | 98 | 0.1 | 0.2 | 0.1 | 0 |
| Midland Regional Hospital, Portlaoise | 47 | 0.1 | 0.2 | 0.1 | 0 |
| Our Lady of Lourdes, Drogheda | 123 | 0.5 | 1.4 | 0.8 | 0.1 |
| Our Lady's Hospital for Sick Children, Crumlin | 485 | 0.6 | 2.8 | 0.7 | 0.4 |
| Portiuncula Hospital, Ballinasloe | 48 | 0.1 | 0.3 | 0.2 | 0 |
| Sligo General Hospital | 80 | 0 | 0.5 | 0.1 | |
| South Tipperary General Hospital, Clonmel | 26 | 0 | 0 | 0 | 0 |
| St. Luke's Hospital, Kilkenny | 68 | 0.05 | 1.3 | 0.1 | 0 |
| Tallaght | 347 | 0.4 | 2 | 1 | 0 |
| University Hospital Limerick | 185 | 0.16 | 2.5 | 0.75 | 0 |
| Waterford Regional Hospital | 73 | 0.25 | 0.5 | 0.1 | 0 |
| Wexford General Hospital | 54 | 0 | 0.5 | 0 | 0 |

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