



**PAEDIATRICS**

**A NATIONAL MODEL  
OF CARE FOR PAEDIATRIC  
HEALTHCARE SERVICES  
IN IRELAND**

**CHAPTER 23:  
PAEDIATRIC  
ENDOCRINOLOGY  
AND DIABETES  
CARE**



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## 23.0 INTRODUCTION

*Paediatric endocrinology encompasses the diagnosis and management of children and adolescents with pathologies that broadly fall into one of two distinct categories:*

- Growth and hormonal disorders – a heterogeneous group of disorders that require specialised investigations, patient education, and chronic treatments with close follow-up. (Endocrinology)
- Diabetes – mainly type 1 diabetes mellitus (T1DM) – a more homogeneous disorder where short- and long-term health outcomes are strongly correlated with high-quality specialised multidisciplinary care

*Paediatric endocrinology and diabetes services face many challenges. These include:*

1. The need to improve both short- and longer-term healthcare outcomes through:
  - a) Improving services for children and adolescents with T1DM. Tight metabolic control reduces the risks of short-term and long-term diabetes-related complications.
  - b) Reducing unacceptable delays in access. Timely investigation and management of children referred by paediatricians and GPs optimises outcomes, and current waiting times for outpatient assessment are unacceptable.
  - c) Timely specialised care of children with conditions that present an immediate threat to life and developmental outcome. Examples include children with severe congenital hyperinsulinism (CHI) at risk of profound and recurrent hypoglycaemia; children with adrenal insufficiency at risk of acute decompensation/death; children where endocrine symptoms are presentations of significant underlying malignant or genetic disorders (e.g. multiple endocrine neoplasia, adrenal tumours).
  - d) Multidisciplinary management of children with rare complex disorders requiring input from multiple subspecialties (e.g. disorders of sexual development)
  - e) Centralised specialist management of children with disorders of the hypothalamic-pituitary-adrenal axis (paediatric endocrinology/neurosurgery/oncology) with risk of peri-operative acute and ongoing chronic complications.
  - f) Co-management by specialist paediatric endocrinologists (alongside orthopaedics and radiology) of children with metabolic bone disorders, e.g. osteogenesis imperfecta. Many of these patients regularly travel to United Kingdom (UK) specialist centres to access this care, at great inconvenience for the families and also at great expense to the Health Service Executive (HSE).
  - g) Establishment of a national care pathway and dedicated multidisciplinary team (MDT) to deliver services for infants with complex severe congenital hyperinsulinism (including appropriate links to the UK for F-DOPA PET scanning).
  - h) Seamless transition of adolescents with endocrine disorders (including diabetes) to the most appropriate adult endocrine services available for the individual condition.
  - i) Providing sufficient clinical psychology support for these patients with complex chronic conditions. Depressive symptoms, for example, are seen in approximately 10% of children with T1DM.
2. Complex, and often rare, endocrine disorders require specialised paediatric endocrine services, in order to provide appropriate, safe and effective care. Care is predominantly consultant delivered with clinical nurse specialist (CNS) and extended MDT support. Current insufficient consultant and CNS numbers, and MDT supports, result in an overwhelming and unsafe number of patients being managed by each individual consultant and team. The implementation of the European Working Time Directive (EWTD) has significantly reduced the availability of doctors in training in acute services, which has implications for care delivery.

3. Increasing expectations of service users in terms of timely access to expert care. Outcomes are improved in many endocrine disorders as a result of early evaluation, and this timely access is in the patient's best interests.
4. The current lack of data-driven decision-making. The current deficit in integrated IT, radiology and laboratory facilities across the services delivering care reduces ability to standardise care, audit outcomes, share care safely, reduce duplication of testing, and ensure best use of limited resources nationally.
5. As 70% of paediatric trainees are female, endocrine workforce planning, as with all other paediatric subspecialties, needs to anticipate the future needs for extended consultant leave (maternity and parental) and flexible work options.
6. The needs of the patient are 24/7. However, at present, services are configured according to office hours, with the exception of consultant on-call cover. This deficit will need to be addressed within teams and will require extended working days and weekend cover for newly diagnosed patients.

Appropriate management of children within two distinct categories of this paediatric subspecialty (i.e. endocrinology and diabetes) requires different but complementary skills.

#### *Endocrinology*

- Common conditions such as familial short and tall stature, constitutional delay in growth and development, and vitamin D-deficient rickets are part of core paediatric training, and this care is delivered by general paediatricians in regional hospitals/community settings.
- In regional settings, conditions that require input from a paediatrician with subspecialty training in paediatric endocrinology are managed along with shared care of complex endocrine disorders.
- Care is provided at tertiary centres for endocrine disorders which, given their complexity, extended MDT requirements and requirement for co-management with other subspecialties, require centralised care. Many require acute admission, and/or transfer from other services (neonatal or regional), specialised diagnostics and follow-up (see Table 2).

#### *Diabetes*

- Children with diabetes (primarily T1DM) are managed by specialised MDTs led by consultants with postgraduate training in paediatric endocrinology and ongoing continuing medical education (CME) (Edge et al., 2012; Pihoker et al., 2009). Specialised MDTs are required to deliver care as close as possible to the patients' home, in line with the regionalised model (Table 2), and in line with the Model of Care for all Children and Young People with T1DM (2015). Rarer forms of diabetes, such as neonatal diabetes, usually require more specialised care.

### **23.0.1 Paediatric Endocrinology in Ireland**

#### *The Scope of Paediatric Endocrinology*

The expertise necessary to manage complex congenital and acquired paediatric endocrine disorders encountered by infants/children is not part of routine paediatric training. Paediatric endocrinology encompasses the care of children with disorders of glucose (i.e. hypoglycaemia and diabetes mellitus); stature (short and tall); puberty; thyroid; water homeostasis; sexual development; adrenal, calcium and bone; pituitary function; rare syndromic/genetic obesity.

Paediatric endocrinologists provide a crucial referral and consult service for neonatologists, general paediatricians, other clinicians in tertiary centres managing complex paediatric disorders, and general practitioners (GPs). As congenital endocrine disorders are common (Ogilvy-Stuart and Midgley, 2006) all neonatal units require prompt access to paediatric endocrinology expertise within a tertiary centre. These disorders can vary in severity and urgency, and the role of the endocrinologist can range from providing advice in test interpretation for general paediatricians and general practitioners to emergency evaluation of disorders of sexual development, management of complex pituitary dysfunction and prolonged/recurrent hypoglycaemia. Delayed identification and treatment of adrenal insufficiency, disorders of glucose homeostasis or hypothyroidism can have detrimental lifelong physical and neurodevelopmental effects for the neonate and child (Steinkrauss et al., 2005). These disorders can be complex, rare, require detailed evaluation, and may require prolonged admission for the establishment of safe and effective therapies (Palladino and Stanley, 2011).

All centres providing tertiary paediatric care require specialised staff within a paediatric endocrinology department. Neurosurgical patients require pre-, perioperative and post-operative management of disorders of sodium and water balance, as well as follow-up for secondary pituitary deficiencies. The majority of current oncology patients require consultation with endocrinology due to the short-term effects of high-dose steroids, secondary diabetes, local tumour, surgery or radiotherapy effects on endocrine systems, and for the management of long-term late endocrine effects of chemotherapy and radiotherapy. Paediatric endocrinologists also provide a consult service for many other subspecialties, for example, disorders of sodium, calcium and glucose homeostasis in the paediatric intensive care unit (PICU), the management of cystic fibrosis-related diabetes in the respiratory service, the management of precocious puberty in the neurology service, the management of hypopituitarism or hypoparathyroidism in the cleft palate service. The range of endocrine disorders in complex patients managed by other services is broad, and consultation is often required in order to provide comprehensive and effective clinical care that optimises patient outcomes.

It is clear that different levels of care are required in different settings. Outpatient referral often requires only evaluation and laboratory testing, and common disorders of growth in puberty may be managed by consultant paediatricians with subspecialty endocrine training in regional centres. Clinicians providing this care may require access to day case beds for specialised hormonal stimulation testing. More complex cases may require access to other subspecialists such as intensive care, surgery, oncology and genetics. Centralising the care of these more complex patients, so as to ensure availability of all relevant subspecialists and extended specialised MDTs, is required in order to ensure optimal outcomes. In addition, provision should be made, where appropriate, for shared care follow-up with the child's paediatric unit on discharge.

#### *Levels of Care in Paediatric Endocrinology*

Complex and rare conditions are generally managed in specialised paediatric endocrinology services or in conjunction (shared care) with a local general paediatrician who has specialist training in paediatric endocrinology.

#### *Neonatal Endocrinology*

Approximately 70,000 infants are born each year in Ireland (HSE Clinical Strategy and Programmes Directorate, 2013); this comprises almost 30,000 births in the three Dublin maternity hospitals and a further 8,000 deliveries in Cork University Maternity Hospital. Paediatric services in Cork and Dublin are frequently consulted by neonatologists in standalone maternity hospitals – and by general paediatricians in regional hospitals – for conditions such as hypoglycaemia (congenital hyperinsulinism, congenital hypopituitarism, metabolic disorders), abnormalities in thyroid function testing, disorders of sexual development, congenital adrenal hyperplasia, and diabetes insipidus; affected infants are regularly transferred to Crumlin and Temple Street from maternity services in Dublin and across Ireland.

### *Specialised Endocrinology Outpatient Services*

Conditions managed predominantly in specialised clinics (depending on the level of expertise available) include congenital and acquired thyroid disorders, growth hormone deficiency (isolated and combined) and syndromic disorders associated with problems of growth and puberty, such as Turner, Prader-Willi, Noonan, Russell-Silver and Klinefelter syndromes.

### *Combined Care with other Subspecialties*

Rare, complex disorders with associated endocrinopathies are managed in highly specialised centres, as they require co-management with other subspecialists, including neurosurgery/ urology/gynaecology/oncology/genetics (e.g. Cushing's syndrome, craniopharyngioma and disorders of sexual development). Severe metabolic bone disease (e.g. osteogenesis imperfecta, hypophosphataemic rickets) requires close collaboration with, and access to, other subspecialty services (orthopaedics/radiology/anaesthesia/genetics). Optimal care of children with known complex endocrine disorders, e.g. diabetes insipidus, who develop intercurrent medical or surgical illness require tertiary endocrinology input, as do many chronic diseases with endocrine comorbidities such as osteoporosis.

### *Paediatric Intensive Care*

Paediatric endocrinology expertise is critical for the intensive care of critically ill children with endocrinopathies such as diabetes insipidus, other disorders of salt and water balance, and severe hypoglycaemia such as diazoxide unresponsive congenital hyperinsulinism.

### *Genetics and Endocrinology*

With improved identification of the genetic basis of many rare disorders, diagnostic pathways are changing rapidly, and treatment options and genetic counselling is improving. A rare disease is defined in the European Union (EU) as a life-threatening or chronically debilitating disease that affects fewer than one individual per 2,000 of the European population; therefore, a variety of endocrine disorders are, by definition, rare. The National Clinical Programme for Rare Diseases has recently been established in Ireland to support models which improve equitable care of patients with rare diseases i.e. centres of expertise. Close collaboration between clinical geneticists and treating endocrinologists will optimise outcomes for rare conditions such as rare disorders of growth and pubertal development (e.g. Turner and Noonan syndromes, SHOX gene deficiency, Klinefelter syndrome and Prader-Willi syndrome, as well as rare adrenal, pituitary and thyroid disorders). In the future, access of Irish patients to international clinical trials in the treatment of rare disorders should be enhanced through National Clinical Programme for Rare Diseases.

### *Obesity*

Childhood obesity rates are increasing in Ireland (Layte and McCrory, 2009). Prevention of childhood obesity is a huge societal challenge and a challenge for the National Clinical Programme for Paediatrics and Neonatology. For the vast majority of affected children and families there is no underlying endocrine disorder. A small number of patients with obesity secondary to underlying genetic aetiologies (congenital leptin deficiencies, MC4R mutations), syndromes (Prader-Willi syndrome) or as a complication of pituitary pathology (e.g. late effects of childhood cancer, craniopharyngioma) will require endocrine related care. Some morbidly obese children and adolescents will also require endocrine co-management of obesity-related complications/secondary morbidities (insulin resistance and type 2 diabetes).

### *Transition from Paediatric to Adult Endocrinology*

Many endocrinology patients have lifelong complex needs. Seamless transition of care to adult endocrinology services is fundamental for positive outcomes. The approximately 100 children who are diagnosed with cancer each year in Ireland require chemotherapy and radiotherapy that carries high risk of late endocrine effects. Improved survival means that endocrinology follow-ups of these children through childhood and adolescence are required. Approximately 50 children require neurosurgery annually for conditions likely to disrupt hypothalamic pituitary function (suprasellar tumours, craniopharyngiomas) and these patients require both short-term and long-term endocrine care. Other endocrine disorders which predictably require adult transition include adolescents with disorders of sex development, congenital adrenal hyperplasia, Prader-Willi Syndrome, and Turner Syndrome. Some rare conditions are managed in subspecialty clinics within dedicated adult centres e.g. pituitary disorders in Beaumont Hospital. Therefore, it is essential that paediatric and adult endocrinologists work together in order to ensure smooth and appropriate transition of complex paediatric endocrine patients to adult services. Recommendations for the transition between the paediatric and adult diabetes services are described in 'Transition from paediatric to young adult diabetes care' (due to be published in late 2015). Many of the concepts described in the document are relevant to transition of endocrine patients.

### *The Endocrinology Team Members*

Endocrinology services are predominantly consultant delivered. Significant investment in consultant numbers is required for future care delivery. Trained endocrine clinical nurse specialists (CNSs) are pivotal members of the multidisciplinary team (MDT), undertaking safe dynamic function testing and following up results, liaising with families and providing psychosocial support and education for a variety of complex disorders (such as stress dosing during intercurrent illness in children with steroid insufficiencies, education in management of diabetes insipidus post neurosurgery). Children with specific endocrine diagnoses also require input from health and social care professionals. Infants with congenital hyperinsulinism and severe hypoglycaemia require dietetic support for tailored extra carbohydrate feeds. Families who have infants born with disorders of sexual development need psychological support at diagnosis, as well as throughout childhood and adolescence. Access to these skill sets within the endocrine MDT is critical in order to deliver high-quality outcomes.

## **23.0.2 Paediatric Diabetes in Ireland**

A detailed model of care for all children with type 1 diabetes in Ireland has been developed along with a specific model of care for the provision of continuous subcutaneous insulin infusion for the treatment of Type 1 diabetes in the under-five years age group. The latter was developed to address the recognised challenges in managing toddler diabetes.

### *Diabetes Epidemiology and Outcomes*

T1DM is a lifelong condition which usually presents in childhood. The condition is characterised by the autoimmune-mediated destruction of the pancreatic beta cells, leading to a requirement for the lifelong provision of exogenous insulin, either as multiple daily injections or subcutaneous infusion via insulin pump. The prevalence of this condition varies between countries, with the highest in Finland (>40 per 100,000) and Sardinia (37.8 per 100,000), and the lowest in Asian countries (Borchers, Uibo and Gershwin, 2010). Ireland is an area of high incidence of childhood T1DM (27.5/100,000/year), and data from the Irish National Childhood Diabetes Register recently reported that the incidence of T1DM is rising by 5% per annum (Roche, 2014).

Optimal glycaemic control is the key to reducing associated morbidities (the Diabetes Control and Complications Trial Research Group, 1993, 1994), and all children with T1DM and their families require intensive education in order to acquire the necessary skills for appropriate self-care. Poor diabetes control is an extremely important modifiable driver of costs associated with this condition (Bachle et al., 2013). Diabetes care provided by a MDT results in fewer days in hospital, a higher level of participation in diabetes self-care practices, decreased re-admission rates, lower glycated haemoglobin (HbA1c) levels and delayed development of complications (Levetan et al., 1995; Zgibor et al., 2002).

Glycosylated haemoglobin (HbA1c) is a useful measure of glycaemic control, and the recommended target in childhood and adolescence is 7.5% (58 mmol/mol) (International Society for Pediatric and Adolescent Diabetes (Pihoker et al., 2009), National Institute for Clinical Excellence (NICE), 2004)).

Short-term complications of T1DM include hypoglycaemia (Cox et al., 1993) which can be severe, associated with seizures, coma and, rarely, death. Fear of severe hypoglycaemia can significantly affect quality of life (Barnard et al., 2010; Johnson et al., 2013a, Hawkes, McDarby and Cody, 2014). Long-term complications include retinopathy, nephropathy and cardiovascular disease, all of which are reduced with improved diabetes management and control (Donaghue et al., 2009; Nathan et al., 2005; The Diabetes Control and Complications Trial Research Group, 1993, 1994). The importance of sustained optimal glycaemic control is increasingly appreciated (Thomas, 2014). This is especially important in paediatric diabetes, where adolescents in particular require intensified resource-dependent MDT support.

Diabetes technology provides an opportunity to improve control and quality of life in selected patients, and is expanding rapidly. Continuous subcutaneous insulin infusion (CSII or 'pump therapy') is increasingly used in the paediatric population with T1DM (Johnson et al., 2013b; Shalitin and Phillip, 2008). Practically, CSII offers improved flexibility and may improve quality of life (Phillip et al., 2007; Shalitin and Phillip, 2008). Improvements in glycaemic control are noted following transition to CSII (Churchill, Ruppe, and Smaldone, 2009), with a similar frequency of hypoglycaemia (Danne et al., 2008; Jeitler et al., 2008). However, extensive education in accurate carbohydrate counting, technical skills and problem-solving (Enander et al., 2012; Mehta et al., 2009) are required in order to successfully manage CSII (Jayasekara, Munn and Lockwood, 2011). This requires significant MDT input. Providing this intensive education and support with current staffing levels is not practical, and extensive waiting lists are experienced by children for whom this treatment would represent optimal medical care. This needs to be addressed if Ireland is to provide a standard of paediatric diabetes care that is comparable with the best centres worldwide.

High-quality diabetes care is complex, and requires intensive consultant-delivered care. Current outcomes in diabetes care nationally are similar to the UK, but much poorer than in other EU countries, such as Germany, where MDTs are well resourced. Major changes are in train in the UK to improve standards of care for children with diabetes. This has required significant investment from the National Health Service (NHS). Investment in staff and information communication technology (ICT) infrastructure is required in order to provide the required standard of care.



## The Medical Journey of the Child with Diabetes

### Diagnosis

Classic symptoms of T1DM at diagnosis include increased thirst and urination. Most patients will have presented to their GP prior to diagnosis, and symptom recognition is key to early diagnosis prior to increasingly severe ketoacidosis. Up to one-third of patients have suffered a metabolic decompensation, progressing to diabetic ketoacidosis (DKA) at diagnosis; approximately one-fifth of these patients are severe cases (Oyarzabal Irigoyen et al., 2012; Rewers et al., 2008). While the outcomes of DKA are generally favourable, this condition carries a risk of cerebral oedema and death (Glaser et al., 2001; Siafarikas and O'Connell, 2010).

Following diagnosis, intensive education is provided by a MDT that includes physicians trained in diabetes care, diabetes nurses, dietitians, social workers and, ideally, psychologists. Key outcomes of this early education include skills relevant to diabetes care, management of high and low blood glucoses, insulin dose adjustment, carbohydrate counting, return to normal routine, sports and schooling, and emergency contacts (Swift, 2009). The provision of structured education is resource intensive, but central to the early empowerment of parents in caring for their child with diabetes. Daily contact with the diabetes team and frequent early follow-up is required in the initial phase post diagnosis.

### Chronic Management

This initial resource-intensive phase post diagnosis transitions to ongoing outpatient management aimed at optimising glycaemic control and quality of life. Recommendations for ongoing ambulatory care provision have been published (Pihoker et al., 2009), and these recommendations have recently been incentivised in the UK through the development of a diabetes tariff (Appendix 1). This tariff provides financial reimbursements to diabetes departments where 13 key standards are met. These standards include the provision of care by a specialist team, three monthly clinic appointments, annual dietetic appointments, and eight or more additional contacts with the MDT per year (O'Brien et al., 2014).

International recommendations are that children with T1DM should be seen every three to four months, but in a manner that is minimally disruptive to the patient. Clinic attendance ensures that diabetes care is closely monitored, is tailored to the patient's needs, and that timely screening for associated co-morbidities and complications is performed. Other aspects of the patient's care include management of psychosocial aspects of chronic illness, of growth and puberty, and of adolescent health issues (driving, contraception, alcohol and smoking).

Children and young people with poor control and HbA1C levels consistently above 9.5% (80 mmol/ mol) require additional support from their diabetes care teams to help them improve their glycaemic control, because they are at increased risk of developing diabetic ketoacidosis and long-term complications (National Institute for Health and Care Excellence (NICE), 2004).

The ability to provide care specific to children's developmental and educational stage is central to the provision of holistic and targeted specialised care. Extremely young children present challenges in hypoglycaemia unawareness, erratic carbohydrate intake and increased insulin sensitivity. School performance in older children can be affected by diabetes care (Blasetti et al., 2011; Gonder-Frederick et al., 2009), and parental fear of hypoglycaemia can be highest in this group (Hawkes et al., 2014). Poor compliance and intentional dose manipulation in adolescents are well-described challenges (Rausch et al., 2012; Schober et al., 2011). Anticipatory guidance is also important, and advice regarding upcoming life events should be provided in order to ensure that safety is maintained (Scully et al., 2014).

### *Transition to Adult Care*

Compromised compliance with medical care during transition between paediatric and adult services is well recognised in T1DM. Between 11% and 25% of patients do not follow up with adult services, and complications in patients with diabetes, such as worsening glycaemic control, and hospitalisations with DKA are common (Pacaud et al., 1996; Pacaud and Yale, 2005; Pacaud et al., 2005). Young women with poor diabetes control who have unplanned pregnancies have greatly increased risks of congenital malformations and stillbirths (Jensen et al., 2004) and this risk is very significantly reduced by tight diabetes control. This highlights the importance of ensuring that a structure is in place to transfer care to adult services from the paediatric team who have built a strong relationship with the adolescent and family over time. In this area of patient care, it is essential that adult and paediatric endocrinologists work closely together to develop models of transitional care that include overlapping of care with joint clinics for all adolescents with diabetes. Recommendations for the transition between the paediatric and adult diabetes services are described in 'Transition from paediatric to young adult diabetes'.

### *The Diabetes Team*

International best practice recommends that diabetes care is provided by a MDT with appropriate training in clinical, educational, dietetic, lifestyle, and mental health aspects of diabetes management in children (Nice, 2004). The Diabetes Expert Advisory group (HSE – Diabetes Expert Advisory Group, 2008) recommended the development of regional MDTs, each serving a minimum of 150 patients. All children and adolescents with T1DM should receive at least four outpatient appointments each year. This should be more frequent for younger children and those with poor control (Pihoker et al., 2009). International recommendations suggest a caseload per diabetes nurse specialist of between 70 and 100 patients (Paediatric Diabetes Special Interest Group, 1993) and access to a dietitian at each diabetes clinic (British Diabetic Association, 1995).

### *Current Practice and Outcomes for Children with Type 1 Diabetes in Ireland*

A recent national audit identified major deficiencies in diabetes services for children and adolescents in the Ireland (Hawkes and Murphy, 2014). In 2012, there were 287 newly diagnosed patients in 17 centres providing care for a total of 2,632 patients. Based on these figures, it is estimated that 17 new patients are diagnosed each year for every 150 established patients in the population. Currently, ambulatory paediatric diabetes care is provided in 19 centres in the Ireland. Seventeen of the 19 centres providing services to children with diabetes in Ireland supplied data to the audit. This audit highlighted discrepancies in MDT resourcing, inequitable access to paediatric diabetes dietitians, specialist nursing and consultant expertise, intervals between outpatients department (OPD) appointments, access to insulin pump therapy, screening for complications/comorbidities, rates of DKA and severe hypoglycaemia, transition to diabetes adult services and overall glycaemic control. Self-reported mean HbA1c levels nationally were well above acceptable targets. Of note, centres with consultants trained specifically in paediatric diabetes and endocrinology had significantly better outcomes. Recent data from one centre have demonstrated a significant impact on the mean HbA1c and rates of admissions with DKA after investment in dedicated paediatric diabetic MDT members (consultants, dedicated dietitian and diabetes nurse specialists).

The centre-based variability in resources and clinical outcomes identified by this audit provides a strong argument for rationalisation and regionalisation of paediatric diabetes care nationally, with inbuilt standards of care and quality assurance. Since the audit was undertaken, significant investment has been made in MDTs in several centres. The audit will be repeated shortly in order to evaluate the impact of these investments.

## 23.1 CURRENT SERVICE PROVISION

### Current Specialist Paediatric Diabetes and Endocrinology Service Overview in Ireland

#### Consultant resources

As paediatric diabetes and endocrinology is complex, and ideally consultant delivered, the number of whole-time equivalent (WTE) consultants assigned to providing this service is of crucial importance.

Currently, just 4.4 WTE consultants provide all tertiary endocrinology and diabetes services nationally, including care for 1,322 children with T1DM. All of these consultants have additional commitments (general paediatrics, adolescent transition care, academic), thus reducing their WTE availability to paediatric endocrinology and diabetes (total currently: 3.2 WTEs Dublin) (Crumlin 1.5 WTEs for endocrinology and diabetes; 1.0 WTE Temple Street; 0.7 WTE Tallaght). A 24/7 endocrine consultant on-call service is provided across the Crumlin and Temple Street sites by 2.6 WTE consultants. An out-of-hours service is also provided by one WTE consultant in Tallaght. There are two consultants with a special interest in endocrinology and diabetes in Cork (estimated 1.2 WTEs to endocrinology and diabetes). General paediatricians who have subspecialty training in endocrinology and diabetes have been appointed to Limerick (0.5 WTE), Drogheda (1.0 WTE), Mullingar (1.0 WTE) and Sligo (1.0 WTE). These consultants in regional centres were not employed specifically to provide diabetes care, but are fully trained and are delivering services to T1DM children in their catchment area, as part of their clinical commitments with limited resources.

Table 23.1: National Personnel Resource Overview (data provided November 2014)

#### Dublin

Paediatric Endocrinologists (WTE) (Crumlin, Temple Street and Tallaght)	Consultants	Specialist Registrars	Registrars	SHOs and Interns
	<b>3.2</b>	2	2	4.5
	1.5: Crumlin 1.0: Temple Street 0.7: Tallaght	1.0: Crumlin 1.0: Temple Street	2: Tallaght	2.5: SHOs 2.0: Crumlin 2.0: Tallaght 0.5: Temple Street  2.0: Interns 1.0: Temple Street 1.0: Tallaght
<b>Endocrinology Clinical Nurse Specialists (CNSs) (WTE)</b>	1.4: Crumlin 1.0: Temple Street 1.3: Tallaght (plus 0.41 Staff Nurse Tallaght)			
<b>Diabetes CNS (WTE)</b>	3.0: Crumlin 2.7: Temple Street 1.4: Tallaght			

<b>Dietitians (WTE)</b>	1.2: Crumlin 0.6: Temple Street 1.0: Tallaght
<b>Advance Nurse Practitioners</b>	0.6: ANP candidate Endocrinology Crumlin 1.0: ANP candidate Diabetes (Tallaght)
<b>Admin and Grade (WTE)</b>	2.2: Crumlin 1.0: Temple Street 1.6: Tallaght
<b>Health and social care professionals (WTE)</b>	0.9: Psychologist Crumlin 0.5: Social worker Crumlin 0.1: Senior psychiatric social worker Temple Street 0.5: Senior psychologist Temple Street 0.1: Liaison psychiatrist Temple Street 1.1: Psychologist Tallaght 0.2: Liaison Psychiatryist Tallaght 0.2: Social worker Tallaght

*Larger centres outside Dublin (Cork, Limerick, Galway, Drogheda, Sligo)*

<b>Consultants</b>  (WTE for diabetes not specified in current posts)	Cork (1.2 WTE Diabetes and Endocrinology) Limerick Sligo Drogheda Galway (locum)
<b>Endocrinology Clinical Nurse Specialists (CNSs) (WTE)</b>	0.5: Cork
<b>Diabetes CNSs (WTE)</b>	2.8: Cork 2.5: Limerick (shared with Galway) 0.5: Sligo (with posts approved and advertised to increase to 2.0 WTEs) plus 1.0 based in Letterkenny 2.0: Drogheda
<b>Dietitians (WTE)</b>	0.6: Cork 0.75: shared Limerick/Galway 0.8: Drogheda 0.2: Sligo (with posts approved to increase to 1 WTE in Sligo and based at Letterkenny) 0.5: based at Letterkenny)
<b>Advance Nurse Practitioners</b>	0: Cork 0: Limerick 0: Galway 0: Sligo
<b>Admin and Grade (WTE)</b>	1.0 : Cork
<b>Health and social care professionals (WTE)</b>	Social worker Cork – none dedicated Social worker Limerick – none dedicated 0.1: Psychologist Drogheda

Smaller centres (currently Level 1) (Letterkenny, Castlebar, Ballinasloe, Kerry, Wexford, Clonmel, Kilkenny, Waterford, Portlaoise, Cavan, Mullingar)

<p><b>Consultants</b></p> <p>Number of consultants seeing paediatric patients with diabetes as part of general paediatrics (not WTE)</p>	<p>1.0: Letterkenny 1.0: Castlebar 2.0: Ballinasloe 1.0: Kerry 2.0: Wexford 3.0: Clonmel 2.0: Kilkenny 1.0: Waterford 1.0: Portlaoise 1.0: Cavan 1.0: Mullingar 1.0: Galway</p>
<p><b>Endocrinology Clinical Nurse Specialists</b> (CNSs) (WTE)</p>	<p>None</p>
<p><b>Diabetes CNSs</b> (WTE)</p>	<p>0.8 Paediatric nurses, 0.03 Adult nurses: Letterkenny 0.2 Paediatric nurses, 0.1 Adult Nurses: Castlebar 0.3 Paediatric nurses, 0.1 Adult Nurses: Ballinasloe Kerry – no data supplied; 0 Paediatric Diabetes nurse 1.0 Paediatric nurse; Wexford 0 Paediatric nurses, 0.2 Adult Nurses: Clonmel 0.5 Paediatric nurses, 0.3 Adult nurses: Kilkenny Waterford – no data supplied 0.3 Paediatric nurses, 0.1 Adult nurses: Portlaoise 0.2 Paediatric nurses, 0.1 Adult nurses: Cavan 0 Paediatric nurses, 0.2 Adult nurses: Mullingar</p>
<p><b>Dietitians</b> (WTE)</p>	<p>0.25: Letterkenny 0.1: Castlebar 0.1: Ballinasloe Kerry – no data supplied Wexford – no data supplied 0.2: Clonmel 0.3: Kilkenny Waterford – no data supplied 0.1: Portlaoise 0.1: Cavan 0: Mullingar</p>
<p><b>Advance nurse practitioners</b></p>	<p>None</p>
<p><b>Admin and Grade</b> (WTE)</p>	<p>0 dedicated</p>
<p><b>Health and social care professionals</b> (WTE)</p>	<p>0 dedicated</p>

## 23.2 PROPOSED MODEL OF CARE

### 23.2.1 Infrastructural Recommendations

#### *Regionalisation of Specialised Care*

In order to provide appropriate levels of care at appropriately equipped centres, three different levels of care are proposed. In keeping with the Review of Paediatric and Neonatal Services and Framework for Future Development (HSE – Clinical Strategy and Programmes Directorate and Royal College of Physicians of Ireland, 2013), children and their families deserve access to the highest standard of care as close as possible to home. Currently, there is variation in standards of diabetes care and inequity of access to insulin pump therapy throughout Ireland, but recent investment in services in Limerick, Drogheda and Galway and the Northwest is welcome. In order to maintain the required standards and expertise, and also in order to justify the employment of appropriately trained team members, it is proposed that a diabetes centre should have at least 150 paediatric patients with T1DM. All hospitals providing acute paediatric care will have staff trained in the acute care of newly diagnosed diabetes, and will treat DKA in line with international guidelines. Children whose diabetes is diagnosed in Level 1 hospitals that do not have access to a paediatrician with endocrinology training will be referred to their nearest diabetes MDT once they have been stabilised in accordance with local agreed guidelines. Children with known T1DM and mild intercurrent illness may be managed in their local hospital in conjunction with their local diabetes MDT, as appropriate.

Given the high cost of many endocrine medications, it is proposed that all patients should be evaluated by a trained paediatric endocrinologist prior to commencing therapy with growth hormone or GnRH analogues.

Table 23.2: Levels of care

Care description	Conditions managed	Required resources
Level 1 Endocrinology (General paediatrics only)	Conditions with a low level of anticipated need for specialised services, e.g. familial short and tall stature, vitamin D deficiency, hypothyroidism follow-up. Acute care of children with diabetes who present with new diagnosis or intercurrent illness	General paediatrician. Current outpatient diabetes workload to be coordinated with regional MDT.
Level 2 Endocrinology (Regional Endocrine and Specialised Diabetes (IPU) service)	Conditions that require input from a paediatrician with subspecialty training in paediatric endocrinology and diabetes. Safe endocrine testing appropriate to the facilities and staffing available.	Consultant paediatrician with subspecialty training in diabetes and endocrinology (supported by MDT for > 150 children with diabetes) and regional endocrinology service.
Level 3 Endocrinology (tertiary service)	National service for rare, complex diabetes and endocrine disorders.	Consultant paediatric endocrinologists supported by full diabetes and endocrinology MDT in each centre. Out-of-hours on-call service.

### *Information Technology Infrastructure*

The availability of data on patient numbers and outcomes is central to the planning and provision, and continuous audit, of appropriately resourced centres and the highest quality of care. Examples of benefits of the Electronic Medical Record (EMR) in improving patient care include the Vermont Oxford Network in neonatology (Soll et al., 2013), where outcomes and effects of interventions can be tracked. EMR also allows for benchmarking of outcomes and the subsequent investigation of possible differences between centres that may account for improved outcomes. Neonatal centres in Ireland are already contributing to this international network. Similar networks are also in place internationally in paediatric diabetes (Gerard-Gonzalez et al., 2013; Miller et al., 2013). Ireland falls far behind in terms of structured IT systems in general, with a lack of integration of radiological and laboratory systems across many paediatric units, which leads to loss of time, loss of efficiency, and can pose a clinical risk.

Data collection is a time-consuming process. Ideally, data should be collected prospectively using a national data management system funded by the HSE and supported by its governance structures, which would be integrated to daily clinical practice across all centres. Data management would contribute positively to workflow, benchmarking and outcomes in paediatric diabetes.

A data management system in paediatric endocrinology would also allow for the tracking of rare diseases in the Irish population, and would provide information on how we can improve and plan services for these conditions. A specific ICT project to capture data on diagnosis and management of congenital hypothyroidism in Ireland, which occurs in approximately one in 3,000 live births (time to diagnosis, time to starting treatment and outcomes), would facilitate quality assurance of this national programme.

## **23.2.2 Staffing Recommendations**

### *Staff and Facilities Required*

#### *Staff*

Based on normative standards adopted in the UK (National Health Service, 2013), nine consultants are required for the new children's hospital, in order to deliver tertiary services nationally and integrated diabetes services for Leinster. Three consultants are required for Cork, in order to provide endocrinology and diabetes services for the Southwest and integrated Level 2 diabetes services for Kerry and Clonmel. An additional seven teams are required in order to provide regional diabetes and endocrinology services (based on the number of children with T1DM nationally) as detailed in Table 4.

#### *Facilities*

Inpatients with severe hypoglycaemia require accurate point-of-care capillary blood glucose testing at ward level, using Yellow Springs instrument (YSI) equipment and interval profiling, as well as safe fasting studies to ensure that normoglycaemia is maintained. Paediatric anaesthesia and surgical support is often required for the establishment of central venous access in these patients, and phlebotomy is required so as to ensure that critical diagnostic testing is obtained at the time of hypoglycaemia. Children who require modified feeds need access to specialised paediatric dietetic services.

Endocrine dynamic testing is central to diagnosing many endocrinopathies. Safe diagnostic dynamic testing requires well-trained, experienced staff using standardised testing guidelines (Appendix 1). Such testing is usually possible as a day case admission, but requires dedicated staff, beds and adequate throughput in order to maintain

skills and provide a safe and high-quality service. In tertiary services, endocrine clinical nurse specialists undertake dynamic testing with consultant support. Regional centres require pro rata endocrine CNS support in order to undertake accurate auxology and endocrine testing, and also in order to support data collection.

*The main diagnostic and monitoring methods utilised in paediatric endocrinology include:*

- longitudinal assessment of growth and puberty
- specific, individually based stimulation tests (e.g. insulin tolerance, glucagon stimulation, LHRH stimulation, thyrotropin releasing hormone (TRH) stimulation, Synacthen, HCG stimulation)
- controlled diagnostic fasting studies and critical (hypoglycaemia) sampling
- water deprivation tests
- multiple blood sampling for hormone levels
- bone biomarkers
- appropriate genetic tests
- specialist imaging (including plain x-rays, ultrasound scanning, computerised tomography (CT)/magnetic resonance imaging (MRI) scan, DXA scans)

At present, samples are processed in a wide variety of laboratories, many with different sample and volume requirements and different costs. There is an urgent need to standardise paediatric endocrine testing in order to simplify processing, standardise units and reference ranges, and also in order to ensure high quality and value for money.

After initial diagnosis, and with parent education and support, many children with complex conditions are managed as outpatients, e.g. children with congenital adrenal hyperplasia with blood capillary profiles and children with diabetes insipidus managed with home refractometers. Shared care arrangements and protocols should be employed.

## 23.3 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION OF MODEL OF CARE

### 23.3.1 Gap Analysis and Requirements to Deliver Service

#### *Diabetes*

Normative data from the UK and Europe have recommended as a minimum that 0.5 WTE consultants with postgraduate training and CME in diabetes, supported by an appropriate MDT, are required in order to provide high-quality standardised care for a cohort of at least 150 children with diabetes. Irish data show that there are currently 2,800 children under 16 years with T1DM. Therefore, 18.6 MDTs are required nationally, with each team managing a cohort of 150 children with T1DM (600 appointments/year) as per international standards; nine MDTs in Dublin/Leinster, three teams in Cork and 6.5 other teams distributed across regional units. National audit data suggest two teams for the West, (Galway, Castlebar and Ballinasloe provide care for nearly 300 children with diabetes); one MDT in Northwest (Sligo with pump service for Letterkenny and a consultant who has a special interest in diabetes based at Letterkenny); one team in the Northeast, and one team in the Midwest. Given that there are approximately 200 children with T1DM in the Southeast, it is proposed that a centre with a MDT based in Waterford University Hospital be established – although it is acknowledged that this will cross hospital group



lines. The Northwest (Sligo/Letterkenny) is recognised as being a “special case”, given the remote geographical location of Letterkenny. Services for children with diabetes in Letterkenny will be coordinated with Sligo, and will require a greater pro rata MDT resource allocation in order to facilitate a high-quality service across two sites in conjunction with a general paediatrician who has an interest in diabetes and who is based in Letterkenny.

### Endocrinology

It is more difficult to establish accurate data on demands for endocrinology services in the absence of a national database. Waiting time for routine appointments is currently seven months in Crumlin; seven months in Temple Street, and six to eight months in Cork University Hospital, with clinics constantly overbooked due to urgent referrals. Census 2011 reports show that Ireland has a population of 979,590 children aged 0-14 years, and an additional 580,250 individuals aged between 15 years and 25 years. Therefore, there are at least 1 million children (aged <16 years) in Ireland. Census projections are for an increase in the childhood population over the next five years, and most of this projected increase will be in Leinster. Census 2011 reports show a 76% increase in pre-schoolers in the Fingal catchment area. International data (Children’s Hospital of Philadelphia) have determined that 45 minutes is required for each new patient consultation and 25 minutes is required for each follow-up consultation. Therefore, one full day for each consultant endocrinologist will deliver 675 appointments per year (comprising three new patients x 45 minutes, 12 returns x 25 minutes over a standard 45-week working year). An additional 225 appointments can be managed with co-attendance by NCHDs (x five (supervised) appointments per week), thus giving a potential total of 900 appointments per year per consultant. Follow-up of investigation results for these OPD referrals requires 0.5 days per week. Ward rounds, consults, attendance at the emergency department (ED) requires 0.2 WTEs (or one day per week distributed over the week). As per the Royal College of Paediatrics and Child Health guidelines and Ireland’s national continuing professional development (CPD) requirements, a further 0.5 day/week is required in order to fulfil continuing medical education requirements, audit preparation, and development of local and national protocols.

### Configuration of Consultant Posts

In regional centres, consultants with a special interest in paediatric endocrinology and diabetes will be responsible for both endocrinology care and for leading a team delivering high-quality, standardised care to 150 children with T1DM. In the new children’s hospital, paediatric endocrinologists will have a full-time commitment to diabetes and endocrinology, as the caseload requires out-of-hours, on-call cover for the endocrinology/diabetes service. In regional services, those with a special interest in paediatric diabetes and endocrinology would remain on the general on-call rota, but may have a reduced general paediatric commitment in centres where the diabetes and endocrinology commitment requires more than 0.5 WTEs.

Table 23.3: Suggested time allocation for consultants

Level 3 Diabetes and Endocrinology – plus Endocrinology on-call service

Day	Mon (14 appts/week)	Tues	Wed (20/week appts/week)	Thurs	Fri
am	Diabetes clinic	Diabetes MDT/ family meetings	Endocrine clinic	Wards Rounds/ ED/Consults/ Dynamic testing	CME/ Audit/ Guidelines
pm	Diabetes clinic	Diabetes administration	Endocrine clinic	Ward rounds/ ED/Consults/ Dynamic testing	Endocrine administration/ results follow-up

Level 2 Diabetes and Endocrinology plus General Paediatrics on call service

Day	Mon (14 appts/week)	Tues	Wed	Thurs	Fri
am	Diabetes clinic	Diabetes MDT/ family meetings	Level 2 Endocrinology clinic	General Paediatrics	CME/Audit/ Guidelines
pm	Diabetes clinic	Diabetes administration	General Paediatrics	General Paediatrics	General Paediatrics

Table 23.4: Current patient numbers, resources and gap analysis

Service description	Number of patients with diabetes	Number of teams required	Current resources	Gap analysis
National Level 3 Tertiary Endocrine/ Diabetes services to be provided at: new children's hospital (Crumlin/ Temple Street/ Tallaght)  Plus all Level 2 regional services for Dublin including Level 2 regional diabetes service for Portlaoise, Mullingar (in/ outreach)	1,322 (485 + 330 + 347 + 53 + 107)	8.8 teams 8.8 Consultants 3 SpRs 8.8 Admin/Data management 17.6 DNS 8.8 Endo CNS 8.8 Dietitians 6 Psychologists 4.5 Social workers	3.2 Consultants 2.0 SpRs 3.8 Admin/Data management 7.6 DNS 4.7 Endo CNS 2.3 Dietitians 2.5 Psychologists 1 Social worker	5.6 consultants 1.0 SpR 5 Admin/Data management 10 DNS 4.1 Endo CNS 6.5 Dietitians 3.5 Psychologists 3.5 Social worker
South/Southwest Regional Diabetes and Endocrinology services for Cork and catchment and regional Diabetes service for Kerry General Hospital and Clonmel	454 (375 + 39 + 36)	3 teams 3 Consultants 1 SpR 6 DNS 2 Endo CNS 3 Dietitians 3 Admin/data management 2 Psychologists 2 Social workers	2 Consultants 0.25 SpR/0.75Reg 2.8 DNS 0.5 Endo CNS 1 Dietitian 1 Admin/data management 0 Psychologist 0 Social worker	1 Consultant 0.75 SpR 3.2 DNS 1.5 Endo CNS 2 Dietitians 2.0 Admin/data management 2 Psychologists 2 Social workers

Service description	Number of patients with diabetes	Number of teams required	Current resources	Gap analysis
Southeast Regional Diabetes and Endocrinology services for Kilkenny, Waterford and Wexford	203 (71 + 74 + 58)	1.35 teams 1.35 Consultants 2.7 PDNS 0.67 Endo CNS 1.35 Dietitian 1.35 Admin/data management 0.67 Psychologist 0.67 Social worker	0.3 Consultants 1 PDNS 0 Endo CNS 0.2 Dietitian 0 Admin/data management 0 Psychologist 0 Social worker	1.05 Consultants 1.7 PDNS 0.67 Endo CNS 1.15 Dietitian 1.35 Admin/ data management 0.67 Psychologist 0.67 Social worker
Northeast Regional Diabetes and Endocrinology services for Cavan and Drogheda	171 (128 + 43)	1.14 teams 1.14 Consultants 2.28 DNS 0.57 Endo CNS 1.14 Dietitian 1.14 Admin/data management 0.57 Psychologist 0.57 Social worker	1 Consultant 1.4 DNS 0 0.8 Dietitian 1.0 Admin/data management 0.1 Psychologist 0 Social worker	0.14 Consultants 0.88 0.57 0.34 Dietitian 0.14 Admin/data management 0.47 Psychologist 0.57 Social worker
Mid-west Regional Diabetes/ Endo services to patients in Limerick	185	1.23 teams 1.23 Consultants 2.5 DNS 0.61 Endo CNS 1.23 Dietitians 1.23 Admin/data management 0.61 Psychologist 0.61 Social worker	0.5 Consultants 2.5 DNS 0 Endo CNS 0.75 Dietitians 0 Admin/data management 0 Psychologist 0 Social worker	0.73 Consultants 0.0 DNS 0.61 Endo CNS 0.48 Dietitians 1.23 Admin/data management 0.61 Psychologist 0.61 Social worker
West Regional Diabetes/ Endo services to patients of UCHG (Galway), incorporating services to Portiuncula and Mayo General Hospital	277 (140 + 61 + 76)	1.85 teams 1.85 Consultants 3.69 DNS 0.92 Endocrine CNS 1.85 Dietitians 1.85 Admin/data management 0.92 Psychologists 0.92 Social workers	Unclear what resources are available currently	

Service description	Number of patients with diabetes	Number of teams required	Current resources	Gap analysis
Northwest Regional Diabetes/ Endo services to patients of Sligo incorporating outreach services to Letterkenny (supporting General Paediatrician with special interest in Letterkenny)	200 (80 + 120)	1.33 teams 1.33 Consultants 3* PDNS 0.67 Endo CNS 1.5* Dietitian 1.33 Admin/data management 0.67 Psychologist 0.67 Social worker	1 Consultant 0.5 PDNS 0 Endo CNS 0.2 Dietitian 0 Admin/data management 0 0	0.33 Consultant 2.5 PDNS 0.67 Endo CNS 1.3 Dietitian 1.33 Admin/data management 0.67 Psychologist 0.67 Social worker

\* Additional resource allocated to the Northwest, as service is provided across two sites. Of the three DNS, 1 WTE will be allocated to Letterkenny. Of the 1.5 dietitians, 0.5 WTEs will be allocated to Letterkenny.

### 23.3.2 Recommendations in the Context of the Proposed New Children’s Hospital

#### *The Endocrinology Department at the New Children’s Hospital and Intra-Specialty Subspecialisation*

To deliver a high-quality service would require a minimum of nine teams (each covering diabetes and endocrinology) with dedicated MDT support including clinical nurse specialists, specialists in congenital hyperinsulinism, metabolic bone health, dietetics, social work and clinical psychology. Each team would provide care for 150 children with T1DM, in addition to a specialty lead in one of eight subspecialties of paediatric endocrinology (listed below) at the new children’s hospital and one team providing care for children in the Midlands area. The subspecialty teams would support general paediatrics and interface with primary care.

1. Diabetes – T1DM, complex diabetes (mitochondrial, neonatal, monogenic syndromic, CFRD, Type 2 Diabetes)
2. Neonatal endocrinology, hyperinsulinism and hypoglycaemia
3. Disorders of sex development, CAH and adrenal disorders
4. Disorders of the pituitary, hypothalamus and central nervous system (including disorders of salt and water balance, neurosurgical liaison, oncology and late effects of childhood cancer)
5. Paediatric bone health and disorders of calcium homeostasis
6. Disordered puberty and reproductive endocrinology
7. Complex and rare growth disorders, including syndromes with endocrine features
8. Complex thyroid disorders

#### *The Endocrine Department at Regional Centres*

To deliver a high-quality integrated regional service would require an additional nine teams across Ireland. Each team would provide care for 150 children with T1DM, in addition to providing a regional endocrine service supporting general paediatrics and interfacing with primary care regionally. In-reach and outreach clinics with the new children’s hospital would enable individual consultants to maintain skills and lead on subspecialty areas of interest.

### *Education, Training and Continuing Professional Development*

All consultants delivering specialised diabetes and endocrine care require specific training in paediatric endocrinology; these consultants are also required by Medical Council rules to maintain CPD. Development of a structured 2-3 year fellowship programme that accepts specialist registrar trainees in paediatric endocrinology at various stages in their training is currently being explored. The availability of such a programme would ensure that services attract and retain high-calibre trainees. In the future, higher specialist training can be facilitated within the framework of the National Clinical Programme for Medical Education and Training and the Royal College of Physicians of Ireland.

The provision of advanced nurse practitioner training in diabetes and endocrinology should also be considered a priority for the new children's hospital.

### *Research*

The development of research in paediatric endocrinology is key to the progression of the specialty nationally and internationally. All paediatric endocrinology consultants currently practising in Ireland are well published, but, in many instances, consultants' workload burden has not facilitated ongoing active research. Following the development of the new children's hospital and its regional networks nationally, there will be potential to further enhance care for children with endocrine disorders worldwide through research. Ireland has the potential to establish itself as a significant contributor to the body of research on this area; this would improve training opportunities for higher specialist trainees, MD and PhD students (clinicians and scientists), and would also help attract and retain local and international fellows, thereby improving both clinical outcomes and academic output. Exchange programmes with international centres for Irish fellows wishing to train in specific areas within paediatric endocrinology would also ensure that a level of expertise is ultimately brought back to Ireland.

### *Patient/Family Experience of the Service*

Standardised electronic questionnaires and patient feedback should be integrated with patient care. Complaints, as well as positive and negative outcomes, should be discussed openly in the setting of a quarterly national morbidity and mortality meeting. In order to utilise this meeting to improve national care, all centres should participate (with video-link facilities when necessary).

## **23.4 PRIORITIES FOR IMPLEMENTATION OF THIS MODEL OF CARE**

### **23.4.1 Resource Provision**

Paediatric services in Ireland are currently in a period of transition, with the development of the new children's hospital and regional integration already underway.

#### *New children's hospital*

As part of the preparations for the development of the new children's hospital, it is recommended that the existing services are better aligned with shared management guidelines. Complex neonatal, PICU and tertiary inpatient work is currently delivered in two sites (Crumlin and Temple Street). Outpatient care is delivered in Crumlin, Temple Street and Tallaght hospitals. MDT resources should be aligned to activity and complexity of patient care, and some resources may need to be consolidated prior to moving to the new children's hospital. The gap analysis outlined in Section 2 should be used to determine where resources are required.

Current patient numbers grossly exceed international norms. Patient journeys are complex and are associated with significant risk in several subspecialty areas, e.g. acute neurosurgery in Temple Street and Beaumont often requiring support out of hours, in addition to transfer to neuro-oncology follow-up in Crumlin. A 24/7 on-call rota is provided by 2.6 WTE consultants, which is unsustainable. There is an urgent need to expand consultant numbers in Crumlin and Temple Street as a priority, in order to provide safe, high-quality care.

### 23.4.2 Regional Centres

As outlined in the Section 2 Gap Analysis, paediatric endocrinology in Cork should be adequately resourced, in order to provide care for patients in the Southwest region: the requirement here would be for three teams. The development of six other regional teams should also be implemented: these should comprise two teams in Galway, one in the Northeast (Drogheda and Cavan), one in the Midwest (Limerick), and one in the Northwest (working with a consultant in Letterkenny who has an interest in diabetes). It is further recommended that a team is developed in the Southeast; this team would be based in Waterford.

### 23.4.3 Endocrine Testing Procedures and Laboratories

More commonly used tests such as glucose; TSH, free T<sub>4</sub>, cortisol, gonadotropins, oestradiol and testosterone are available in the majority of hospitals. However, there is widespread variation in requirements with respect to sample type and minimally acceptable volumes, in addition to assay types used.

*Anticipated challenges that need to be addressed include:*

- Increased turnaround time leading to delays in diagnosis can be anticipated when samples are sent abroad (e.g. sending insulin samples to the UK may delay confirmation of a diagnosis of congenital hyperinsulinism). This risk may be mitigated where local (national) laboratories can deliver quality-assured results on paediatric sample sizes in a defined timeframe.
- A national policy to streamline endocrine testing – both basal and dynamic. This would result in generating a critical mass of samples, which may justify analysis in dedicated centres. Crumlin and Temple Street have already arranged that the quarterly CAH clinics are timed to take place the same week, so that the laboratory tests (17O HP profiles, renins, androgens) can be batched, thus resulting in much shorter turnaround times for patients.
- Lack of sensitivity of some assays currently used in adult centres for paediatric patients (e.g. a measurable oestradiol outside of the adult pubertal range may be highly significant in a young child).
- A need to standardise units. For example, GH expressed as mU/L and µg/L, insulin expressed as µg/L or pmol/L. There is an absence of reference ranges for some analytes specific to paediatric age, gender and pubertal stage.

## 23.5 PROGRAMME METRICS AND EVALUATION

- Accurate, validated data are key to establishing patient numbers and, therefore, appropriate resources would need to be allocated, so as to ensure the collection of such data. The incidence of T<sub>1</sub>DM is increasing at a rate of 5% per annum, and thus it is likely that incremental increases in staffing will be required in order to maintain MDT ratios. ICT investment is also required, so as to facilitate regular auditing. All MDT members have responsibility for contributing to the collection of accurate audit data.

- Regular national audit of process of diabetes service delivery
  - structured education from diagnosis
  - frequency of clinic appointments
  - frequency of HbA<sub>1c</sub> checks and numbers in target
  - comorbidity screening
  - re-admission rates
- Regular audit of DKA management
  - incidence
  - adherence to best practice management guidelines
- Time from receipt of an endocrine referral to OPD assessment
- Number of patients waiting longer than 16 weeks for an endocrine OPD appointment
- Time from decision to performing endocrine testing to receipt of results
- Time to starting thyroxine in infants with positive newborn screening for congenital hypothyroidism
- Patient and family experience of the service

## 23.6 SUMMARY

Paediatric endocrinology and diabetes is a rapidly expanding subspecialty of paediatrics, encompassing a wide variety of acute, chronic, common and rare endocrine disorders. Type 1 diabetes forms a significant component of the workload (i.e. patients seen), with well-established, evidence-based international recommendations on the structure of the MDT delivery of care, in line with the Paediatric Diabetes Model of Care. Other paediatric endocrine disorders form a more heterogeneous group covering a spectrum of relatively common and extremely rare conditions. Advancing knowledge on the genetic, epigenetic and environmental basis of these disorders is expanding, with increasing improvements in the treatment and outcomes of a range of conditions. If the requisite supports and structures outlined in this report are put in place, then paediatric, paediatric endocrinology in Ireland could be world class: our young patients deserve nothing less.

## 23.7 KEY RECOMMENDATIONS

- Increase the medical, nursing, dietetic, and health and social care professional staffing of the multidisciplinary team providing diabetes and endocrinology care.
- In the new children's hospital, develop designated lead clinicians in each of eight subspecialties of paediatric endocrinology, as outlined in this chapter.
- Provide data management and IT resources, in order to track clinical activities and facilitate electronic interface capability.
- Prioritise timely access to paediatric endocrinology diagnostics.
- Provide adequate space and environment, in order to deliver ambulatory and inpatient tertiary endocrinology services at the new children's hospital and in regional centres.
- Implement national standards for paediatric diabetes care.
- Develop curricula for multidisciplinary postgraduate training in endocrinology in Ireland.

## 23.8 ABBREVIATIONS AND ACRONYMS

CHI	congenital hyperinsulinism	MDT	multidisciplinary team
CME	continuing medical education	NCH	new children's hospital
CNS	clinical nurse specialist	NCHD	non-consultant hospital doctor
CPD	continuing professional development	NHS	National Health Service
CSII	continuous subcutaneous insulin infusion	PICU	paediatric intensive care unit
DKA	diabetic ketoacidosis	T1DM	type 1 diabetes mellitus
EMR	electronic medical record	UK	United Kingdom
HbA1c	glycated haemoglobin	YSI	Yellow Springs instrument
IT	information technology		

## 23.9 APPENDICES

### Appendix 1: NHS Best Practice for Paediatric Diabetes Guidelines (Tariff)

#### *National Health Service best practice for paediatric diabetes guidelines*

Every child cared for by specialist team<sup>1</sup>

Consultant/specialist with BSPED<sup>2</sup> training; paediatric nurse with RCN<sup>4</sup> diabetes training; paediatric dietitian with paediatric diabetes training

Newly diagnosed patient should be discussed with team within 24 hours, and be seen by senior member of team on next working day

Structured education programme at diagnosis, with follow-ups as needed

Four clinic appointments offered annually

HbA1c checked four times annually, with result available at every clinic

Offered dietitian appointment annually

At least eight additional contacts<sup>5</sup> per year by the team

Annual review as per NICE<sup>3</sup> guidelines

Annual psychological assessment and service access provided as needed

24-hour advice to emergency management for family and health professionals

Partake in National Paediatric Diabetes Audit; attend local Paediatric Diabetes Network meetings; have a clear policy for transition to adults services

Clear policy for high HbA1cs and persistent DNAs<sup>6</sup>

<sup>1</sup> Consisting of a doctor, nurse and dietitian, as a minimum, with specific training in paediatric diabetes;

<sup>2</sup> British Society for Paediatric Endocrinology and Diabetes

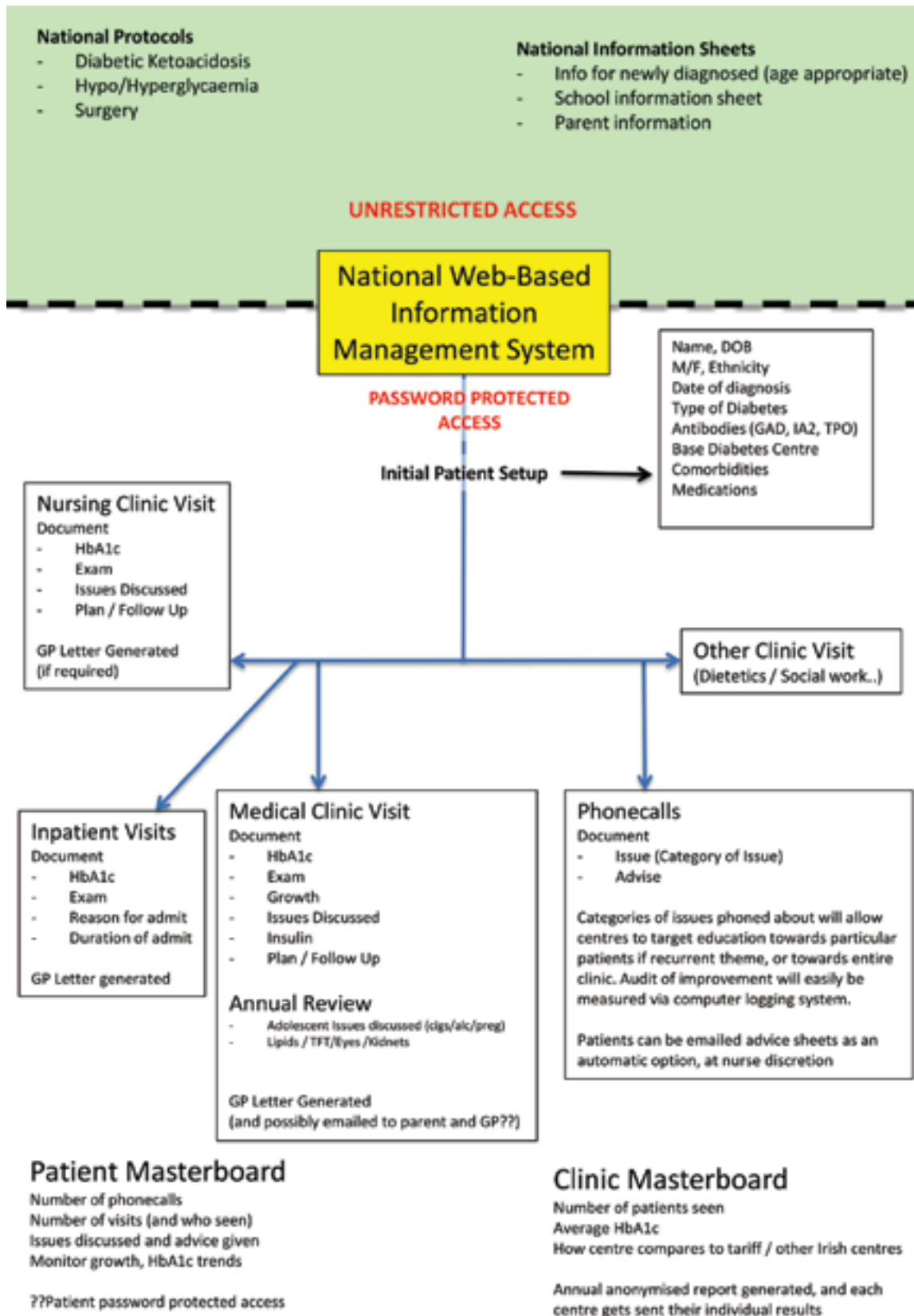
<sup>3</sup> National Institute of Health and Clinical Excellence

<sup>4</sup> Royal College of Nursing

<sup>5</sup> Such as phone calls, emails, school visits



## Appendix 2: Outline of Proposed Data Management System



## Appendix 3

### Endocrine Testing Protocols

Diabetes and Endocrinology Centre and Departments of Clinical Biochemistry  
The Children's University Hospital, Temple Street and Our Lady's Children's Hospital, Crumlin

July 2008

#### Preliminary requirements which apply to all tests:

1. Consent form signed by parents
2. Patient admitted by doctor
3. Patient weighed and dose calculated
4. Medication ordered from pharmacy
5. IV sheet signed by doctor

## 23.10 REFERENCES

Bachle, C., Icks, A., Strassburger, K., Flechtner-Mors, M., Hungele, A., Beyer, P. et al. (2013) 'Direct diabetes-related costs in young patients with early-onset, long-lasting type 1 diabetes' PLoS One, 8(8), e70567.

Barnard, K., Thomas, S., Royle, P., Noyes, K. and Waugh, N. (2010) 'Fear of hypoglycaemia in parents of young children with type 1 diabetes: a systematic review' BMC Pediatr, 10, 50.

Blasetti, A., Chiuri, R.M., Tocco, A.M., Di Giulio, C., Mattei, P.A., Ballone, E. et al. (2011). 'The effect of recurrent severe hypoglycemia on cognitive performance in children with type 1 diabetes: a meta-analysis' J Child Neurol, 26(11), 1383-1391.

Borchers, A.T., Uibo, R. and Gershwin, M.E. (2010) 'The geoepidemiology of type 1 diabetes' Autoimmun Rev, 9(5), A355-365.

British Diabetic Association. The principles of good practice for the care of young people with diabetes. London: British Diabetic Association, 1995.

Churchill, J.N., Ruppe, R.L. and Smaldone, A. (2009) 'Use of continuous insulin infusion pumps in young children with type 1 diabetes: a systematic review' J Pediatr Health Care, 23(3), 173-179.

Cox, D.J., Gonder-Frederick, L., Antoun, B., Cryer, P.E. and Clarke, W.L. (1993) 'Perceived symptoms in the recognition of hypoglycemia' Diabetes Care, 16(2), 519-527.

Danne, T., Battelino, T., Jarosz-Chobot, P., Kordonouri, O., Pankowska, E., Ludvigsson, J. et al. (2008) 'Establishing glycaemic control with continuous subcutaneous insulin infusion in children and adolescents with type 1 diabetes: experience of the PedPump Study in 17 countries' Diabetologia, 51(9), 1594-1601.

Donaghue, K.C., Chiarelli, F., Trotta, D., Allgrove, J. and Dahl-Jorgensen, K. (2009) 'Microvascular and macrovascular complications associated with diabetes in children and adolescents' Pediatr Diabetes, 10 Suppl 12, 195-203.

Edge, J., Ackland, F.M., Payne, S., McAuley, A., Hind, E. and Burren, C. et al. (2012) 'Inpatient care for children with diabetes: are standards being met?' *Arch Dis Child*, 97(7), 599-603.

Enander, R., Gundevall, C., Stromgren, A., Chaplin, J. and Hanas, R. (2012) 'Carbohydrate counting with a bolus calculator improves post-prandial blood glucose levels in children and adolescents with type 1 diabetes using insulin pumps' *Pediatr Diabetes*, 13(7), 545-551.

Gerard-Gonzalez, A., Gitelman, S.E., Cheng, P., Dubose, S.N., Miller, K.M. and Olson, B.A. et al. (2013) 'Comparison of autoantibody-positive and autoantibody-negative pediatric participants enrolled in the T1D Exchange clinic registry' *J Diabetes*, 5(2), 216-223.

Glaser, N., Barnett, P., McCaslin, I., Nelson, D., Trainor, J., Louie, J. et al. (2001) 'Risk factors for cerebral edema in children with diabetic ketoacidosis' *The Pediatric Emergency Medicine Collaborative Research Committee of the American Academy of Pediatrics. N Engl J Med*, 344(4), 264-269.

Gonder-Frederick, L.A., Zrebiec, J.F., Bauchowitz, A.U., Ritterband, L. M., Magee, J.C., Cox, D.J. et al. (2009) 'Cognitive function is disrupted by both hypo- and hyperglycemia in school-aged children with type 1 diabetes: a field study' *Diabetes Care*, 32(6), 1001-1006.

Hawkes, C.P., McDarby, V. and Cody, D. (2014) 'Fear of hypoglycemia in parents of children with type 1 diabetes' *J Paediatr Child Health*.

Hawkes, C.P. and Murphy, N.P. (2014) 'Paediatric type 1 diabetes in Ireland – results of the first national audit' *Ir Med J*, 107(4), 102-104.

HSE – Clinical Strategy and Programmes Directorate and Royal College of Physicians of Ireland (2013). Review of Paediatric and Neonatology Services and Framework for Future Development. Available at <http://hse.ie/eng/about/Who/clinical/natclinprog/paediatricsandneonatology/revframe13.pdf>  
Accessed 31 August 2015

HSE – Diabetes Expert Advisory Group (2008) First Report. Available at [http://www.hse.ie/eng/services/publications/topics/Diabetes/Diabetic\\_Expert\\_Advisory\\_Group\\_First\\_report\\_2008.pdf](http://www.hse.ie/eng/services/publications/topics/Diabetes/Diabetic_Expert_Advisory_Group_First_report_2008.pdf) Accessed 31 August 2015

Jayasekara, R.S., Munn, Z. and Lockwood, C. (2011) 'Effect of educational components and strategies associated with insulin pump therapy: a systematic review' *Int J Evid Based Healthc*, 9(4), 346-361.

Jeitler, K., Horvath, K., Berghold, A., Gratzner, T.W., Neeser, K., Pieber, T.R. et al. (2008) 'Continuous subcutaneous insulin infusion versus multiple daily insulin injections in patients with diabetes mellitus: systematic review and meta-analysis' *Diabetologia*, 51(6), 941-951.

Jensen, D.M., Damm, P., Moelsted-Pedersen, L., Ovesen, P., Westergaard, J.G., Moeller, M. et al. (2004) 'Outcomes in type 1 diabetic pregnancies: a nationwide, population-based study' *Diabetes Care*, 27(12), 2819-2823.

Johnson, S.R., Cooper, M.N., Davis, E.A. and Jones, T.W. (2013) 'Hypoglycaemia, fear of hypoglycaemia and quality of life in children with Type 1 diabetes and their parents' *Diabet Med*, 30(9), 1126-1131.

- Johnson, S.R., Cooper, M.N., Jones, T.W. and Davis, E.A. (2013) 'Long-term outcome of insulin pump therapy in children with type 1 diabetes assessed in a large population-based case-control study' *Diabetologia*, 56(11), 2392-2400.
- Layte, R. and McCrory, C., (2011). Growing Up in Ireland, Report 2. Department of Children and Youth affairs. Dublin. Available at [http://www.growingup.ie/fileadmin/user\\_upload/documents/Second\\_Child\\_Cohort\\_Reports/Growing\\_Up\\_in\\_Ireland\\_-\\_Overweight\\_and\\_Obesity\\_Among\\_9-Year-Olds.pdf](http://www.growingup.ie/fileadmin/user_upload/documents/Second_Child_Cohort_Reports/Growing_Up_in_Ireland_-_Overweight_and_Obesity_Among_9-Year-Olds.pdf) Accessed 31 August 2015
- Levetan, C.S., Salas, J.R., Wilets, I.F. and Zumoff, B. (1995) 'Impact of endocrine and diabetes team consultation on hospital length of stay for patients with diabetes' *Am J Med*, 99(1), 22-28.
- Mehta, S.N., Quinn, N., Volkening, L.K. and Laffel, L.M. (2009) 'Impact of carbohydrate counting on glycemic control in children with type 1 diabetes' *Diabetes Care*, 32(6), 1014-1016.
- Miller, K.M., Beck, R.W., Bergenstal, R.M., Golland, R.S., Haller, M.J., McGill, J.B. et al. (2013) 'Evidence of a strong association between frequency of self-monitoring of blood glucose and hemoglobin A1c levels in T1D exchange clinic registry participants' *Diabetes Care*, 36(7), 2009-2014.
- Nathan, D.M., Cleary, P.A., Backlund, J.Y., Genuth, S.M., Lachin, J. M., Orchard, T.J. et al. (2005) 'Intensive diabetes treatment and cardiovascular disease in patients with type 1 diabetes' *N Engl J Med*, 353(25), 2643-2653.
- National Health Service (2013) National paediatric service improvement delivery plan 2013-2018. Available at <http://sweet-project.eu/relaunch/images/NHSPublications/DiabetesService.pdf> Accessed 31 August 2015
- National Institute for Health and Care Excellence (NICE) (2004) 'Type 1 diabetes: Diagnosis and management of type 1 diabetes in children, young people and adults. from : <http://www.nice.org.uk/guidance/cg15/resources/guidance-type-1-diabetes-diagnosis-and-management-of-type-1-diabetes-in-children-young-people-and-adults-pdf>. Accessed 31 August 2013.
- O'Brien, N., McGlacken-Byrne, S.M., Hawkes, C.P. and Murphy, N.P. (2014) 'Is the UK type 1 diabetes tariff applicable in an Irish setting?' *Ir Med J*, 107, 204-207.
- Ogilvy-Stuart, A. and Midgley, P. (2006) *Practical Neonatal Endocrinology*: Cambridge University Press.
- Oyarzabal Irigoyen, M., Garcia Cuartero, B., Barrio Castellanos, R., Torres Lacruz, M., Gomez Gila, A.L. and Gonzalez Casado, I. (2012) 'Ketoacidosis at onset of type 1 diabetes mellitus in pediatric age in Spain and review of the literature' *Pediatr Endocrinol Rev*, 9(3), 669-671.
- Pacaud, D., McConnell, B., Huot, C., Aebi, C. and Yale, J. (1996) 'Transition from pediatric care to adult care for insulin-dependent diabetes patients' *Can J Diabetes Care*, 20(4), 14-20.
- Pacaud, D. and Yale, J.F. (2005) 'Exploring a black hole: Transition from paediatric to adult care services for youth with diabetes' *Paediatr Child Health*, 10(1), 31-34.

Pacaud, D., Yale, J.F., Stephure, D., Trussell, R. and Davies, H.D. (2005) 'Problems in transition from pediatric care to adult care for individuals with diabetes' *Can J Diabetes*, 29(1), 13-18.

Paediatric Diabetes Special Interest Group. The role and qualifications of the nurse specialising in paediatric diabetes. London: Royal College of Nursing of the United Kingdom, 1993.

Palladino, A.A. and Stanley, C.A. (2011) 'A specialized team approach to diagnosis and medical versus surgical treatment of infants with congenital hyperinsulinism' *Seminars in Pediatric Surgery*, 20(1), 32-37.

Phillip, M., Battelino, T., Rodriguez, H., Danne, T., Kaufman, F., European Society for Paediatric Endocrinology et al. (2007) 'Use of insulin pump therapy in the pediatric age-group: consensus statement from the European Society for Paediatric Endocrinology, the Lawson Wilkins Pediatric Endocrine Society, and the International Society for Pediatric and Adolescent Diabetes, endorsed by the American Diabetes Association and the European Association for the Study of Diabetes' *Diabetes Care*, 30(6), 1653-1662.

Pihoker, C., Forsander, G., Wolfsdorf, J. and Klingensmith, G.J. (2009) 'The delivery of ambulatory diabetes care to children and adolescents with diabetes' *Pediatric Diabetes*, 10, 58-70.

Rausch, J.R., Hood, K.K., Delamater, A., Shroff Pendley, J., Rohan, J.M., Reeves, G. et al. (2012) 'Changes in treatment adherence and glycemic control during the transition to adolescence in type 1 diabetes' *Diabetes Care*, 35(6), 1219-1224.

Rewers, A., Klingensmith, G., Davis, C., Petitti, D.B., Pihoker, C., Rodriguez, B. et al. (2008) 'Presence of diabetic ketoacidosis at diagnosis of diabetes mellitus in youth: the Search for Diabetes in Youth Study' *Pediatrics*, 121(5), e1258-1266.

Roche, E.F. (2014) 'The National Paediatric Diabetes Register and its impact on healthcare' *Ir Med J*, 107(7), 197-198.

Schober, E., Wagner, G., Berger, G., Gerber, D., Mengl, M., Sonnenstatter, S. et al. (2011) 'Prevalence of intentional under- and overdosing of insulin in children and adolescents with type 1 diabetes' *Pediatr Diabetes*, 12(7), 627-631.

Scully, D., Hawkes, C.P., McGlacken-Byrne, S.M. and Murphy, N. (2014) 'Difficulties associated with diabetes management during the Junior Certificate examination' *Ir Med J*, 107(5), 154-156.

Shalitin, S. and Phillip, M. (2008) 'The use of insulin pump therapy in the pediatric age group' *Horm Res*, 70(1), 14-21.

Siafarikas, A. and O'Connell, S. (2010) 'Type 1 diabetes in children – emergency management' *Aust Fam Physician*, 39(5), 290-293.

Soll, R.F., Edwards, E.M., Badger, G.J., Kenny, M.J., Morrow, K.A., Buzas, J.S. et al. (2013) 'Obstetric and neonatal care practices for infants 501 to 1500 g from 2000 to 2009' *Pediatrics*, 132(2), 222-228.

Steinkrauss, L., Lipman, T.H., Hendell, C.D., Gerdes, M., Thornton, P.S. and Stanley, C.A. (2005) 'Effects of Hypoglycemia on Developmental Outcome in Children With Congenital Hyperinsulinism' *Journal of Pediatric Nursing*, 20(2), 109-118.

Swift, P.G. (2009) 'Diabetes education in children and adolescents' *Pediatr Diabetes*, 10 Suppl 12, 51-57.

The Diabetes Control and Complications Trial Research Group. (1993) 'The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. The Diabetes Control and Complications Trial Research Group' *N Engl J Med*, 329(14), 977-986.

The Diabetes Control and Complications Trial Research Group. (1994) 'Effect of intensive diabetes treatment on the development and progression of long-term complications in adolescents with insulin-dependent diabetes mellitus: Diabetes Control and Complications Trial' *J Pediatr*, 125(2), 177-188.

Thomas, M.C. (2014) 'Glycemic exposure, glycemic control, and metabolic karma in diabetic complications' *Adv Chronic Kidney Dis*, 21(3), 311-317.

Zgibor, J.C., Songer, T.J., Kelsey, S.F., Drash, A.L. and Orchard, T.J. (2002) 'Influence of health care providers on the development of diabetes complications: long-term follow-up from the Pittsburgh Epidemiology of Diabetes Complications Study' *Diabetes Care*, 25(9), 1584-1590.