



PAEDIATRICS

A NATIONAL MODEL OF CARE FOR PAEDIATRIC HEALTHCARE SERVICES IN IRELAND

CHAPTER 26: PAEDIATRIC GASTROENTEROLOGY



Féidhmeannacht na Seirbhíse Sláinte
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**ROYAL
COLLEGE OF
PHYSICIANS
OF IRELAND**

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26.0 INTRODUCTION

Paediatric gastroenterology encompasses the management of disorders of the intestine, liver and pancreas, and conditions leading to intestinal failure/severe nutritional compromise. Tertiary paediatric gastroenterology, hepatology and nutrition services for Ireland are provided in one centre, Our Lady's Children's Hospital, Crumlin (Crumlin), and will move to the new children's hospital when it is built. This is in line with international recommendations that specialised services should be delivered in tertiary care centres of excellence.

The diagnosis and management of the following tertiary conditions are included among the national paediatric gastroenterology services:

- Inflammatory bowel disease (IBD) – medical and surgical care provided centrally, with shared care provided locally by general practitioners (GPs) and general paediatricians
- Non-IBD intestinal inflammation – eosinophilic colitis, immunodeficiency-associated enterocolitis
- Coeliac disease – diagnostic endoscopy and histopathology service (Crumlin and Tallaght currently), with continued care provided locally by GPs and general paediatricians
- Malabsorption
- Enteropathy/chronic diarrhoea
- Gastrointestinal polyps and polyposis syndromes
- Peptic ulcer disease
- Oesophageal diseases – dysmotility, reflux oesophagitis, eosinophilic oesophagitis, Barrett's oesophagus
- Gastrointestinal motility disorders: achalasia, oesophageal dysmotility and chronic intestinal pseudo obstruction
- Gastrointestinal haemorrhage – major upper gastrointestinal haemorrhage, variceal bleeding, peptic ulcer disease, oesophagitis, vascular anomalies; haematochezia not due to Meckel's diverticulum
- Exocrine pancreatic insufficiency and pancreatic disorders – including recurrent acute and chronic pancreatitis, fibrosing pancreatitis
- Neonatal-/infancy-onset liver diseases – including neonatal cholestasis, biliary atresia, Alagille syndrome, alpha 1 antitrypsin deficiency, giant cell hepatitis, familial intrahepatic cholestasis syndromes, neonatal sclerosing cholangitis, neonatal haemochromatosis, hepatic vascular anomalies, fulminant acute liver failure
- Non-neonatal onset liver diseases: autoimmune hepatitis, Wilson disease, cystic fibrosis-associated liver disease, portal hypertension, extrahepatic portal venous obstruction, chronic liver disease/failure, refractory ascites, acute and fulminant liver failure
- Infectious hepatitis – hepatitis B and C treated in conjunction with paediatric infectious disease team at the national centre
- Intestinal failure requiring prolonged parenteral nutrition support – post-significant surgical resection in neonatal period, congenital diarrhoea syndromes, chronic intestinal pseudo obstruction, severe dysmotility conditions, manifestations of mitochondrial disease, idiopathic intestinal failure
- Transplantation – whole or split donor liver transplantation, live related liver transplantation, intestinal transplantation, combined multi-visceral organ transplantation
- Hepatobiliary surgery – choledochal cyst, bile duct anomalies, Kasai procedure, intra-operative cholangiography, porto-systemic shunt surgery

Specialised gastrointestinal investigations that should be provided by a specialist paediatric centre of excellence include the following:

- Upper gastrointestinal diagnostic endoscopy
- Upper gastrointestinal therapeutic endoscopy – variceal band ligation, variceal sclerotherapy, bleeding peptic ulcers
- Small intestinal enteroscopy – diagnostic and therapeutic*
- Diagnostic ileo-colonoscopy
- Therapeutic ileo-colonoscopy (e.g. polypectomy) – need to develop and adhere to national paediatric standards
- Video-capsule endoscopy*
- Diagnostic breath tests – e.g. hydrogen breath tests*
- Pancreatic function testing*
- Gastrointestinal physiology investigations – pH probe, manometry, motility/EGG testing*
- Liver biopsy
- Paediatric magnetic resonance enterography (MRE)
- CT angiography
- Paediatric nuclear medicine studies, e.g. HIDA scan
- Paediatric interventional radiology – liver biopsy, PICC line insertion, feeding tube insertion, percutaneous transhepatic cholangiography, arterial embolisation etc.
- Specialist paediatric pathology investigations and interpretation

**currently unavailable in Ireland*

The prevalence of conditions/procedures is as follows:

Coeliac disease	200 per 100,000 children aged under 16 years
Inflammatory bowel disease	50 per 100,000 children aged under 16 years
Diagnostic endoscopy	200 per 100,000 children aged under 16 years
Intestinal failure (TPN >28 days)	100-120 per 1,000,000 aged under 16 years

The UK Standards for the Healthcare of People with Inflammatory Bowel Disease (IBD Standards Group, 2013) sets out six standards for patients with IBD, for example. The gastroenterology service strives to attain these standards for all patient groups under their care. These standards are:

1. High-quality clinical care delivered by a multidisciplinary team (MDT)
2. Local delivery of care
3. Maintaining a patient-centred service
4. Patient education and support
5. Use of data, information technology and audit
6. Evidence-based practice and research

26.1 CURRENT SERVICE PROVISION

Staffing

The gastroenterology service in Crumlin has developed from a service with one consultant in 1990 to its current staffing levels. However, demand for the service outstrips the current staffing capacity. The function of the service is to provide a comprehensive paediatric gastroenterology service to Ireland, which has just 2.5 WTE consultants, one specialist registrar (SpR), one non-SpR registrar and one senior house officer (SHO). There are five designated inpatient beds.

A comprehensive MDT has been established with the following:

- 5.3 WTE clinical nurse specialists with special areas of expertise, including nutrition support (2), liver disease (1.8) and inflammatory bowel disease (1.5)
- 0.8 WTE dietitians
- 0.7 WTE social workers
- 0.5 WTE clinical psychologists (Hepatitis C funding)
- 3.0 WTE administrative support personnel for general administration and endoscopy support

The division has no clinical database and there is no database manager. This is a significant deficit for a tertiary unit.

Referrals

Referral criteria and sources are determined according to pathways of care:

- The service accepts referrals from primary and secondary care clinicians for patients who require specialist investigation or management within agreed protocols.
- GP referrals are screened for their suitability for specialist care. Rapid referral from a GP from within or outside the local catchment area is necessary due to the urgency of the need for specialist investigation, such as endoscopy, (in cases of gastrointestinal bleeding or suspected IBD, for example). However, the percentage of referrals from primary care (currently 72%) is disproportionately high.
- Patients are also referred for the assessment and management of nutritional problems where input of the nutrition support team is required.

The current deficit in secondary general paediatrics in Dublin has resulted in many cases being inappropriately referred to the gastroenterology service.

Primary care referrals	The gastroenterology service accepts referrals from primary care and from emergency departments in Dublin. The lack of a comprehensive general paediatric service in Crumlin and Tallaght has resulted in patients with minor gastrointestinal (GI) problems are referred directly to the tertiary gastroenterology service.
Secondary care referrals	Paediatric consultants from all hospitals in Ireland refer directly to this service via letter or fax. There is a 24/365 on-call service for urgent/emergency cases.
Tertiary care referrals	Inpatient support for patients with complex conditions, and for GI consultations with other paediatric specialists, is provided. Close links with are maintained with centres in the United Kingdom (UK), including Birmingham, King's College Hospital and Great Ormond Street Hospital.

Access

The gastroenterology unit provides family-centred specialist care with pooled medical and multidisciplinary sub-specialties with a high level of expertise. The unit maintains excellent links to international centres in order to support clinical requirements. Although procedures, protocols, guidelines and care pathways need to be developed, pro-forma guidelines for the management of constipation care are already available, as are guidelines for the management of inflammatory bowel disease.

In terms of the current service, the approximate numbers of children and adolescents attending the unit are set out below together with details of the conditions they are being treated for. As follows:

Inflammatory bowel disease	490
Liver disease	450
Home TPN/intestinal failure/enteropathy	34
Coeliac disease (local catchment area cases)	150
Complex oesophageal disease	150
Complex pancreatic disease	20
Miscellaneous/other	50

All patients from outside Dublin are managed in shared care arrangements with local paediatricians.

There are 5.5 consultant-led clinics per week, with 20-30 attendances per clinic. All patients are seen by a consultant. Between 2008 and 2012, there was a 50% increase in new patient referrals.

In addition to seeing these patients, urgent reviews are facilitated weekly and additional clinics including outreach clinics, transition clinics, joint cystic fibrosis (CF)/liver disease clinics and combined themed clinics are also held in the unit. At present, there are significant clinical capacity issues, and the unit is the only referral centre for children in Ireland with gastrointestinal, liver or complex nutritional needs.

Patients often wait significant lengths of time before an appointment becomes available. Waiting times in each clinic visit may be significant (up to three hours) in order to assess and address the needs of each individual patient. Providing safe, high-quality care can be compromised by these high levels of demand. Depending on their clinical need, referred patients may require initial admission to the unit.

Equity of access for all children is ensured by common guidelines and a common admission policy for the specialist service. The tertiary paediatric gastroenterology service ensures provision of a full portfolio of tertiary services across the regional network.

New patients of any age under 16 years who present for treatment will be accepted, and in general no referrals to adult services should be made for those aged under 16 years. For those aged 16-18 years, referral to either paediatric or adult gastroenterology services may be clinically appropriate.

Hepatology Support

There is an urgent review drop-in service, which manages approximately 250 patients per year. Formal education is provided for approximately 80 new patients per year.

Dietetics

There are just over 1,800 dietetic contacts per year, and therefore the dietetic service needs to be strengthened. There has been an increase in the number of patients using nutrition therapy for first-line treatment of Crohn's disease, which requires increased dietetic support. A significant proportion of the referrals require close liaison with local dietetic services and with dietetics colleagues in the UK.

Inflammatory Bowel Disease (IBD) Support

There is a drop-in service, with about 500 patients seen per year in addition to looking after patients attending regular outpatients department (OPD) and day case appointments. Telephone support to patients and families is provided by IBD clinical nurse specialists (CNSs); currently more than 5,000 telephone calls are received each year. A total of 250 patients are currently receiving immunomodulator/biologic therapy and require close surveillance.

Clinical Psychology

The clinical psychology service needs to be strengthened. Many patients and their families with chronic diseases require ongoing support at tertiary and local level. Limited staff and resources results in unacceptably long delays as well as extremely limited regional access to psychological support.

Social Work

Approximately 150-180 new cases are referred from gastroenterology each year. The recent increase in UK referrals for hepatobiliary surgery has further increased the workload demands on the service. In addition, cuts to medical cards and discretionary allowance cards have resulted in an increase in demand for social welfare supports.

Discharge from Specialist Gastroenterology Service

Discharge occurs when the patient no longer needs to be managed within a specialist environment. For the medical conditions listed below, most patients will be discharged from the specialist service to receive local follow-up, with input from the specialist centre when required:

- coeliac disease
- peptic ulcer disease including H. pylori gastritis
- functional abdominal pain
- multiple food intolerances (actual and perceived) as part of a network including a paediatric allergist and a local paediatrician

Current Service Issues

Significant current service issues include the following:

- Manpower – the optimal delivery of tertiary gastroenterology care is through a well-resourced national 'hub', with regional outreach 'spokes' delivered through local general paediatric centres. Currently, the national 'hub' centre is inadequately resourced at all staff grades. This has knock-on consequences for service delivery centrally and regionally. The current level of consultant gastroenterology cover in Crumlin/Tallaght alone is approximately one-third of what would be expected in any reasonable international comparison. The inadequate staffing levels in the unit can lead to high levels of personal stress and burnout, in addition to posing clinical governance concerns regarding the potential for misadventure due to inadequate staffing levels. Similar parallels exist for other staffing categories within the MDT.
- Direct referrals from primary care – these account for the majority (72%) of new outpatient referrals. Most of these referrals would be more appropriately managed in a general paediatrics setting. The number of direct referrals from primary care results in inappropriately long waiting times for non-tertiary referrals.

- Tertiary outpatient clinic appointments – the number of outpatient clinic slots taken up by non-tertiary referrals compromises timely access and review of tertiary patients. As a result, tertiary patients are not seen as frequently as they should be, and clinics overrun significantly.
- Theatre capacity for endoscopy lists – the number of procedures performed annually in Crumlin and Tallaght has increased in recent years. Current endoscopy capacity is approximately a half to two-thirds of actual needs across both sites (i.e. 50-66%). Children continue to wait for unacceptably long periods to undergo endoscopy.
- National standards for paediatric endoscopy – clinicians continue to refer children to adult rather than paediatric endoscopy specialists countrywide. Paediatric endoscopy standards for the indications, conduct and interpretation of endoscopy, similar to recent adult standards, need to be developed for national implementation.
- Space constraints – the current lack of designated rooms for MDT members in a centralised area is a barrier to appropriate delivery of ambulatory care and to the functioning of the MDT.
- Nurse-led clinics – due to understaffing at nurse specialist level, and also due to a lack of designated rooms, there are no nurse specialist-led clinics in the division for any condition.
- Dietitian-led clinics – due to understaffing and a lack of designated rooms, there are no clinics for conditions such as coeliac disease, cholestatic liver disease and IBD; such clinics are available in UK centres.
- IBD – the incidence of IBD has increased by almost 100% in the past decade. There are now 100 new cases per year in children aged under 16 years. Paediatric IBD is a tertiary condition which requires timely access to clinics, diagnostic imaging and endoscopy. The above patient and endoscopy issues directly impact this patient group most of all. Expanded and timely access to routine monitoring is not available, which impacts clinical decision-making.
- Liver disease – the workload involved in providing tertiary-level hepatology care is underappreciated at many levels. Delayed recognition of neonatal cholestasis remains an ongoing public health concern. The specialist nurse service needs more time and support in order to engage in initiatives to address this at a public level, e.g. public health nurse education, national guidelines development. Survival pre- and post-liver transplant has improved dramatically in recent years in Crumlin. However, there is an ongoing need to strengthen shared care practices, develop educational material, and deliver education sessions in the community. Recent infection control practices in Crumlin, as a consequence of patient referrals to the UK, has resulted in significant loss of hepatology nurse specialist time to infection control-related matters, in place of addressing the clinical hepatology needs of children.
- Hepatobiliary surgery – the national hepatobiliary surgery service in Crumlin has been effectively suspended since 2012. As a result, children who now require surgery for biliary atresia, choledochal cyst repair and lobar resection are being referred to UK centres. Unless this situation is reversed, there is a potential for deskilling of ward and theatre staff, and a lack of national specialist surgical expertise and opinion. Furthermore, the infection control policies in Crumlin mean that such patients require significantly more hepatology CNS time than was previously required, thus further compromising CNSs' availability to provide support to other hepatology patients. Patients travelling to the UK require significant financial and psycho-social support from social work services.
- Data management – the lack of a data manager makes it very difficult to track activity and clinical outcomes accurately, and to plan resources accordingly.

- Administrative support – unacceptable delays in transcribing clinical letters have posed a major clinical governance risk for the division previously. This directly impacts on patient clinical care and undermines confidence in the system for healthcare professionals.
- Transition to adult services – our nurse specialists have been proactive in improving transition. However, this is not optimal, given the limited availability of nurse specialist personnel in the division. National guidelines on transition services are required.
- Care pathways and clinical guidelines – these have not been adequately developed to date. Again, more appropriate ‘hub’ staffing levels would enable a comprehensive roll-out of structures and supports for the gastroenterology service nationally.

26.2 PROPOSED MODEL OF CARE

The vision of this model of care is to first strengthen the core gastroenterology services in the national centre and develop them to international resource standards. This will enable the provision of more structured shared care pathways and outreach clinics to support the needs of tertiary gastroenterology patients and general paediatricians nationally.

A national paediatric gastroenterology, hepatology and nutrition support service is interdependent with other specialties, including adequate paediatric consultant resources in anaesthetics, radiology, interventional radiology, surgery, immunology, intensive care medicine and pathology.

The caseload includes:

- *Conditions needing specialist care from presentation* – specialist gastroenterology and nutrition care is led by a specialist team who provide treatment and follow-up for children with complex and life-long conditions such as inflammatory bowel disease and intestinal failure, until such time as the care of these patients is transitioned to adult services. All management changes are made in the specialist centre, with appropriate liaison and information sharing with secondary and primary care, and in some cases shared management with secondary care (including outreach clinics).
- *Conditions that can be managed mostly in a local hospital (secondary care)* – but then require temporary referral to specialist care, with the vast majority subsequently discharged to local follow-up
- *Conditions requiring referral from secondary care for further investigation only available at the specialist centre.*

Care should be delivered in a well-defined clinical network, with clear systems in place for communication across the network which offers 24/7 access to specialist advice, as well as shared care guidelines based on evidence and national guidelines. Many conditions do not have a definitive diagnostic test, and therefore accurate and timely diagnosis relies on the clinical skills and experience of the assessing clinician, with support provided by associated subspecialties. For this reason, co-location with other specialties in a tertiary paediatric centre is essential. Specialist gastroenterology, hepatology and nutrition services are also essential, in order to support other paediatric subspecialties (including neonatology, paediatric surgery, oncology and PICU); again, co-location with relevant specialties is essential.

Referral to specialist care is recommended if:

- Conditions are rarely seen in general paediatric practice or are very severe/extreme presentations of a more common condition (e.g. severe constipation or severe gastro-oesophageal reflux).
- Conditions require complex, long-term management.
- Specific difficulties are encountered in very young children.
- Children with certain chronic disease require longer-term nutritional support.

The service will offer the following care pathways and components:

- rapid access for the assessment and management of new referrals – inpatient, outpatient and day case
- rapid access to specialist advice as well as inpatient, outpatient and day case assessment of children managed by the specialist service
- longer-term monitoring of cases through outpatient assessment
- prompt access to inpatient beds for the management of acutely ill children
- access to support services, including paediatric surgery, radiology and intensive care
- access for planned assessment and investigation as inpatient or day case, with clearly defined referral/management pathways, scheduled treatment and follow-up with well-defined care pathways
- children's wards and paediatric nurses for all inpatient, outpatient and day case stays
- The service will offer a full range of diagnostic investigations, including emergency access to endoscopy services in accredited paediatric facilities with accredited paediatric anaesthetists and diagnostic/interventional radiology procedures).
- Treatment, including medical and surgical management of gastroenterological disease; nutritional and psychological support for the child and their family; liaison with, and support of, education; counselling on treatment and prognosis.
- Many children with gastroenterological diseases have a lifelong chronic disease, and their contact with the paediatric gastroenterology service can be prolonged and intense. The service must ensure continuity of care at a senior level in order to achieve consistent management.
- Management is supported by a MDT – see below.
- Discharge processes must ensure timely and appropriate communications with services that are expected to provide other aspects of the patient's pathway, in line with national guidelines.

The essential components of the National Paediatric Gastroenterology, Hepatology and Nutrition Service are:

- sufficient consultant numbers to provide consultant continuity with cross-cover and access to expert opinion by telephone on a 24-hour basis
- sufficient paediatric gastroenterology/hepatology/nutrition nurse specialists to support inpatient care (including MDT meetings), discharge planning and re-admission avoidance; to cover specialist clinics, ensure regional liaison, as well as perform service evaluation and development
- paediatric dietitian support for inpatients (including MDT meetings), outpatient clinics, and regional liaison, service evaluation and development
- paediatric radiologists with appropriate experience and sufficient time to support the assessment, investigation and continued management of children referred to the unit
- endoscopy performed by endoscopists with training and/or extensive experience in diagnostic and therapeutic endoscopy and colonoscopy in children
- endoscopy procedures carried out in a child-friendly environment with appropriate anaesthetic sessions, and facilities with accredited paediatric anaesthetists
- histopathologists with expertise in paediatric gastrointestinal histopathology

- paediatric gastrointestinal physiology laboratory, with appropriate up-to-date technology to enable tertiary investigations (e.g. pH probe, manometry, EGG, motility testing, capsule endoscopy, breath testing)
- paediatric surgeons with expertise in children with complex gastrointestinal disease (e.g. IBD surgery, hepatobiliary surgery, neonatal short gut syndrome) with allocated time for joint assessment of complex patients including multidisciplinary meetings and clinics
- clinical psychologists and/or age-appropriate mental health support
- liaison with child and adolescent psychiatry
- dietitian, pharmacist and clinical biochemistry staff with experience in paediatric parenteral nutrition
- pharmacist with experience in immunosuppression medication, including transplant medication
- dedicated social work support for children who have complex care needs, in order to enable discharge planning and continuing support
- integration of training programme at fellowship level for trainees in paediatric gastroenterology, including paediatric endoscopy.
- adequate time available for the provision for MDT meetings (for example case conferences, nutrition meetings, radiology meetings, clinico-pathological conferences), joint clinics (e.g. with paediatric surgery, adult physicians as part of transitional care and local clinicians in order to facilitate care close to home through outreach)
- A designated liaison/lead paediatrician in each regional paediatric unit for patients with gastrointestinal, nutritional or liver disease, with allocated clinical sessions to facilitate shared care, as well as sufficient facilities and IT supports to enable this care
- sufficient administrative and clerical support to facilitate rapid access to assessment and management, with clear and effective communication lines across the network – including administrative support for outreach services, as well as capability for regional and national audit, data management and research
- ability to rapidly refer to other specialties for their input
- ability to promptly discharge and refer back to local paediatric services for continued care on completion of tertiary GI involvement

Specialised Nutrition Support Services are for the investigation and/or management of the complex nutritional needs of patients requiring enteral nutrition (EN) or parenteral nutrition (PN) for intestinal failure and home PN (HPN). This must be delivered by a MDT (senior clinician, nurse specialist, dietitian, pharmacist, clinical psychologist, speech and language therapist, biochemist, surgeon).

Shared Care Ethos

Progress in relation to shared care pathways with regional paediatric departments will ensure that the burden will shift from the current central provision of non-tertiary-level supports to local provision of these needs (dietetic monitoring, psychological assessment and support, social work, disease activity monitoring, medications), thus reducing patient travel. Local services will need to be adequately resourced and upskilled if necessary, and provision needs to be made for this. Telemedicine and interactive IT support infrastructure will greatly enhance the support that the core centre can provide for regional hub centres and for their health and social care professionals (HSCPs) in particular.

26.3 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION OF MODEL OF CARE

Staffing Resources

It is difficult to indicate final staffing numbers, as the service needs may vary over time. The table below outlines the current and suggested requirements, but these will need to be reviewed according as the service develops. There is a significant deficit in the number of core professionals necessary to appropriately staff the MDT. Service requirements should be reviewed regularly, so as to allow for changes in patient numbers and clinical presentations. In order for the service to function as a hub-and-spoke model, adequate manpower resources are also needed at a local level.

Staff category	Current (WTE)	Proposed (WTE) minimum
Consultant	3.5	7.0
Fellow in Gastroenterology	0	1.0
Specialist registrar	1.0	2.0
Registrar	1.0	1.0
SHO	1.0	1.0
Specialty trained nurses	0	3.0
Advance nurse practitioner	0	3.0
Clinical nurse specialist	5.0	12.0
Dietitian	0.75	2.5
Physiotherapist	0	0.25
Pharmacist	0	1.0
Occupational therapist	0	0.25
Psychologist	0.5	2.0
Social worker	0.7	1.5

Note, the above figures are subject to review, depending on service development.

Infrastructure

At least eight designated and protected inpatient beds with en-suite facilities are needed in order to meet the needs of patients. The number of beds required may vary, depending on the demands of the service, including allowing for prolonged inpatient stays for medically unstable patients. The centralisation of these beds in a single unit would enhance patient experience and care.

Adequately sized, centrally located OPD services with access to administrative support are required, with sufficient designated physical space to enable simultaneous MDT consultations, drop-in patient assessments and parent education (e.g. home PN training, post-transplant care, nutrition therapy) support.

Access to Endoscopy

There is inadequate timely access to endoscopy. This has direct and indirect patient consequences. The lack of dedicated endoscopy staff and a purpose-built paediatric endoscopy suite compound the issue further. As a result, many children in regional centres are referred to adult practitioners, in the hope that their procedure can be expedited. This is not the best interests of children's health.

Hepatobiliary Surgery

The recent loss of consultant-provided hepatobiliary surgery in Crumlin has significant consequences for children nationally, especially those who are now forced to travel to the UK for procedures that were previously provided in Crumlin. This situation also has an impact on surgical oncology services. Patients experience the difficulty of dealing with multiple professionals in both sites, which adds to distress and can complicate the clinical decision-making process (e.g. meeting two different dietetic teams, two sets of CNSs, two sets of consultants and medical teams).

Information Technology (IT) and Administrative Support

IT infrastructure is virtually non-existent. Infrastructure needs to be developed in order to enable the creation and maintenance of a patient database, thus allowing accurate statistics to be recorded and audited, and also facilitating the creation of web-based portals for professionals to access care sheets and care plans, disease-related information, outpatient referrals and queries. Such infrastructure is also required in order to enable the development of a web-based portal for parents that would deliver supports and information sheets, and also to enable electronic record keeping to facilitate the provision of timely and accurate records, especially for endoscopy services.

Given the depth and complexity of the medical conditions of patients attending such a service, it is imperative that rapid communication of clinical assessments and medication changes to local caregivers takes place. The administrative support resources in the division are such that it can take between two and three months to have letters to referral sources transcribed, instead of having this work completed within two weeks maximum.

Education and Training

The Gastroenterology Department is actively engaged in research, and has received over €2.5 million in grants in the past five years. During this time, department colleagues have had 33 papers published in high-impact journals, including JAMA, Gastroenterology, The American Journal of Gastroenterology, the Journal of Crohn's and Colitis, the Journal of Hepatology, Archives of Disease in Childhood, Paediatrics, Journal of Paediatrics, Infection and Immunity and Journal of Pediatric Gastroenterology and Nutrition. The department is actively engaged in a number of audits in the areas of hepatology, inpatient parenteral nutrition and IBD. Established research links have been made through the National Children's Research Centre (NCRC). Non-consultant hospital doctors (NCHDs) are encouraged to participate in, and audit, research activities during their attachments; to present at national and international meetings and, ultimately, to submit manuscripts for review in peer-reviewed journals.

The national service is well placed to provide higher sub-specialist (fellowship) training in paediatric gastroenterology, but this opportunity will remain unrealised without adequate resources and a full complement of facilities on-site.

MDT members are active in providing education to patients and their families, as well as participating in the education of other healthcare professions:

- age-appropriate focus groups for children with IBD aged 10-12 years and 13-15 years, and also for transition groups
- age-appropriate patient information leaflets for IBD patients
- participation in internal study days on IBD, hepatology and nutrition for ward staff
- delivering seminars at regional paediatric centres
- ongoing development and review of diet sheets for patients
- ongoing development and review of information for ward staff

Staff are also engaged in continuing professional development (CPD) within their own professions, in addition to completing higher levels of study appropriate to their caseload. The level of time/infrastructure supports currently available to enable MDT members to deliver/participate in educational activities is inadequate, due to the volume of ongoing service demands. The lack of access to telemedicine, Skype facilities and other communication technologies impairs staff members' ability to more readily distribute educational material and programmes to regional centres.

Patient Resources

There are a limited number of parent and patient information sheets/booklets covering certain aspects of the main tertiary GI diseases. It would require significant time and resource management to improve these materials and bring them up to the international standards appropriate for a national referral centre. The lack of a website and web-based technology has limited dissemination of parent/patient information to date. The development of transition documents and pre-transition assessments is currently underway. Once available, these will be helpful for both regional hub centres and the national centre.

26.4 GOVERNANCE

Core principles include:

1. To minimise mortality and morbidity by providing the most appropriate care for children with gastrointestinal, nutritional and liver disease.
2. To ensure that there is a sufficient, skilled and competent multidisciplinary workforce to manage children with gastrointestinal, nutritional and liver disease.
3. To ensure that national guidelines are developed and continually appraised, in order to provide guidance for both centrally and locally provided care.
4. To ensure that children are treated in line with national guidelines and agreed local pathways.
5. To ensure that shared care and clinical networks deliver good specialist care close to home through integrated pathways of care.
6. To ensure that children have their healthcare and any social care plans coordinated.
7. To ensure maintenance or improvements in children's clinical condition (in conditions where this is measurable), in order to enable normal activities of daily living and optimal school attendance.
8. A written transition process with a transition lead.

MDT meetings take place on alternate weeks; during these meetings complex cases are discussed and all complex, home parenteral nutrition patients are reviewed. Healthcare professionals are required to work within the code of conduct of their individual professions. The ability to adhere to guidelines set out by professional bodies (e.g., HSE, DoH, HIQA) is subject to resources available. The lack of coordinated/integrated healthcare records and IT facilities across all three children's hospital sites is a potential threat to clinical governance integrity. The clinical pathology conference takes place on an alternate week basis; at this conference all patients who are undergoing endoscopy and other procedures are reviewed, in order to seek a consensus on diagnosis and disposition. Morbidity and mortality meetings occur on a regular basis, in order to assess adverse effects throughout the year.

The division structure is such that the gastroenterology department is supported by a GI leadership team comprising representative members of consultants, clinical nurse specialists, health and social care professionals, and secretarial groups. This group organises and manages issues around patient care and department structures,

and the GI leadership team provides the interface with hospital management. Crumlin also recently established a paediatric endoscopy committee; the purpose of this committee is to improve the clinical governance surrounding the organisation and running of paediatric endoscopy in Crumlin. The committee reports to the clinical management team in Crumlin. It is also responsible for endorsing standard operating procedures for use in paediatric endoscopy.

Standards of care across local and regional networks include the following:

- Treatment is offered in line with national policies and guidance, agreed care pathways and referral criteria.
- The care provided promotes equity to access services, based on the clinical needs of the population served.
- The gastroenterology department requires sufficient clinical and support staff to ensure a multidisciplinary approach to provision of services in respect of, and at all times in accordance with, good clinical practice, good healthcare practice and recommendations, in line with relevant guidelines from European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN).

26.5 PROGRAMME METRICS AND EVALUATION

The key performance indicators (KPIs) currently recorded include the following:

- time from referral to endoscopy
- time delay to perform endoscopy out of 'clinical window'
- number of patients waiting endoscopy for more than 13 weeks
- successful drainage and transplant risk following Kasai procedure for biliary atresia
- disease-free status at one year for children/adolescents with inflammatory bowel disease
- vitamin D status of patients with IBD one year after diagnosis
- central line sepsis rates in patients with long-term parenteral nutrition
- percutaneous endoscopic gastrostomy (PEG) feeding/enterostomy complication rates
- time from dictation of letters to dispatch of letters to referral sources
- patient and family experience of the service

Endoscopy procedures are an integral component of the paediatric gastroenterology service. National standards for paediatric endoscopy endorsed, by the Faculty of Paediatrics, Royal College of Physicians of Ireland, are urgently required. Procedures for those aged under 16 years should be provided centrally at the National Centre for Paediatric Gastroenterology. Currently, many young children continue to undergo endoscopic procedures in adult endoscopy forward/surgical centres without appropriate paediatric gastroenterology supervision of clinical indications, findings and follow-up.

Web-based resources for referrals, clinical guidelines, patient and family information resources, booking and coordination of procedures and appointments, and the issuing of reports are not currently possible, due to lack of IT support. Crumlin is currently exploring the possibility of using electronic endoscopic records, which would enable the acquisition of certain data sets, relevant clinical audit, and increased outcomes and efficiencies.

It is possible to benchmark the research productivity of the unit against comparable unit nationally and internationally, allowing for the case mix and staffing levels.

26.6 KEY RECOMMENDATIONS

- Significantly increase the medical, nursing and health and social care staffing of the multidisciplinary team providing tertiary gastroenterology care at the national centre.
- Prioritise timely access to paediatric endoscopy under anaesthesia at the national centre.
- Provide adequate space and appropriate environment to deliver ambulatory and inpatient tertiary gastroenterology services at the national centre.
- Provide data management and IT resources, in order to track clinical activities and facilitate electronic interface capability.
- Develop national standards for paediatric endoscopy services, endorsed by the Faculty of Paediatrics.
- Restoration of a consultant-led paediatric hepatobiliary surgery service in Ireland.
- Increase multidisciplinary healthcare professional staffing of regional centres to enable local and shared care.

26.7 ABBREVIATIONS AND ACRONYMS

CF	cystic fibrosis
CNS	clinical nurse specialist
CPD	continuing professional development
CT	computer-aided tomography
DoH	Department of Health
EGG	ElectroGastroGram
EN	enteral nutrition
ESPGHAN	European Society for Paediatric Gastroenterology, Hepatology and Nutrition
GI	gastrointestinal
GP	general practitioner
HIDA	hydroxy iminodiacetic acid
HIQA	Health Information and Quality Authority
HPN	home parenteral nutrition
HSCP	health and social care professional
HSE	Health Service Executive
IBD	inflammatory bowel disease
IT	information technology
MDT	multidisciplinary team
MRE	magnetic resonance enterography
NCHD	non-consultant hospital doctor
NCRC	National Children's Research Centre
OPD	outpatients department
PEG	percutaneous endoscopic gastrostomy
PICU	paediatric intensive care unit
PN	parenteral nutrition
SHO	senior house officer
SpR	specialist registrar
TPN	total parenteral nutrition
UK	United Kingdom
WTE	whole-time equivalent

26.8 REFERENCES

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