

Paediatric Gastroenterology, Hepatology and Nutrition Services in Scotland

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Paediatric Gastroenterology Hepatology and Nutrition (PGHN) Services in Scotland

Executive Summary

Tertiary PGHN services in Scotland are provided by three regional services. 2.1 whole time equivalent (WTE) consultants in Glasgow provide a service within Yorkhill although no outreach services are provided to the west of Scotland. 1.0 WTE consultants in Edinburgh provide services within the Royal Hospital for Sick Children and also outreach services with clinics in Kirkcaldy and Dumfries. 1.3 WTE consultants provide a service based in Aberdeen and Dundee with a plan to start an outreach service in Inverness later this year. These services have developed in an ad hoc manner and to date, proper regional planning has only occurred within one of these areas. In the past there has been no formal national planning of this service.

The number of complex patients with gastrointestinal problems has increased quite dramatically in recent years. This is due to a combination of factors. Firstly, the technology for maintaining nutritional support in children has improved dramatically over the last 10 years. In the past, only a handful of children were sent home on enteral tube or gastrostomy feeding but at present, over 600 such patients are known to the above centres and it is likely that there are many more presently being seen in District General Hospitals. The incidence of inflammatory bowel disease and particularly Crohn's Disease in children under the age of 16 has increased four-fold in Scotland over the last 30 years. The incidence was 1.0 per 100,000 children under the age of 16 in 1973 and had risen to 4.2 per 100,000 children by 1999. As most of these children are teenagers, concern has arisen that large numbers of these children are being managed in adult gastroenterology and adult surgical units. An audit carried out by the British Paediatric Surveillance Unit in 1999 has shown that in Scotland, 53% of children under the age of 16 with inflammatory bowel disease are cared for in adult units. Recent audits have also shown the sub-optimal nature of care provided by specialists, not familiar with the management of growth failure during adolescence. The PGHN specialists in Scotland, very much wish to be able to offer these children an appropriate service.

Collectively, we wish to develop the current PGHN services with proper staffing and resourcing in each centre. We wish to develop a comprehensive service across Scotland linking in with Consultants in each of the District General Hospitals to create a Scotland wide network. Dietetic and nursing staff will be integral to the development of this service. We also wish to develop expertise within Scotland in the management of less common but more complex paediatric gastro-intestinal problems. The services for children receiving nutritional support at home, both enteral and parenteral will continue to increase and this needs to be properly resourced and managed.

In order to meet these goals, it is likely that the number of WTE Paediatric Gastroenterologists in Scotland will need to at least double over the coming years with a minimum of 3.0 WTE in each regional service. This will need to be matched by a similar rise in specialist nursing and dietetic staff.

Paediatric Gastroenterology, Hepatology and Nutrition Services in Scotland

Introduction and Overview

Paediatric gastroenterology, hepatology and nutrition (PGHN) represent a major subspecialty dedicated to the care of children with gut, liver and nutritional diseases and problems. Services for children in Scotland are patchy, uncoordinated, and have developed piecemeal. The principle unmet tertiary clinical needs in Scotland are in the care of children with inflammatory bowel disease, resources for shared care with paediatricians in district hospitals, coordinated enteral and parenteral nutritional support for children in hospital and in the community, and the acute and continuing management of certain uncommon GI and liver diseases.

The following paper reviews the growing pressure on PGHN services in Scotland, generated by the rising incidence of certain conditions, increasing expectation in terms of patients and clinical standards, and inadequate current staffing levels. The requirement for multidisciplinary team working, through a network of services connecting together the principal tertiary centres in Scotland, is outlined, followed by the steps required to deliver a comprehensive service for children with PGHN problems in Scotland.

Definition and Scope

Paediatric gastroenterology can be divided into three main areas:

1. Gastroenterology is concerned with intestinal disease involving the oesophagus, stomach, pancreas, small intestine and colon.
2. Hepatology relates to diseases of the liver.
3. Nutrition involves the care for children with compromised nutrition and includes nutritional assessment and clinical nutrition support.

The spectrum of common conditions seen and procedures performed by paediatric gastroenterologists is wide. The most common conditions are outlined in table 1.

Specialists in paediatric gastroenterology hepatology and nutrition are dependent on other health professionals in their care of children with gastrointestinal disease (table 2). The majority of these links are essential for the provision of a high standard of patient care, and as outlined in 'A Guide for Purchasers of Paediatric Gastroenterology, Hepatology and Nutrition Service' (1), are requirements for the provision of specialist services.

Table 1. Conditions seen by specialists in PGHN. Those conditions marked with an asterix will be discussed further in subsequent sections of this document.

Gastroenterology	Severe gastro-oesophageal reflux Peptic ulcer disease Severe food allergic disease of the gut Coeliac disease* Inflammatory bowel disease* Intractable diarrhoea Intractable constipation Intractable abdominal pain Complex motility disorders Intestinal failure Diagnostic and interventional endoscopy*
Hepatology	Prolonged conjugated jaundice in the newborn* Chronic liver disease in childhood* Care of post liver transplant patients Portal hypertension Therapeutic endoscopy Diagnostic liver biopsy Hepatitis B and C*
Malnutrition (Undernutrition & Obesity)	Nutritional and feeding assessment Failure to thrive Obesity Insertion and replacement of gastrostomies Management of enteral tube feeding - hospital - home* Management of parenteral nutrition - hospital - home*

Table 2. Major links to other services. (GI – Gastrointestinal)

Paediatric	General Paediatrics Neonatal Paediatrics Respiratory and cystic fibrosis Oncology Neurology Community child health Paediatric surgery Paediatric intensive care
Laboratory / Diagnostic	Radiology Pathology Biochemistry Microbiology
Child and Adolescent Mental Health	Psychiatry Psychology
Adult Services	Gastroenterology Surgery
Nursing	Nutrition nurse specialist GI / Hepatology nurse specialist
Allied Health Professionals	Dietetics Pharmacy Speech therapy

Incidence and Prevalence of Common Conditions

For many of the conditions seen by Paediatric Gastroenterologists there is poor information about incidence and prevalence. Many conditions are chronic, clear diagnostic coding is lacking and children are frequently seen in an outpatient environment. The Information Services Division (ISD) is unable to provide reliable data. Data are however available from a few national studies and additionally from databases in each of the tertiary centres. Information about changes in incidence and prevalence over time is also largely lacking, with the exception of very good Scottish data on inflammatory bowel disease (IBD) (2,3).

Inflammatory Bowel Disease

Inflammatory bowel disease (IBD) comprises Crohn's disease, ulcerative colitis and indeterminate colitis. Retrospective studies of childhood IBD in Scotland, carried out by the late Prof. Anne Ferguson, 1968 to 1983 (2) and 1981 to 1995 (3) have provided the best data on changes in IBD incidence anywhere in the world. A smaller study from NE Scotland has shown a doubling to the incidence of Crohn's disease between 1980-89 and 1990-99 (4). In addition a further study by the British Paediatric Surveillance Unit (BPSU) (5) in 1998-1999 prospectively documented the incidence of IBD in children under the age of 16 across the United Kingdom. In Scotland there has been a fourfold rise in the incidence of childhood Crohn's disease over a 30-year period. (table 3) This rise has been mirrored in most European countries, although the highest rates are found in Scotland. The prevalence of Crohn's disease in 1995 was 9.5 per 100,000 population. A more modest rise in ulcerative colitis (UC) has been seen over the same period. The majority of the children were between 10-16 years of age at diagnosis.

With changes in environmental circumstances the age at which patients present with IBD is steadily decreasing. This has had a dramatic effect on the number of patients under the age of 16 years.

These incidence figures, if they continue to rise at the present rate will equate to 90 new cases of childhood IBD per year with a total 500-600 children in Scotland with IBD. This is likely to be an underestimate as there are a significant number of children under 16 years, who are never seen in a PGHN centre.

Table 3. Incidence per 100,000 Children aged < 16 years

	Crohn's	Ulcerative Colitis	All IBD
1971-75	1.0		
1975-80	1.4		
1981-85	1.9	0.8	
1986-90	2.6	1.4	
1991-95	3.1	1.8	
1990-99	4.4 (Grampian)		
1998-99 (BPSU)	4.2 Scotland	1.8	6.5
	3.1 England	1.4	5.2
	3.2 Wales	1.7	5.2
	3.1 UK	1.4	5.2

Coeliac Disease

Although there are no population studies of the incidence of coeliac disease in the whole of Scotland, there is very clear evidence of a rapid rise in the incidence of this condition across all European populations. In a study in the region of SE Scotland, using data from 4 independent sources, the incidence of coeliac disease rose in the paediatric population during the period of 1990-99 from 0.8 to 4.8 per 100,000 childhood population. This rise has resulted from the development of non-invasive screening techniques, which can diagnose the condition in a pre symptomatic state. The previous prevalence was thought to be between 1 in 2000 of the population but is now known to be 10 times higher at about 1 in 100 to 200 (6). In children with type 1 diabetes (7) and in children with Down's syndrome the incidence is approximately 1 in 20. The majority of these patients, many of whom are children, are waiting to be diagnosed. Specialist paediatric endoscopy facilities, and experienced histopathology and dietetics are required to confirm the diagnosis and to manage children with coeliac disease.

Nutritional Support

Fifteen years ago all children with intestinal failure died and children with feeding and swallowing difficulties grew poorly, frequently aspirated, suffered pain from oesophagitis and many had slow painful deaths from starvation and infection. With the development of safe methods for the delivery of home parenteral nutrition (PN) (8) and the longterm use of tube feeding (9), often by gastrostomy, the incidence of these treatment modalities has increased from almost zero 10 years ago to over 600 home enteral fed (table 3) and 11 home PN children in Scotland. In a cohort of children with endoscopically placed gastrostomies (10), 96% were still alive 5 years after insertion and only 18% of the remainder had stopped feeding. As a result of this the number of enterally fed children is increasing year on year without the necessary increase in patient support and funding. This group of patients never previously existed and at present no parallel adult service exists for onward referral.

Under the auspices of the Scottish Executive, a home PN Managed Clinical Network has been formed. This encompasses a paediatric subgroup, which is supported by all Scottish centres.

Hepatitis B and C

With the increasing drug problem in Scotland more children are at risk of infection with hepatitis B and C. None of the Scottish centres have accurate data in incidence and prevalence. PGHN specialists offer support to our neonatal, infectious diseases and community child health colleagues. At present services in Scotland for these children are disjointed. These patients may also be seen at one of the visiting hepatology clinics.

Neonatal Hepatitis

All children with neonatal hepatitis should be managed in a PGHN centre. Late referral of these patients continues to compromise their care with delayed initiation of supportive treatment. Patients continue to be misdiagnosed in both primary and secondary care and any child with persistent conjugated hyperbilirubinaemia needs urgent referral. Approximately 30 children a year are seen in Scotland of which 2 or 3 are likely to have biliary atresia. These children are managed jointly with support from one of the three tertiary UK hepatology centres. All children with biliary atresia or progressive liver disease should be referred to one of these centres for further management and joint care (11).

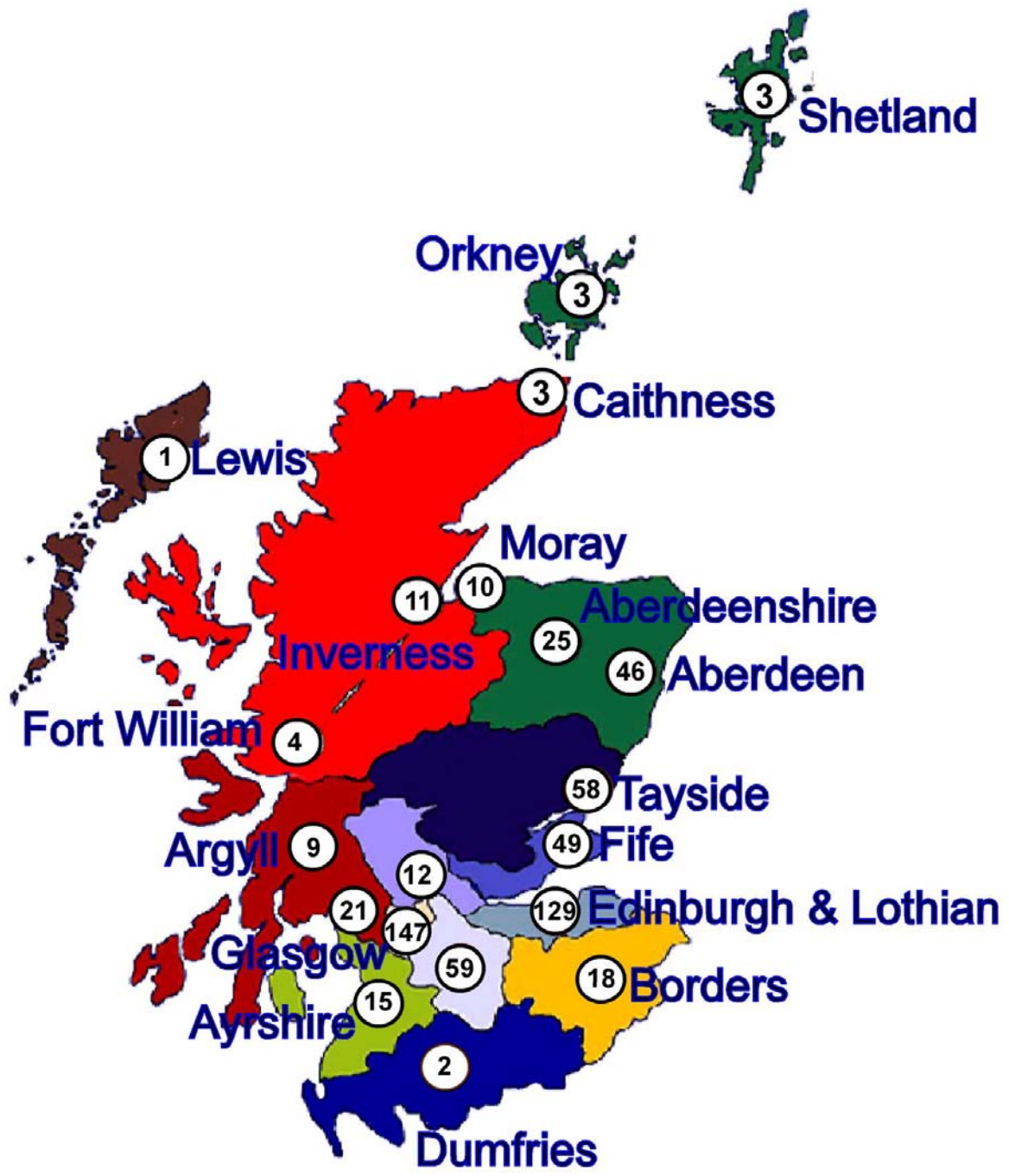


Figure 1 Home enteral Nutrition (HEN). An outline of the number and location of children, known to the centres in Edinburgh, Glasgow, Dundee and Aberdeen who are receiving HEN. These figures are likely to under represent the number of children cared for in peripheral units where there are no paediatric dietitians or paediatric nutrition teams.

Table 4. Activity data from Scottish PGHN Centres for year 2003-2004. Sources; personal recall, departmental database, IT department. In addition a large number of children are investigated in DGH's by adult gastroenterologists or surgeons. The exact number of such children is not known.

Condition	Edinburgh	Glasgow	North of Scotland Network		Total
			Aberdeen	Dundee	
GI food allergic disease	30	35	100	25	190
Coeliac disease	110	60	40	15	225
Inflammatory bowel disease	125	125	70	40	360
Intestinal failure	8	14	5	0	27
Prolonged newborn jaundice	10	15	8	3	36
Liver transplant follow-up	21	10	5	0	36
Home enteral feeding	206	258	104	70	638
Home parenteral nutrition	4	7	0	0	11
Procedures					
Endoscopy - upper GI	255	250	120	80	705
- lower GI	105	115	50	30	300
Liver Biopsy	20	22	10	2	54
Outpatients					
Gastroenterology - new	525	400	300	150	1375
- return	1150	1050	800	500	3500
Hepatology - new	30	30	10	15	85
- return	175	200	60	40	475
Nutrition - new	75	100	50	10	235
- return	275	420	200	30	925
Inpatients					
Admitted to ward	230	250	180	20	680
Day cases	550	550	300	90	1490

Current Services

Brief History

PGHN is a young speciality, which only started to develop widely within the United Kingdom in the 1980's. While Scotland had consultants with an interest at this time, it was much slower than the rest of the UK in appointing specialists. The first three appointments were to academic posts, more by chance than planning, and as a consequence were not always backed up by the resources needed to provide an adequate clinical service.

Consultant Posts

	Year of appointment (present WTE)	Total WTE
Aberdeen	1992 (0.6 wte), 2002 (0.7 wte)	1.3 wte
Glasgow	1994 (0.3 wte), 2002 (0.9 wte), 2002 (0.9 wte)	2.1 wte
Edinburgh	1997 (0.5 wte), 2001 (0.5 wte)	1.0 wte

Development of Services

The three centres have developed differing strategies to provide and maintain their services. This review offers a welcome opportunity to take stock of the present situation and to move forward in a coherent and sustainable manner. The Scottish Paediatric Gastroenterology Hepatology and Nutrition Group (SPGHAN) have been meeting regularly since 1997 in an attempt to promote and co-ordinate clinical services from both a regional and national perspective.

Edinburgh

Dr David C Wilson	Senior Lecturer in Paediatric Gastroenterology and Nutrition (Honorary Consultant) (0.5 WTE)
Dr Peter M Gillett	Consultant in Paediatric Gastroenterology and Nutrition (0.5 WTE)
Ms Pamela Rogers	Gastroenterology and Hepatology Nurse Specialist (1.0 WTE)
Ms Catherine Paxton	Nutrition Nurse Specialist (1.0 WTE)
Ms Alison Coates	Specialist Dietitian (0.5 WTE)

A PGHN service is provided by the two consultants, and the named core members of the multi-disciplinary team. In addition to an inpatient service at the Royal Hospital for Sick Children (RHSC) in Edinburgh, outreach clinics are held at Dumfries and Galloway Royal Infirmary, and at Victoria Hospital, Kirkcaldy, Fife. All patients from St John's Hospital, Livingston, West Lothian and from Borders General Hospital are seen in RHSC, Edinburgh, but there are very close links, with immediate access to consultants, and rapid transfer or outpatient review. By offering shared care with district general hospitals the quality of care offered to patients has increased and has removed the need for children to be investigated by adult physicians or surgeons who may have little knowledge of growth and development or by general paediatricians who may have no subspecialty training in gastroenterology. Transition

clinics for teenagers with IBD are performed in Edinburgh and Kirkcaldy, and for teenagers with liver disease in Edinburgh, all with the relevant paediatric and adult specialist teams.

This service is under great strain as it has developed without necessary resources. Prior to 1997 there had been no regional paediatric gastroenterology service in Edinburgh, meaning that this service has developed from scratch. The outreach service is not resourced, other than through the block contract. In addition both consultants are only officially working half time in this speciality (but are each providing over 40 hours per week of direct clinical care, as proven by work diaries in Spring 2004). One has a 0.5 WTE academic commitments as a full time employee of the University of Edinburgh, and the other has a 0.5 WTE commitment to general paediatrics.

The service in Edinburgh and the South East of Scotland is not sustainable without further investment in both consultant and other support staff. Proper regional planning has not yet taken place and without investment in the service the present outreach service may have to be withdrawn.

Glasgow

Dr Paraic McGrogan	Consultant in Paediatric Gastroenterology and Nutrition (0.9 WTE)
Dr Kamal Hassan	Consultant in Paediatric Gastroenterology and Nutrition (0.9 WTE)
Professor Lawrence Weaver	Professor of Child Health (0.3WTE)
Ms Christinia McGuckin	Parenteral Nutrition Nurse Specialist(1.0WTE)
Ms Elaine Buchannan	Clinical Dietetic Specialist (0.5WTE)
Mrs Tracy Probert	Specialist Dietitian (0.5WTE)

A PGHN support service is provided at the Hospital for Sick Children, Yorkhill, Glasgow. No outreach services are offered to any of the surrounding district general hospitals because of a lack of resources. At present there is a large unmet need from children presently seen in DGHs who are regularly not offered the opportunity of shared care with a consultant in PGHN.

Prior to 2002 the clinical service was provided by a general paediatrician with an interest in gastroenterology (0.3 WTE) and by the Professor of Child Health (0.3 WTE). Following the retirement of the consultant with an interest, two consultant paediatric gastroenterologists were appointed (0.9WTE) each. Their ability to provide a high quality service is compromised by the pressure of work from the large number of patients, and supporting other tertiary services. The pressure is further compounded by difficulty accessing facilities for endoscopy and inadequate support staff. The service has suffered by its late development compared to other paediatric subspecialities. The nutritional team is not appropriately resourced.

While the previous limited service has undoubtedly improved significantly with recent appointments further expansion of the present provisions will be required before it becomes possible to offer all children in the West of Scotland a high quality of service.

Aberdeen, Dundee and the North of Scotland PGHN Network

Dr W Michael Bisset	Consultant in Paediatric Gastroenterology and Nutrition (0.6 WTE)
Dr Gamal Mahdi	Consultant in Paediatric Gastroenterology and Nutrition (0.7 WTE)
Prof Stewart Forsyth	Consultant Paediatrician with an interest, Dundee
Dr David Goudie	Consultant Paediatrician with an interest, Inverness
Miss Kathleen Ross	Chief Dietitian (0.5 WTE)
Mrs Merrie Dwan	Nutrition nurse specialist (1.0 WTE)

A PGHN service is offered at the Royal Aberdeen Children's Hospital with an extensive outreach service (including endoscopy) offered at Ninewells Hospital in Dundee. The Dundee service is jointly provided with a local consultant. A tertiary service for children in Highland is also provided through telephone advice and the review and investigation of children in Aberdeen. An outreach clinic in Highland was first offered in Jan 1998 and is now due to start in September 2004. Many Highland children continue to be investigated and managed by adult specialists. The development of services has benefited from the formation of an 'embryo' managed clinical network which has been fully supported, although not yet funded, by the regional planning process. This has allowed the appointment of a second consultant in 2002 with the resulting development of increased services in Tayside.

This service is continuing to evolve and we hope that the services to Tayside can be increased over the coming year and that Highland will become a full network member. There is under provision of dietetic and paediatric nursing support across the North of Scotland which is needed particularly for the ongoing care of children on enteral nutritional. The service has tried to work within its means but it seems clear that it will need to expand if the large unmet need which presently exist is to be addressed. The aim is to offer all children the opportunity of initial investigation or shared care with a PGHN specialist.

Paediatric Hepatology Services

All three Scottish tertiary centres link closely with the three UK supraregional paediatric hepatology centres in Leeds, Birmingham and King's College London. Initial investigation and treatment of many liver conditions can be carried out in Scotland but where further investigation or treatment is required, patients are transferred to one of the national centres. All patients with biliary atresia and patients requiring liver transplantation should be transferred.

Outreach paediatric hepatology clinics (all day) from King's College are provided in Aberdeen (2 per year), Edinburgh (2 per year) and Glasgow (4 per year) and from Birmingham in Edinburgh (3 per year). This service is funded by the Department of Health in England. In addition Edinburgh and Glasgow have dedicated Hepatology clinics at other times.

Referral Pathways and Gaps in Present Services

Very few formal referral pathways exist for PGHN. Most are informal and based on geographical considerations. There is a hub and spoke model with general paediatricians from district general hospitals referring into one of the three centres / networks. In its 'Guide for Purchasers' (1) the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) outlined the essential services that should be available to any DGH making a referral to a specialist centre. (table 5).

Table 5. Essential criteria for a specialist PGHAN service Items 5,6,and 8 are very incomplete across Scotland and in some areas are completely lacking. Item 1 cannot always be guaranteed and inpatient bed availability, outpatient waiting lists and secretarial support seriously compromise points 2,3, and 7.

1. Access to expert opinion by telephone 24 hours/day.
2. Ability for rapid outpatient referral to defined 'urgent / emergency referral clinic'
3. Capacity to accept in-patient transfers at short notice.
4. Capacity to admit children directly for specialist investigations without prior clinical assessment
5. Regular joint outreach clinics at referring hospitals to assess new patients and review shared care patients as necessary
6. Designated paediatrician at shared care hospital with adequate support services to provide shared care and act as referring consultant to specialist centre
7. Rapid communication of out-patient and in-patient management plans to designated referring consultant
8. Regular meetings teams within managed clinical network to review guidelines / communication / training needs

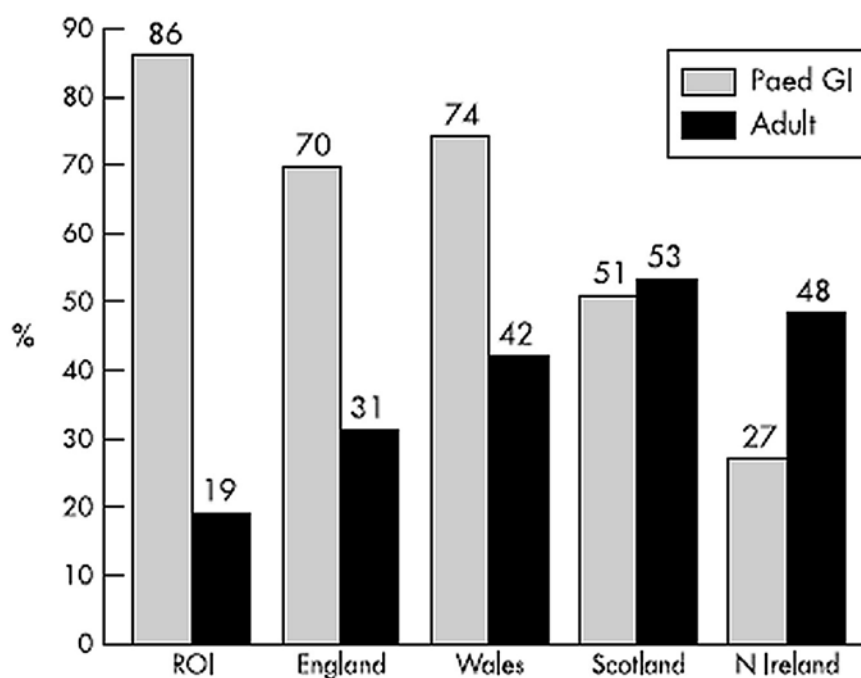
Inflammatory Bowel Disease

All children in Scotland who have PGHN disease should have access to a consultant in PGHN if a specialist opinion is required and patients needing specialist investigation and treatment should be seen at the earliest opportunity. The British Paediatric Surveillance Unit (BPSU) study of paediatric (<16 years) inflammatory bowel disease (IBD) held between 1998-99 (12) has shown that the goal outlined above are not met in Scotland. Only 50% of children in Scotland are initially managed by a PGHN specialist as opposed to 70% in England, 74% in Wales and 86% in the Republic of Ireland. (Figure 3) The figures for the Scottish regions are North 59%, South 48% and West 43%. 72% of children referred to one of the three tertiary centres were seen by a specialist in PGHN compared to only 6% who were diagnosed in other hospitals.

Children treated exclusively by adult specialists were more likely to receive systemic steroids, receive rectal preparations and undergo surgery compared to children managed by a paediatric gastroenterologist who were much more likely to receive nutritional therapy. Active nutritional

therapy is known to be the best way to promote optimal growth in adolescents with IBD. An audit of patient care in Scotland of children with IBD, prior to the appointment of the first specialist in PGHN, showed widespread stunting of growth in adolescents with Crohn's disease with patterns of growth failure which indicate sub-optimal treatment (13). Additionally where follow-up was being carried out by adult physicians and surgeons, there was a neglect of growth and development monitoring (14). The BPSU study (12) provides no evidence that things have improved for those children outwith the care of specialist centres.

Figure 3. Selected specialist involvement by country. Paed GI; specialist in PGHN; adult; adult gastroenterologist and / or adult surgeon: ROI, Republic of Ireland. Analysis of 739 new cases. (12)



Complex Disabilities

Children with complex disabilities often require the care of the specialists in PGHN. These children may have extreme feeding difficulties and malnutrition. The majority require nutrition support, and feeding issues can have a detrimental effect on the quality of life of the whole family. Within the three centres there are multi-disciplinary feeding teams. There is however, a need to develop the supportive role offered to colleagues within the DGHs that also have large numbers of similar patients. There is also concern that there appears to be no parallel service within adult practice and when these children are too old for paediatric services, they and the families are left unsupported.

Transitional Services

This highlights the issues of the transitional services between paediatric and adult services. In Edinburgh transitional clinics have developed for children with inflammatory bowel disease and children who are post liver transplant in moving to the adult service in the adolescent period. In Glasgow and Aberdeen there are currently no transitional clinics and patients are generally transferred on an ad hoc basis after the age of 16 years. It is recognised by both the

paediatric and adult gastroenterologists that resources are needed to develop these transitional clinics.

There are still unmet needs for the adolescent patient with IBD presenting to the adult services. It is not uncommon for the adult gastroenterologist to request his paediatric colleague to undertake the care after the patient's initial assessment by the adult services. This is often due to specific issues such as delayed growth, delayed puberty, nutritional or psychological issues. Worse still many of these adolescents who may be psychologically immature and have many years of further growth potential, may never get the opportunity to be referred to a specialist PGHN service. The present age limit for paediatric services needs to be raised in all three centres with investment in adolescent services.

Information Technology

While each centre has databases of individual patient groups there is no comprehensive IT strategy between the Scottish centres. Data provided by ISD is incomplete and a dedicated paediatric IT system is needed for specialist services within Scotland. The ability to audit outcome and to improve clinical practice is compromised by this lack of data.

Review of Current Practice

As with many paediatric specialities, the evidence base for existing treatment protocols does not reach the high standard required by organisations such as SIGN. Many treatment protocols have been derived from the personal experience of staff or extrapolated from adult practice. The ability to perform high quality double blind controlled trials is seriously compromised by patient numbers (not just in Scotland but across the UK as a whole) and by ethical constraints. There is however evidence from a number of clinical papers of improved outcome where children are investigated and treated in appropriate specialist centres. This is explored more fully on page 4 of the 'Guide for Purchasers' (1) A number of examples are given below:

- jejunal biopsy failure and inappropriate use of gluten-free diets in children suspected of having coeliac disease (15).
- patchy quality of care of children with inflammatory bowel disease (5, 16).
- improved outcomes in children receiving parenteral nutrition when cared for in a specialist centre with a multidisciplinary nutritional care team (17-19).
- Adverse outcomes are associated with delay or failure, to refer children with liver disease:
 - increased morbidity and necessity for urgent liver transplantation in biliary atresia (20-22).
 - irreversible brain damage following delay in initiating treatment in children with inborn errors of metabolism.
 - increased morbidity and mortality from delayed referral of infants and children with a choledochal cyst (23).

- failure to recognise or refer children with acute liver failure may lead to irreversible brain damage and death, or insufficient time to acquire a donor for liver transplantation (24).

Evidence-based guidelines on the management of children and teenagers with IBD are currently being produced by a working group within BSPGHAN, but although methodologically robust, suffer from a lack of methodologically sound Randomised Controlled Trials upon which to base the guidelines. Consensus-based guidelines are available, for example from the Working Groups of the World Congress of PGHAN, and attempt to address issues using “best available evidence”.

Of equal concern to the provision of specialist care by appropriately trained paediatric staff is the fact that many children are likely to be investigated and managed by adult physicians and surgeon in a non-child friendly environment. The cut-off for new paediatric referrals is 12 years in Glasgow, 14 years in Aberdeen, and 14 years in Edinburgh. As most children continue growing until the age of 16 and even longer if suffering from chronic disease, it is most inappropriate for these adolescents to be managed by physician / surgeons with little understanding or training in issues relating to growth and pubertal development.(14) Adult surgeons carry out most endoscopic procedures on children in non-specialist centres. This is primarily because they have access to anaesthetics to facilitate the procedure rather than extensive experience in colonoscopy. Many procedures are incomplete and the clinician may have little or no knowledge of normal childhood mucosal appearances or histology. An audit in SE Scotland of 148 children with IBD has shown that the performance of sigmoidoscopy by adult practitioners is associated with both significant diagnostic delay and diagnostic failure in paediatric IBD (25).

Children may end up on adult wards, will attend adult out patient clinics and not have access to the standard of nursing care laid down by national guidelines for children(26). Many paediatricians in DGH’s feel unable to support patients with severe GI disease because of lack of local support and the lack of clear referral pathways and shared care networks. With the new consultant contract DGH consultants may be so overwhelmed by acute paediatrics that they will be unable to support outreach tertiary services. In addition DGH dietitians or nurses frequently find themselves looking after children with complex GI problems without adequate support of their local paediatrician or peer group.

Workforce Planning and Training

At present the day to day clinical service is provided by two specialists in PGHN in Edinburgh, Glasgow and Aberdeen. On call rotas of 1 in 2 are not sustainable under the European working time directive. Many out-of-hours problems in GI patients may be managed by the on call paediatrician or paediatric surgeon with appropriate protocols. A telephone advisory service by specialist in PGHN is desirable and could be provides across Scotland by the present consultant staff. In the short term it is unlikely that any Scottish centre will attain the necessary 6 or 7 consultants, who would be needed to provide a sustainable 24 / 7 / 365 service, indeed there are probably no UK centres able to deliver such a service.

None of the specialists in PGHN working in Scotland received their primary specialist training in Scotland (3 England, 3 Canada, 1 USA) and only three attended Scottish medical schools. Attempts to promote PGHN training in Scotland with the formation of a Scottish training programme have been thwarted by lack of co-operation between post-graduate deans. All three centres in Scotland have been visited and approved by the College Speciality

Advisory Committee in paediatric gastroenterology. Other than the need to spend six months in a tertiary hepatology centre in England the remainder of training can be done within Scotland. If the 50% of Scottish children who presently do not have access to specialist care is to be reduced there is clearly a need to increase both the present number of consultants but also AHPs and nurses who equally support the clinical service.

Of the present consultant complement there is likely to be one retiral within the next 10 years, although it should be noted that one consultant has already resigned after one year in post to work in North America. Unless there is a sustainable service, staff retention may become an important issue. Recruitment is presently difficult with few applicants for national grid SpR posts and an average of two applicants for each consultant post.

Quality Standards / Outcome indicators

Formal quality standards and outcome indicators in PGHN are few and far between. There have however been a number of publications outlining suboptimal outcomes and some of these have already been outlined in the section on the review of current practice. For a child to be investigated and managed by a consultant with no specialist training in PGHN or in Paediatrics constitutes a failure of quality standards. This has already been outlined in the section on 'gaps in the present services'. There is evidence that endoscopic procedures carried out by adult specialist are likely not only to be incomplete but the children are less likely to be offered appropriate medical therapy (12). Historically the consequence of this for Scottish children has been growth failure and stunting (13).

Standards of Training

Medical Staff

There are clearly defined standards for training in Paediatric Gastroenterology. Previously these were regulated by the Joint Committee on Higher Medical Training (JCHMT) but at present the Royal College of Paediatrics and Child Health oversees the College Speciality Advisory Committee (CSAC) on Paediatric Gastroenterology Hepatology and Nutrition. These guidelines are available online at the British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN) web site at <http://bspghan.org.uk/training.htm> This training programme lasts three years and is based on 2-3 centres and equates to years 3, 4 and 5 of the SpR training. The CSAC group has assessed and given approval to all three centres to undertake tertiary training. The SPGANG group has developed a rotation to allow full training in gastroenterology and nutrition within Scotland with their hepatology attachment being undertaken and funded at King's College, London. In addition to clinical training the SpR needs to learn appropriate procedural skills in both diagnostic and therapeutic endoscopies. This is carried out under the supervision of consultants within the three centres. There is also an opportunity for paediatricians to train with an interest in PGHN.

Scotland has been recognised as being able to provide a national tertiary SpR training number for PGHN although, there has been difficulty over the funding issue with regional postgraduate deans and as such no trainee was appointed this year.

Guidelines for specialist training in nutrition within paediatric gastroenterology hepatology and nutrition are also produced by BSPGHAN and can be viewed at:

<http://bspghan.org.uk/document/CSACNutCurric.PDF>

Draft guidelines for the training of Paediatricians with an interest in Paediatric Gastroenterology can be viewed at: <http://bspghan.org.uk/training.htm>

Guidelines for training in Endoscopy have been produced by both the BSPGHAN and the Royal College of Physicians (RCP) Royal College of Surgeons (RCS). They can be viewed at BSPGHAN: <http://bspghan.org.uk/training.htm>
RCP / RCS: http://www.bsg.org.uk/pdf_word_docs/jag_recommendations_2004.pdf

Dietitians

Dietitians typically enter paediatric dietetics after two or more years of general dietetics. The Paediatric Group of the British Dietetic Association runs three accredited post-graduate courses. These are three-day residential courses, Introduction to Paediatric dietetics and two advanced modules, the first of which covers gastroenterology and nutrition support. Dietitians working in paediatric gastroenterology can obtain relevant continuing professional development as associate members of BSPGHAN.

Nursing Staff

Nurses working as Gastroenterology, Hepatology and Nutrition Nurse Specialists may be either solely paediatric trained or dual trained (paediatric and adult trained). Most will be expected to have obtained or be working towards degree level, either bachelor level or masters level. Nurses will have typically worked in a general ward area for at least 2 to 3 years prior to specialising. Nurses working with Gastroenterology, Hepatology and Nutrition teams would be expected to have completed a relevant accredited course such as Paediatric Hepatology and Transplantation (formally ENB 15). Nurses working within the team will also be expected to obtain relevant Continuing Professional Development as associate members of the BSPGHAN, and other groups, such as the Managed Clinical Network for Home Parenteral Nutrition in Scotland.

Standards of Service

Few of the reports by QIS in Scotland or NICE in England are directly relevant to PGHN. Standard produced by recognised national bodies are outlined below.

- The Guide to Purchasers of Paediatric Gastroenterology Hepatology and Nutrition Services also references a number of informal and formal standards (1).
<http://bspghan.org.uk/document/GuidelinesforPurchasersSeptember2003.pdf>
- QIS: Food Fluid and Nutritional Care in Hospitals
<http://www.nhshealthquality.org/nhsqis/files/F>

In adherence to the above standards produced by QIS Scotland, each centre has a multi disciplinary standing committee for nutrition. In addition centres have multi disciplinary nutritional support teams to provide assessment of children with complex nutritional problems and to co-ordinate their nutritional support. This recent QIS report requires assessment of all children attending hospital and has massive implication for expansion of resources and professionals involved within the nutritional team. At present most DGHs do not have a paediatric dietitians let alone a nutrition team for children

- QIS: Nasogastric and Gastrostomy Tube Feeding; for children being cared for in the community. <http://www.nhshealthquality.org/nhsqis/files/GastrostomyNMPDU.pdf>

D of H: (NSCAG) Designated centres for biliary atresia surgery in England (D of H 199/0268)

http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4025401&chk=9fQcTo

There is no similar advice from the Scottish Executive with regard to the management of children with biliary atresia. In the last three years all children presenting with biliary atresia and with whom a paediatric gastroenterologist has been involved have been transferred to one of the super regional centres in England. Currently, there is an on-going discussion with our paediatric surgical colleagues trying to formalise this management step but as yet no clinical conclusion has been agreed.

- BAPEN: Current Perspectives on Paediatric Parenteral Nutrition (ISBN 1 899 467 408) <http://www.bapen.org.uk/>
- BAPEN: Standards and Guidelines for Nutritional Support of Patients in Hospitals (ISBN 1 899 467 106) <http://www.bapen.org.uk/>
- BAPEN: Home Parenteral Nutrition - Quality Criteria for Clinical Services and the Supply of Nutrient Fluids and Equipment (ISBN 1 899 467 157) <http://www.bapen.org.uk/>
- BAPEN The King's Fund Report - A Positive Approach to Nutrition as Treatment
Click the title to download the full publication in pdf format
(ISBN 1 85717 016 4)
http://www.bapen.org.uk/pdfs/publications/kings_fund_sum.pdf
- D of H: Getting the Right Start: National Services Framework for Children. Standards for hospital services. April 2003 (25)
<http://www.dh.gov.uk/assetRoot/04/06/72/51/04067251.pdf>

Audit

Edinburgh

Participation in BPSU and National register of IBD (1997 to present)

Audit of effect of formation of a nutrition support team on nutritional knowledge, surveillance and practice (1998)

Incidence of paediatric coeliac disease in SE Scotland from 1990 to 1999 (2002)

Diagnostic delay and failure in the diagnosis of paediatric coeliac disease (2002)

Incidence of home enteral tube feeding (1997 to 2002).

Infection rates in children receiving percutaneous endoscopic gastrostomy 1997-9 (2001)

Methotrexate use in azathioprine-resistant paediatric Crohn's disease 1998-2002 (2003).

Routine dietetic management of obese children 1995-2000 (2004).

Adequacy of calcium intake in children with coeliac disease (2003)

Diagnosis of central DVT in children receiving long term parenteral nutrition (2004)

Biochemical monitoring of children having long term enteral tube feeding (2004)
Investigation of time to diagnosis of paediatric IBD 1997-2003 (2004).
Diagnostic utility of barium swallows in children (2004)

Aberdeen

Audit of a multidisciplinary tertiary care encopresis clinic (1993-1995)
Paediatric GI endoscopy; An audit of 250 consecutive cases (1994-95)
Paediatric gastrostomy feeding from a medical and parental perspective. (1997)
The value of HIDA scan in assessing neonatal conjugated hyperbilirubinaemia (1998)
Presentation and management of juvenile onset IBD in North East Scotland (2002)
Prevalence of Coeliac disease in children with type I diabetes. (2002)
Percutaneous endoscopic gastrostomy: A promising 10 years experience (2004)
Participation in BPSU and National register of IBD (1997 to present)

Glasgow

Bone mineral density and growth in IBD patients (2002)
Bone Fracture rate in IBD patients (2003)
Assessment of abnormal liver function tests over 5 years in Yorkhill (2003)
Prevalence and presentation of Intestinal Spirochaetosis in Children (2004)
Participation in BPSU and National register of IBD (1997 to present)
Polymeric diet in the management of Crohns disease (2004)

Parent Participation

Parents and families are involved with PGHAN professionals through local patient groups, for example branches of the Crohn's in Childhood Research Association, Children's Liver Disease Foundation, and Coeliac UK. These act as fora for education, sharing views on local services, and addressing unmet needs.

Education and Information

Patient organisations and electronic libraries are the main source of information for patients and parents. Helpful leaflets and helplines are available for some organisations. Overall however, information is often limited and professionals frequently do not have as much time as they would like to pass information on to parents or children. This is clearly an area that needs to be addressed across all areas of the service.

The following organisations also provide patient information.

- Children's Liver Disease Foundation, 36 Great Charles Street, Birmingham, B3 3JY, United Kingdom. Tel: 0121 212 3839 Fax: 0121 212 4300 E-mail: cldf@childliverdisease.org Website: <http://www.childliverdisease.org>
- Coeliac UK, PO Box 220, High Wycombe, Bucks HP11 2HY, United Kingdom. Tel: 01494 437278 Fax: 01494 474349 E-mail adminsec@coeliac.co.uk Website: <http://www.coeliac.co.uk>

- Crohn's in Childhood Research Association, Parkgate House, 356 West Barnes Lane, Motspur Park, Surrey KT3 6NB, United Kingdom Tel: 020 8949 6209 Fax: 020 8942 2044 Email: support@ciara.org Website <http://www.cicra.org>
- National Association for Crohn's and Colitis, 4 Beaumont House, Sutton Road, St Albans, Herts. AL1 5HH. Tel: 0845 130 2233 Website: <http://www.nacc.org.uk/>
- Cystic Fibrosis Trust, 11 London Road, Bromley, Kent BR1 1BY, United Kingdom. Tel: 020 8464 7211 Fax - 020 8313 0472 Website: <http://www.cftrust.org.uk>
- Gut Motility Disorders Support Network, 7 Walden Road, Swards End, Saffron Walden CB10 2LE, United Kingdom. Tel: 01799 520580 E-mail: help@gmdnet.org.uk Website: <http://www.cafamily.org.uk/Direct/g42.html>
- Ileostomy and Internal Pouch Support Group, National Secretary, P.O. Box 132, Scunthorpe, Humberside DN15 9YW, United Kingdom. Tel: 0800 018 4724 Fax: 01724 721601 E-mail ia@ileostomypouch.demon.co.uk Website: <http://www.ileostomypouch.demon.co.uk>
- The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition NASPGHAN, PO Box 6, Flourtown, PA 19031, USA Tel: (215) 233-0808 Fax: (215) 233-3939 E-mail naspghan@naspghan.org Website <http://www.naspghan.org/>
- Patients on Intravenous & Nasogastric Nutrition Therapy, PO Box 3126, Christchurch, Dorset BH23 2XS, United Kingdom. E-mail: pinnt@dial.pipex.com Website: <http://www.pinnt.com>
- British Association of Parenteral and Enteral Nutrition. BAPEN Office, Secure Hold, Business Centre, Studley Road, Redditch, Worcestershire, BN98 7LG Tel: 01527 457850 Fax: 01527 458718 Website <http://www.bapen.org.uk/>

Research

National

The major collaborative area for research is in the genetics of early-onset IBD. This is supported by all regional centres for PGHAN as collaborators, and is funded by a Wellcome Trust Molecular and Cell Biology Panel Programme Grant (072789/Z/03/Z) for £682,723 (1.1.04 to 31.12.08). One specialist registrar in PGHAN is currently a PhD student in the project.

Edinburgh

Major interests include the genetics of IBD with the national study outlined above, based in Edinburgh. Inflammatory markers in IBD and the safety of MMR and its relation to autism and IBD are presently under investigation. A study of antibiotic prophylaxis in gastrostomy insertion is in progress. Further research includes the study of reflexology for childhood constipation and the measurement serological markers of hepatic fibrosis.

Glasgow

The main foci of scientific interest have been and are in non-invasive methods of nutritional and GI assessment, particularly in children with chronic disease and malnutrition, nutrition support, childhood *Helicobacter pylori* infection, and the mechanisms of action of prebiotics and probiotics in early life.

Aberdeen

The research of the unit relates largely to IBD in childhood. Recently concluded studies have helped validate the use of non-invasive makers of intestinal inflammation in IBD. A study looking into the modulation of intestinal inflammation through the use of probiotics is planned and will start shortly.

Dundee

The principal research theme has been the investigation of the relationship of infant nutrition and metabolism to later childhood health and development. In particular, with the Dundee Infant Feeding Study significant long-term health benefits from breast feeding have been demonstrated. More recently the relationship of long chain polyunsaturated fatty acids to child health and development has been investigating.

Over the last 5 years the Scottish PGHN centres have produced 62 papers which have appeared in peer review journals. These are listed in Appendix 1. In addition a large number of review articles, book chapters and letters have also been published.

Involvement of Stakeholders

A high quality service in PGHN is dependant on close links with the professions outlined in Table 2. Consultants are totally dependant on the expertise of their AHP colleagues (particularly dietitians) and on their Nutrition and GI nurse specialist. Very often these professionals are appointed as an afterthought or worse, not at all. Good quality care is dependent on the firm foundations of a robust General Paediatric and Paediatric Surgical service. Regional and national speciality planning is something that has never happened in the past and the present process gives us an invaluable opportunity to clearly define the optimum staffing configuration and model of service delivery to provide a high quality service.

Dietetics

Working Practices

Dietitians are key members of the multi-disciplinary team working closely with nutrition nurses and other clinical professionals. There are opportunities for dietetic led services; eg coeliac clinics and PEG follow up clinics

Supporting colleagues

Within Scotland many dietitians work part time in paediatrics, generally in a DGH or community setting. Specialist dietitians recognise the need to support these colleagues and informal networks have developed. Throughout Scotland there is shared dietetic care of children between the major centres and DGHs.

The paediatric dietetic leads from the four major centres meet regularly and see education and developing robust networks to support good practise as a priority.

GI and Nutrition Nurses

Working Practices

Nurse Specialists working within the areas of Gastroenterology, Hepatology and Nutrition are key members of the multi-disciplinary team. They are currently involved with establishing and the running of Nurse-led clinics for gastrostomy care, constipation and immunosuppression (methotrexate and azathioprine) clinics for children and teenagers with complex inflammatory bowel disease. Within the role of Nurse Specialist is a large teaching component for families and staff. They also play an important role during the transition of teenagers from the paediatric to the adult setting, and participate in formal transition clinics.

Supporting Colleagues

The Nurse Specialists have an important role in the shared care of patients and families referred to specialist areas such as supraregional UK paediatric transplant centres. They also provide education and support to District General Hospital and Primary Care staff. Nurses meet on a regular basis at BSPGHAN meetings, as well as having regular telephone contact regarding patient updates. This has resulted in formal and informal networks being established.

Options for Improved Service Delivery

The new consultant contract offers an opportunity to rationalise and strengthen PGHN services, including the development of managed clinical networks. In district hospitals acute paediatric services are being prioritised, eclipsing the needs for sub-speciality support. Scottish consultant specialists in PGHN are all working in excess of 50 hours; most working over 40 hours on direct clinical care. There will be constraints on hours worked, both by the funding of the new consultant contract and the European working time directive. At present a high quality service is provided in the three Scottish PGHN centres. These services are under strain and cannot be sustained unless there is real investment in the service.

Problems

- Up to 50% of Scottish children do not have ready access to PGHN services
- PGHN services have developed in an ad hoc manner
- There are inadequate doctors, nurses and AHPs to provide a comprehensive PGHN service for Scotland
- The number of children with complex GI or nutritional problems is increasing
- There are geographical regions without specialist services that are unable to invest in regional centres
- The expectation of parents frequently exceeds the capacity to deliver first class PGHN service
- Children are not small adults, and investigation and management by adult doctors is inappropriate

Future Service Model

Scotland has been late in providing PGHN services. However progress over the last decade has been quite significant. There are three regional centres, one each in the North, West and East. At present they primarily serve their surrounding populations. Increasing outreach needs to be provided and formal service and funding links made with adjacent Health Authorities.

All PGHN centres work well together and must develop further joint working, common protocols and referral guidelines. There is at present a virtual Scottish PGHN Network. This has to be consolidated and developed further.

The initiative to develop managed clinical networks in PGHN has progressed slowly because of funding constraints. If the Scottish Health Department wishes a high quality service it must invest appropriately and ensure that Health Boards purchase services appropriately..

A comprehensive out-of-hours service is not possible in centres of two or three consultants. Cross covering with colleagues in medical paediatrics and paediatric surgery will provide a safe service for the vast majority of patients. There are adequate consultants in Scotland to provide an out of hours telephone advice service. There are few PGHN problems that cannot be dealt with by a general paediatrician, with appropriate specialist advice.

PGHN services are multi-disciplinary. To maintain and develop clinical networks the Scottish Health Department needs to expand the number of consultants, dietitians and specialist nurses within all centres to at least double the present numbers. There need to be at least three WTE consultants in the North and the East and four in the West. This will allow the development of out-reach clinics, supporting closely with DGH paediatricians who may wish to take a lead role. It will also allow stronger links with adult colleagues in transitional clinics and colleagues within other paediatric specialities. Dietetic and nursing support must be expanded significantly in the DGHs to support managed clinical networks that provide optimal and equitable access for children and their families throughout Scotland.

Optimal Configuration of PGHN Services for Scotland

1. **Tertiary Services:** The first aim in developing the current services in PGHN must be the proper staffing and resourcing of each of the three Scottish tertiary centres. This will require a minimum of three WTE consultant specialists in PGHN to provide a comprehensive service, with multi-professional support teams, including dedicated dietitians and nurse specialists, in each centre.
2. **Secondary Services:** The second aim is developing comprehensive services for the whole of Scotland, to support the clinical workload of district hospitals, must be the creation of a PGHN Network. The optimal shape and configuration of this will involve the identification and/or training of consultant paediatricians with an interest in PGHN, and the development of resources for shared care. Supporting staff in dietetics and nursing are essential to the development of these services.

3. **Special Problems:** The third aim in developing comprehensive PGHN services in Scotland must be the provision of expertise for the assessment and care of uncommon, high-intensity medical and surgical problems which require acute and chronic tertiary 24 hour specialist expertise – intestinal failure, acute liver failure etc. The three tertiary centres, with properly-resourced dietetic, nursing and general paediatric and surgical, support, will have the potential to act as single virtual centre.
4. **Home Feeding:** The fourth aim in providing a comprehensive service in PGHN must be the provision of multi-professional services for children receiving home enteral nutritional support, led by specialist nurses and dietitians.

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Appendix 1

Peer review publications for Scottish PGHN centres in the last five years. Data combined and presented in alphabetical order of first author:

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