



National Steering Group for Specialist Children's Services
Paediatric Gastroenterology, Hepatology and
Nutrition (PGHAN) Service
Executive Summary

Background

A Review of Paediatric Gastroenterology services in Scotland report published in 2004 identified key actions required to progress the service.

It recommended

- Regional delivery of the service, with a Managed Clinical Network linking the 3 regions together to ensure a comprehensive, equitable and optimal service;
- The 3 regional services should act as one for specialist advice and management of rare and complex problems;
- Investment to increase staff numbers in all staff groups (medical, nursing, dietetic) was required to support development of regional networked services;
- The raising of the age of admission to children's services to 16 to ensure young people with PGHAN problems are seen and treated in a paediatric service was imperative.

Outcomes

All children under the age of 16 years with a PGHAN problem should have ready access to the expert opinion of a specialist PGHAN team. National and regional referral pathways will be established to support this.

All children under 16 years requiring endoscopy for suspected Inflammatory Bowel Disease (IBD) will have this carried out under the supervision of a PGHAN team. Evidence is available to demonstrate that young people with IBD who are treated in adult services are often not appropriately investigated, monitored or offered the appropriate treatment when compared to PGHAN services.

All neonates with hepatitis will be managed by a PGHAN centre/team (approximately 30 cases/year) to ensure appropriate diagnosis and treatment is provided to reduce the risk of associated morbidity/mortality due to delay in or failure to refer to a specialist team. This will link to the specialist services provided by the three UK paediatric hepatology centres.

Development of standards/guidelines to enable measurement/monitoring of progress toward meeting the goals outlined above.

Risks

Key performance indicators that relate to the care of children with PGHN problems do not presently exist. The present shortfall in services is hidden as a result of this.

Lack of investment in staff at a regional and local level has led to a de-motivated group of clinicians who are working in some areas at crisis level. Children are travelling large distances to see a Specialist (e.g. Dumfries to Edinburgh), where there was once an outreach service. Children in some District General Hospitals have to wait 11 weeks for a Dietetic appointment (e.g. West Lothian).

There are no paediatricians in DGHs in the West of Scotland who have trained with an interest, nor outreach clinics which would allow access for children and young people to the Specialist, and Specialist support to the local Paediatrician. This has proved a major obstacle in the establishment of a regional network in the West of Scotland

Without adopting a consistent approach to data collection, referral pathways and standard setting, children continue to be treated sub-optimally in non specialist and adult services, and outcomes across Scotland for children remain variable

Network arrangements

This specialty has identified that it requires a regional managed service network approach, with established multi disciplinary teams based in the 3 regional centres (Glasgow, Edinburgh, and Aberdeen/Dundee)

- The facility should be created within job plans to ensure clinical meetings are standard practice across the network utilising IT resources;
- Within this, the Children's Hospitals would then be able to identify Consultants/Specialist Nurses/Dieticians to provide outreach clinics to District General Hospitals;
- Identified Paediatricians/Local Nurses/Dieticians at DGH level should be encouraged to attend a clinic at the specialist centre on a regular basis.

A national network comprising identified clinicians and patient/parent representatives could support the development of the service, by formulating standards and guidelines and sharing information and developing opportunities for further research, if this infrastructure is established.

24/7 specialist advice could be available to Paediatricians across the country via a Scotland wide 'on call' service. Formalisation of the clinical links between specialist PGHAN, dietetic and nursing staff needs to be extended to cover all areas of Scotland. Full staffing of regional centres is required before this can be delivered.

A Paediatric sub group of the Home Parenteral Nutrition (HPN) MCN is well established. The Scottish PGHAN services should link to other Scottish (i.e. PN) or UK wide (i.e. Hepatology) networks.

National / Regional / Local Planning

National

- Support for a bridging MCN to link together the Regional Managed Service Networks, and develop standards and guidelines across the service / disciplines;
- The establishment of a national database to ensure the collation of accurate data to inform future planning of services. This includes children with IBD, coeliac disease, Hepatitis B and C, and liver disease;
- Work with other national groups to ensure the development of an electronic patient record linked to laboratory services so that all PGHAN staff in Scotland have access to the appropriate clinical information 24/7.

Regional

- Each region would benefit from securing network management time, and undertaking a comprehensive baseline audit of current service provision/needs analysis to map progress and assist future planning, e.g.
 - Number of children with IBD being seen in adult services;
 - Number of children with Hepatitis B and C;
 - Mapping progress of workforce developments as highlighted in the 'Review of Paediatric Gastro Hepatology and Nutrition service' 2004.
- Regions to establish dialogue to identify and agree with Lead Regional Paediatric Gastroenterologist and local Paediatricians, which District General Hospitals need to develop a Paediatrician with special interest role.
- Appointments/identification of Paediatricians with special interest are a priority in order to establish joint outreach clinics in District General Hospitals to assess new referrals and review children receiving shared care, ensuring children are treated locally while still having access to visiting Specialists.

Local

- Within an agreed framework, DGHs to identify a Paediatrician with Special Interest as required (see above).
- Each DGH to identify Named Nurse/Children's Community Nurse to act as a link/key worker for this group of children.
- Each DGH to identify Named Dietician.

Resource Consequences

Establishment of a national data base linked to an electronic patient record – this has been demonstrated by the Cleft Lip and Palate MCN to be an invaluable resource. The resources presently available through the Generic Clinical System (GCS) Project should facilitate this and need to be available to both the regional and national PGHN networks.

- IT equipment being available to allow 24/7 access to specialist on call service;
- Clinician time to enable outreach clinics and endoscopy lists (see staffing and workforce), DGH ward reviews and regular Continued Professional Development and training sessions for all staff;
- Provision for Paediatricians with an interest to do in-reach clinics in the tertiary centres.

Staffing and workforce issues

Medical

Development of capacity within the workforce to deliver the service outlined above has been updated in October 2007. Meeting these recommendations is essential if Scotland is to offer its children and young people a safe, sustainable high quality service. While some progress has been made since the last review in 2004, many parts of the service remain stretched and many children live out with the reach of the present service.

	Presently funded consultant provision	Shortfall in consultant provision
Glasgow	5 consultants (3.9 WTE)	1 consultant (1.0 WTE)
Edinburgh	3 consultants (2.6 WTE)	1 consultant (0.8 WTE)
Aberdeen/Dundee	2 consultants (1.25 WTE)	1 consultant (0.7 WTE)

The Regional Planning Groups need to ensure that DGHs work in partnership with the Children's Hospitals to deliver safe PGHN services as close to the child's home as possible. The role of the Consultant with an interest is crucial to this process.

Currently Dumfries, Kirkcaldy and West Lothian have identified Paediatricians to work with the Edinburgh service. This needs to be expanded to the Borders. The service in the North links with Paediatrician in Dundee and Inverness. The West of Scotland has no identified network at a DGH level.

Specialist Nurses.

Specialist Nurses provide a valuable resource for children, young people and their families. Roles have been extended to support the nutrition service, and provide continuity of care, treatment and advice to children with IBD. Each region has developed Specialist Nurse roles in response to local need and specialist interest.

There is scope to further develop nursing roles to provide nurse led outpatient clinics, and telephone helplines. Edinburgh and Glasgow have established IBD Nurse specialist roles, but the workload is overwhelming, and extra resources are required. The North of Scotland have identified the need for an additional IBD nursing resource in Aberdeen and Inverness with increased hours in Dundee.

Glasgow are in the process of negotiating a Specialist Nurse post to support the nutrition side of the service, and have identified the need for support for children with chronic liver disease and post transplant care.

Shortfall in specialist nurse provision

Edinburgh	1 WTE
Glasgow	2.5 WTE
North of Scotland, split across Aberdeen, Inverness and Dundee	0.95 WTE

It has not been possible to quantify the shortfall in community paediatric nursing support. These nurses are vital for the local support of children with PGHAN problems.

Dieticians

1. Dieticians play a vital role in supporting children with PGHN problems and there are opportunities to further develop dietetic led clinics ie coeliac disease. Both Edinburgh and the North of Scotland have identified an urgent need to increase current dietetic provision to children and young people to provide the following:
 - Additional nutritional input for children with IBD required;
 - Not all GI clinics presently supported. More ongoing input required;
 - Additional time needed to fully support GI and liver patients.

Shortfall in specialist dietetic provision

Edinburgh	0.8 WTE
Glasgow	1.0 WTE
North of Scotland, split across Aberdeen, Inverness and Dundee	0.8 WTE

It has not been possible to quantify the shortfall in DGH dietetic support. These non-specialist dietitians are vital for the local support of children with PGHAN problems and often work in isolation without the supported of specialist PGHN colleagues.

Psychologists

Psychologists are integral members of the multi-disciplinary team to the support of children with chronic disease.

- Children and young people with IBD are at greater risk of developing problems with depression, anxiety and social dysfunction than those with other chronic health conditions
- Families awaiting liver transplant experience more psychological difficulties and family dysfunction than those undergoing renal transplant and find it more difficult to return to adaptive family functioning post transplant

There is a shortfall in specialist psychologist provision across the country for this service.

Recommendations

	Action	By when
1.	Each region to establish a managed service network based on the 2004 report.	2008/09
2.	Each Region to review PGHAN service provision, and produce an implementation plan to address identified need	2008/09
3.	Develop a national network comprising identified Clinicians and patient/parent representatives.	2009
4.	Develop national standards / guidelines and care pathways for key conditions e.g. IBD,	2008/09
5.	Review of data requirements and establishment of a national data base	2009/10