



National Steering Group for Specialist Children's Services

Endocrinology Working Group

Executive Summary

Background

Paediatric Endocrinology is concerned with the diagnosis and management of children and young people with hormonal disorders (including growth and puberty problems). Whilst specialised endocrinology services are not available in every local hospital, considerable support is provided to a number of District General Hospitals via outreach support, from Glasgow and Edinburgh Children's Hospitals.

The quality of care presently provided within the endocrine service is high and a number of referral pathways exist into specialist centres within Scotland and the United Kingdom. However the challenge facing the service in the future is the sustainability of an accessible service which does not require children and families to travel excessive distances for support.

With this in mind the review group focused on the following -

- Completion of a review of current patterns of endocrinology care for children and young people up to 16 years of age across Scotland;
- Completion of a review of laboratory provision for endocrine services;
- Identification of solutions for the sustainability of quality care across Scotland;
- To produce a report for consultation with relevant groups, including specialist and non-specialist teams in remote localities.

Summary of Process

The following activity was undertaken as part of the review process –

- Analysis of ISD available data;
- An information gathering exercise involving all those involved in the provision; of endocrine care across Scotland;
- A review of laboratory services;
- A literature review.

It should be noted that this review has been undertaken within an extremely short time and not all aspects of the service have been fully explored, such as future workforce requirements. The recommendations have taken this into consideration.

Incidence and prevalence

The gathering of reliable information has been challenging, due to the various ways in which it is recorded. For example SMR01 data collected by ISD identifies the number of children recorded with endocrinology diagnoses, seen as inpatients or day cases. However many children are seen as outpatients, and the information stream SMR00 collected from outpatient clinics does not record diagnoses. We are

therefore unable to accurately estimate the numbers of children seen in outpatients with endocrinology problems.

Models of Care

There is a strong view that there requires to be common national diagnostic, investigative and treatment protocols (including integrated care pathways where appropriate) and development of managed clinical networks on a regional or national basis. To drive this forward it is felt that there requires to be a national network established, pulling together specialist centres, district general hospitals and rural general hospitals. It is envisaged that this network would be a co-ordinating mechanism responsible for the future development and sustainability of endocrine services across Scotland.

The nature of endocrine conditions will require there to be a UK dimension to the development of models of care for rare conditions.

Workforce Issues

Similar to other specialist areas workforce issues are the key to providing a sustainable service. Fortunately the endocrine service currently has a good level of Consultants working within the service and, in the short-term, there shouldn't be any challenges to the services from this area. Unfortunately issues have been identified which highlight a need for more specialist nursing and allied health professional input. This is an area which requires to be further reviewed and it is envisaged that the establishment of a national network group would allow this to be progressed further.

Laboratory Services

Questionnaires were sent via the Scottish Association for Clinical Biochemistry Audit Group to all laboratories in Scotland, to gather information on the provision of endocrine testing. A detailed report of this work is included within the full report.

The key recommendations from this work include -

- Robust procedures for equipment replacement, staff succession planning and training for biomedical and clinical scientist staff in Scotland;
- Development of formalised referral pathways for complex/specialised endocrine testing at appropriate labs (see separate Review of Specialised Pathology and Laboratory Medicine Services in Scotland);
- Progression towards development and implementation of evidence-based, method-specific Paediatric Reference (normal) Ranges on a national basis;
- National agreement on Dynamic Function Test protocols and interpretative guidelines;

- National agreement on Hypoglycaemia investigation protocols and their interpretation.

Recommendations

	Action	By when
1	Establishment of a National Service Network for endocrinology services.	March 2009
2	Review of Workforce demands, pressures on services leading to development of a workforce plan.	March 2010
3	Develop pathways of care for key conditions.	July 2009
4.	Progress key laboratory recommendations for endocrine services.	March 2010
5	Develop national standards of care to cover all aspects of endocrine care.	March 2010