National Steering Group for Specialist Children's Services

Complex Respiratory/Cystic Fibrosis Review

Executive Summary

DRAFT – NOVEMBER 2007

Introduction

As part of the National Delivery Plan for Specialist Children's Services in Scotland, work has been undertaken which aims to transform the current, fragmented approach to the provision of specialist paediatric services with an integrated service that improves access and quality of care. Many common respiratory illnesses can be very well managed in primary and secondary care. However, those children with severe or complicated presentation of common illnesses e.g. asthma or pneumonia, or with rare respiratory disease require the involvement of a specialist, multidisciplinary team.

Children with complex respiratory problems should be able to access high quality, effective and timely advice, assessment, diagnosis and treatment to enable them to live to their optimum health potential, and achieve independence as they grow and develop.

An informal paediatric respiratory organisation (Scottish Paediatric Respiratory Interest Group - SPRING) comprising interested clinicians has evolved in Scotland over the last few years. This report reflects the views of clinicians working within that group and a small multidisciplinary working party convened to produce this report.

Background

Tertiary respiratory services are required for the purposes of supporting the local clinicians in diagnosis and management of complex problems of common disease e.g. difficult asthma, as well as providing full or shared care for rare disease. In addition, tertiary services have important links to many other paediatric specialties (in particular intensive care, neonatology cardiology and cardiothoracic surgery, oncology, ENT and neurology). The services are dependant not only on highly skilled consultant medical staff but also other essential disciplines including specialist nurses, dietetics, physiotherapy, physiological measurement technicians and psychology. The provision of ready access to specialist investigation facilities is also key to service delivery.

Incidence/prevalence of Respiratory conditions

Respiratory conditions are the commonest cause of paediatric hospital admission, accounting for 14% of UK hospital admissions and over 50% of long-term illness in children. Asthma is the commonest cause of school absence, Cystic Fibrosis the commonest life limiting inherited condition.

Mapping of current services

Tertiary respiratory services are currently provided in Aberdeen, Dundee, Edinburgh and Glasgow with varying levels of staff. The presence of Paediatric Intensive Care Unit (PICU) in Edinburgh and Glasgow is a significant influence on the service, particularly with respect to other national services and complex ventilatory support. For some diseases, such as CF, very significant inequalities in access to and provision of specialist advice and care are being increasingly recognised. However, for other patient groups, who do not have strong support groups, their equity of access to high quality respiratory services remains hidden and is unmet. Clinicians find it difficult to commission and fund these low volume, but complex and high cost services, which are often established on an ad hoc basis, without planning or co-ordination.

Whilst there are many conditions which can be placed under the banner of complex respiratory; for the purposes of this review it was agreed to focus on the two particular areas below, as improvements in these areas will have a positive effect on other aspects of the complex respiratory service and provide and template for further developments.

- Cystic Fibrosis (CF)
- Long-term Ventilation/Sleep disorder breathing

Cystic Fibrosis Situation

In Scotland children and young people with CF attend 10 different hospitals. Not all of these hospitals have designated CF clinics, but each has a medical consultant with training and/or a special interest in CF. Tertiary CF services are currently provided in Aberdeen, Dundee, Edinburgh and Glasgow with varying levels of staffing. A review of paediatric CF services demonstrated that all of these clinics have inadequate provision of medical, nursing and AHP staffing, as defined by "*Standards for the clinical care of children and adults with CF in the UK in 2001*". There is real concern than inequalities in service provision are increasingly echoing similar problems elsewhere in NHS Scotland, recently outlined by the Chief Medical Officer.

Models of care for Cystic Fibrosis

To address these service issues, it is proposed that a National Service Network (NSN) should be established. This would enhance support for local clinics and reduce the current inequalities, by augmenting the three regional specialist centre multidisciplinary teams and developing outreach clinics. In addition a NSN would provide the infrastructure to develop national standards of care, education, audit and research throughout Scotland. Every patient would have access to specialist care while having their care based locally.

The establishment of a NSN, will require additional investment for staffing and resources as outlined within the full report.

Long –term Ventilation/ Sleep disordered Breathing

Background

Long-term ventilation (LTV) is a mode of respiratory therapy which can be delivered in a variety of settings including the child or young person's home. It is a relatively new development which has had a significant impact for a number of children who would previously have died of respiratory failure. There is evidence that many of these children experience a significantly improved quality of life.

There are several groups of children who may require LTV –

- Children surviving a period of neonatal or paediatric intensive care with significant ongoing respiratory insufficiency
- Children with some chronic and degenerative conditions such as – neuromuscular disorders and skeletal disorders
- Children with congenital respiratory control disorders
- Children with obstructive airway problems including obstructive sleep apnoea

Whilst this service needs to be led by the NHS, it requires to work closely with social work and education services to provide high quality integrated care of children and young people, who often have complex needs.

Sleep disordered breathing

The demand for diagnostic and treatment services is increasing rapidly due to increasing knowledge, differing expectations of what can be achieved and availability of expertise. In addition, the increasing prevalence of obesity is leading to increased numbers of children with obstructive apnoea and sleep hypoventilation.

Current Situation

Whilst there are examples of good service there is not equality of provision or access provided across Scotland in the areas of sleep breathing diagnosis and management. Consequently it is felt that there are significant improvements which could be made. To clearly identify the currently level of the service and challenges it may face, there is a need to undertake a multi-agency review, as well as a needs assessment to clearly identify future demands.

Recommendations

Similar to other services, the development of Managed Clinical Networks is seen as the best way of delivering Tertiary Respiratory Medicine across Scotland, while ensuring equity of access. Without substantial investment in resources in Tertiary Paediatric Respiratory Medicine it will not be possible to meet these aspirations or even maintain the current level of service with the impending changes to working patterns set by the European Working Time Directives.

Specific recommendation for Cystic Fibrosis and Long-term Ventilation and Sleep disorder breathing are outlined below.

Cystic Fibrosis

	Action	**By when**
1.	In year 1, establish a National Service Network, provided via three regional centres (West, South East and North), incorporating outreach services to DGH's.	August 2008
2.	In year 1, each Region to produce an implementation plan for CF services, ensuring that the Cystic Fibrosis Trust Standards are met.	March 2009
3.	In year 2, appoint additional staff for 3 Regional Centres to support service network and ensure minimum staffing levels recommended by the Cystic Fibrosis Trust are achieved.	March 2010
4.	In year 3, appoint staff for DGH's support service network and ensure minimum staffing levels recommended by Cystic Fibrosis Trust are achieved.	March 2010
5.	Develop pathways of care, ensuring effective transition to Adult service.	March 2009
6.	Undertake a review of services to ensure Cystic Fibrosis Trust Standards are being achieved in all centres providing CF care.	March 2010

Long - term Ventilation

	Action	By when
1.	Undertake a national multi-agency review of long-term ventilation provision for children and young people, including invasive and non-invasive ventilation.	March 2009
2.	Complete a needs assessment on children and young people's future needs/demands for long-term ventilation.	Decemb er 2009
3.	Identify resource requirements for current and future provision of long-term ventilation.	March 2009
4.	Develop quality standards to ensure equity and sustainability of long-term ventilation services.	March 2010

Sleep breathing Disorder

	Actions	By when
1.	Complete review of current service provision.	March 2009
2.	Complete a needs assessment on children's and young people's future needs/demands for sleep breathing disorders.	March 2009
3.	Develop quality standards to ensure equity and sustainability of sleep disorder services.	March 2010