Cleft Lip and Palate Surgery in Scotland: Outcomes

In the run up the current consultation exercise the issue was raised of differential outcomes for speech between the Edinburgh and Glasgow specialist cleft lip and palate surgical services. In considering those concerns National Specialist Services Committee agreed that the consultation should include material on outcomes and the purpose of this paper is to provide that information. It is important to set this material in context. The process in which it has been collected is a long standing one established to drive improvement in clinical services. Until the current service change proposals were proposed no issues had been raised about outcomes in Scottish services by any of the number of clinicians from across Scotland who had participated in the process of collecting and reviewing this data. Further review of the audit information indicates that surgical services in Scotland are safe and in line with the rest of the UK.

Speech outcome data have for a number of years been collected and reported in a systematic way by individual cleft centres across the United Kingdom. More recently these data have been collected centrally by the CRANE database for the English, Welsh and Northern Ireland Cleft services. By pooling all the data it is now possible to compare the raw, un risk-stratified outcomes for each centre.

Speech outcome data for the Scottish Centres from the period in question have been provided by the individual boards and are shown plotted on graphs provided by the CRANE Database. The plots include pooled 2007 and 2008 data as well as separate plots for the most recently available 2009 data.

Review of the data, graphs below, enables confirmation that both Edinburgh and Glasgow speech outcomes are:-

- within the normal range of those achieved across the rest of UK cleft services
- have improved over the period for which data is available;

It is also important to set this data in context. A number of factors other than surgical skill are important:-

- Over the period in question it has been shown that there are statistically significant differences in the social and economic deprivation (SIMD) scores for the patients served by the Glasgow surgical service versus those served by the Edinburgh surgical services. While the impact of social deprivation on cleft outcomes is not fully understood, discussions relating to the introduction of some degree of “risk stratification” in the comparison on cleft units outcomes (including social deprivation) is now a subject of debate within the UK cleft community.

- Speech therapy resource is also important to speech outcomes and there is differential access to speech therapy between the Edinburgh and Glasgow services.

- Speech outcomes are only obtainable some 5 to 6 years following primary cleft repair and as such it should be noted that these data only provide a historic reflection of outcomes for the centres contributing. Furthermore given the small number of children born in Scotland each year with an oro-nasal cleft it may be more valuable to watch trends over multiple years than look at simple, single-year raw data.
Speech Standard 2: Speech Difficulties

Number of cases with CAPS-A scores

% cases without speech difficulties

Region I Unit

ul99.8%

ul95 %

National Average 2004-06

ll99.8%

ll95 %
Other Surgical Outcomes

The information below comments on a range of other surgical outcomes, again confirming that surgical outcomes in both Edinburgh and Glasgow are within norms for the UK.

The information is an extract of data provided to Cleft Care Scotland National Managed Clinical Network by professionals working in the network for the purpose of national audit. It is usually presented as Scotland-wide data.

Audit of the maxillary growth pattern in 5 year old children born with a unilateral cleft lip and palate (UCLP) and bilateral cleft lip and palate (BCLP)

It has long been suggested that patients with treated clefts have restricted growth of the maxillary bone complex and it is believed that the extent of scarring following surgical repair of clefts may contribute to this restriction in growth. Multiple methods of scoring maxillary growth using dental occlusion have been developed.

The assessment in cleft is a compromise as to what is an ideal measure of growth, and what is practically possible as near as possible to the initial intervention in question so as an adequately audit the procedure.

The Craniofacial Society of Great Britain has for some time advocated auditing the maxillary growth patterns in Unilateral cleft lip and palate patients at age 5 years using a validated scoring system called the 5 year old index. Scoring for BCLP patient is known as the BCLP Yardstick. The scoring is carried out using dental impressions and or suitable photographic records. The index outcome is broken down into 5 groups (1&2 good growth result: Green, 3 moderate growth result: Amber, and 4&5 Poor growth results: Red and missing data is shown in Black).

Edinburgh and Glasgow UCLP Scores:

The data numbers expected for East and West, patient records submitted, absent data and data not scored is shown in the table below.

<table>
<thead>
<tr>
<th>Region</th>
<th>No of children with UCLP born in 2006, 2007 &amp; 2008</th>
<th>No of records submitted</th>
<th>No of records not submitted</th>
<th>No of records orthodontist unable to score</th>
<th>No of records scored</th>
</tr>
</thead>
<tbody>
<tr>
<td>East</td>
<td>25</td>
<td>18</td>
<td>7</td>
<td>1</td>
<td>17</td>
</tr>
<tr>
<td>West</td>
<td>32</td>
<td>25</td>
<td>7</td>
<td>3</td>
<td>22</td>
</tr>
</tbody>
</table>

Average results for the 2000-2008 show that 30% of patient data for the UCLP patients for Scotland was missing for this audit and this remained unchanged with the 2008 audit period. Audit results for 57 children born with a UCLP in Scotland during 2006, 2007 and 2008 are shown below along with Scotland-wide results against the rest of the UK. 39 models/photos were available for independent scoring by 2 consultant orthodontists from Cleft Units in England. 31% of records were missing for a number of reasons including failed appointments, data not being provided to the Network Office for collation or the orthodontist being unable to score the data provided. 2009 data has recently been collated by the Network and submitted for scoring.
UCLP Scotland-wide data:
Collated 5 year index results for Scotland in relation to the rest of the UK & E for children born between 2000 and 2008 are provided below.

The most recent Scotland-wide audit results for 2008 births are shown below.
Edinburgh and Glasgow BCLP Scores:

The Cleft Care Scotland National Managed Clinical Network has recently started to collate 5 year old BCLP data for scoring using the BCLP yardstick. However numbers are small related to the percentage of children born within Scotland with BCLP. 12 models/photos were available for independent scoring out-with Scotland. 2009 data has recently been collated by the Network and submitted for scoring.

The data numbers expected for East and West, patient records, submitted and absent data is shown in the table below.

<table>
<thead>
<tr>
<th>Region</th>
<th>No of children with BCLP born in 2007 &amp; 2008</th>
<th>No of records submitted</th>
<th>No of records not submitted</th>
<th>No of records orthodontist unable to score</th>
<th>No of records scored</th>
</tr>
</thead>
<tbody>
<tr>
<td>East</td>
<td>13</td>
<td>7</td>
<td>6</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>West</td>
<td>9</td>
<td>8</td>
<td>1</td>
<td>0</td>
<td>8</td>
</tr>
</tbody>
</table>

5 Year BCLP Yardstick Scores for children born with BCLP in 2007 & 2008 (n=22)

BCLP Scotland-wide data:

Collated 5 year results for Scotland in relation to the rest of the UK & E for children born between 2005 and 2008 are provided below.
Audit of the alveolar bone graft results in of children who have undergone alveolar bone grafting

Results are measured on a 4 point scale known as the Kindelan ‘bone-fill’ scale. Kindelan 1 and 2 results indicate a good result. Bone-grafting should ideally be undertaken before eruption of the permanent canine teeth and in some cases lateral incisors to benefit from the tooth erupting through the grafted site and to allow remodelling and consolidation of the bone in the cleft site as it erupts. It is important for outcome to consider grafting before the canine erupts into the cleft site hence our standard that grafts should be completed prior to 12 years of age. The data numbers expected for east and west, patient records, submitted and absent data is shown in the table below. Scoring was undertaken by two Consultant Orthodontists based in Scotland.

<table>
<thead>
<tr>
<th>Region</th>
<th>No of children on ABG list</th>
<th>No of records submitted</th>
<th>No of records not submitted</th>
<th>No of records orthodontist unable to score</th>
<th>No of records scored</th>
</tr>
</thead>
<tbody>
<tr>
<td>East</td>
<td>33</td>
<td>25</td>
<td>8</td>
<td>0</td>
<td>25</td>
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<tr>
<td>West</td>
<td>36</td>
<td>34</td>
<td>0</td>
<td>0</td>
<td>34</td>
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</table>

Edinburgh and Glasgow Kindelan Scores: