Down Syndrome Medical Interest Group

MEDICAL SURVEILLANCE OF CHILDREN WITH DOWN SYNDROME UNDER THE AGE OF 5: AN AUDIT OF COMPLIANCE WITH RECENT LOCAL GUIDELINES BASED ON DSMIG RECOMMENDATIONS

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Background The Down Syndrome Medical Interest Group (DSMIG) publishes guidance concerning the minimum safe standard of medical surveillance for children with Down syndrome. In 2019, local guidance was created to collate the current DSMIG guidance, which is spread across multiple documents, into a single place and summarise the complex surveillance for children with Down syndrome under the age of 5. Our local guidance also makes additional recommendations for surveillance, including electronically coding the diagnosis of Down syndrome; a previous 2015 audit at our centre found that 93% of children with Down syndrome who were lost to follow up had no electronic record diagnosis recorded.

Objectives To identify whether children under the age of 5 with Down syndrome known to our local community paediatric team are managed in line with the minimum safe standard of medical surveillance recommend by the DSMIG and our local guidelines.

Methods We identified 12 recommendations for audit: 7 recommendations concerning the timing and content of appointments with a community paediatrician, 4 concerning investigations (See table 1) and 1 recommendation to electronically code the diagnosis of Down syndrome. We reviewed the notes of each child with Down syndrome under 5 and recorded whether local care had met these standards.

Results We identified 20 children under the age of 5 with a known diagnosis of Down syndrome currently under the care of our team. The proportion of children whose management was in line with each guideline is shown in table 1.

Conclusions Management was not 100% compliant with local guidance in any of the audited domains. Several guidelines represent a minimum safe standard so 100% compliance should be targeted. Discussion of warning signs for C-spine instability and testing for coeliac antibodies were least frequently completed. We observed that local guidance concerning thyroid function testing and audiology were not consistent with current DSMIG guidelines. Height was not recorded 25% of the time. To improve the quality of our service, the findings have been presented locally. We will create an appointment proforma for local community paediatricians, and we will update our local guidance to bring all domains inline with the minimum safe standard set out by the DSMIG. DSMIG guidelines are detailed and useful, but are spread across multiple documents and some community paediatricians may not be aware of every recommendation: creating local guidance concerning surveillance in young children with Down syndrome and increasing awareness of the guidelines for this age group may help improve the standard of medical surveillance in the first years of life.

Abstract 991 Table 1

<table>
<thead>
<tr>
<th>Category</th>
<th>Diagnosis</th>
<th>Appointment Timing</th>
<th>Last Appointment Content</th>
<th>Biochemical/Specialist Tests</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Diagnosis of Down syndrome on electronic notes</td>
<td>Within Last 6 Months Recorded</td>
<td>Height And Weight Recorded On correct Growth Chart</td>
<td>Sleep Apnoea Symptoms Discussed</td>
</tr>
<tr>
<td>Compliance (%)</td>
<td>65%</td>
<td>55%</td>
<td>75%</td>
<td>95%</td>
</tr>
</tbody>
</table>