Supplementary Online Content


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This supplementary material has been provided by the authors to give readers additional information about their work.
## eTable 1A. Most Common Congenital Anomaly Diagnoses by Organ System Among Children With Trisomy 13

Includes diagnoses reported on more than 5 children. Individual children may carry more than one diagnosis. Table 1 includes the total number of children with diagnoses in each organ system.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Trisomy 13 (N=174)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cardiac</strong></td>
<td></td>
</tr>
<tr>
<td>Patent ductus arteriosus</td>
<td>55 (31.6)</td>
</tr>
<tr>
<td>Atrial septal defect</td>
<td>48 (27.6)</td>
</tr>
<tr>
<td>Ventricular septal defect</td>
<td>48 (27.6)</td>
</tr>
<tr>
<td>Other cardiac anomaly</td>
<td>43 (24.7)</td>
</tr>
<tr>
<td>Tetralogy of Fallot</td>
<td>16 (9.2)</td>
</tr>
<tr>
<td><strong>Gastrointestinal</strong></td>
<td></td>
</tr>
<tr>
<td>Other intestinal anomaly</td>
<td>7 (4.0)</td>
</tr>
<tr>
<td>Intestinal fixation anomaly</td>
<td>6 (3.4)</td>
</tr>
<tr>
<td><strong>Genitourinary</strong></td>
<td></td>
</tr>
<tr>
<td>Undescended testicles</td>
<td>11 (6.3)</td>
</tr>
<tr>
<td>Cystic kidney</td>
<td>10 (5.7)</td>
</tr>
<tr>
<td>Hydronephrosis</td>
<td>7 (4.0)</td>
</tr>
<tr>
<td>Other renal malformation</td>
<td>7 (4.0)</td>
</tr>
<tr>
<td><strong>Ear, nose and throat</strong></td>
<td></td>
</tr>
<tr>
<td>Cleft palate</td>
<td>46 (26.4)</td>
</tr>
<tr>
<td>Cleft lip and palate</td>
<td>23 (13.2)</td>
</tr>
<tr>
<td>Other face or neck anomaly</td>
<td>6 (3.4)</td>
</tr>
<tr>
<td><strong>Neurologic</strong></td>
<td></td>
</tr>
<tr>
<td>Microcephalus</td>
<td>14 (8.0)</td>
</tr>
<tr>
<td>Holoprosencephaly</td>
<td>13 (7.5)</td>
</tr>
<tr>
<td>Reduction deformity</td>
<td>9 (5.2)</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>7 (4.0)</td>
</tr>
</tbody>
</table>
eTable 1B. Most Common Congenital Anomaly Diagnoses by Organ System Among Children With Trisomy 18
Includes diagnoses reported on more than 5 children. Individual children may carry more than one diagnosis. Table 1 includes the total number of children with diagnoses in each organ system

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Children with diagnosis (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cardiac</strong></td>
<td></td>
</tr>
<tr>
<td>Ventricular septal defect</td>
<td>107 (42.1)</td>
</tr>
<tr>
<td>Patent ductus arteriosus</td>
<td>84 (33.1)</td>
</tr>
<tr>
<td>Other cardiac anomaly</td>
<td>72 (28.3)</td>
</tr>
<tr>
<td>Atrial septal defect</td>
<td>48 (18.9)</td>
</tr>
<tr>
<td>Aortic valve insufficiency</td>
<td>18 (7.1)</td>
</tr>
<tr>
<td><strong>Gastrointestinal</strong></td>
<td></td>
</tr>
<tr>
<td>Tracheo-esophageal fistula</td>
<td>12 (4.7)</td>
</tr>
<tr>
<td><strong>Genitourinary</strong></td>
<td></td>
</tr>
<tr>
<td>Other renal malformation</td>
<td>13 (5.1)</td>
</tr>
<tr>
<td>Hypospadias</td>
<td>10 (3.9)</td>
</tr>
<tr>
<td>Undescended testicle</td>
<td>10 (3.9)</td>
</tr>
<tr>
<td>Horseshoe kidney</td>
<td>6 (2.4)</td>
</tr>
<tr>
<td>Ureteral obstruction</td>
<td>6 (2.4)</td>
</tr>
<tr>
<td><strong>Ear, nose and throat</strong></td>
<td></td>
</tr>
<tr>
<td>Cleft palate</td>
<td>10 (3.9)</td>
</tr>
<tr>
<td>Other face or neck anomaly</td>
<td>7 (2.8)</td>
</tr>
<tr>
<td>Choanal atresia</td>
<td>6 (2.4)</td>
</tr>
<tr>
<td><strong>Neurologic</strong></td>
<td></td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>12 (4.7)</td>
</tr>
<tr>
<td>Microcephalus</td>
<td>11 (4.3)</td>
</tr>
<tr>
<td>Reduction deformity</td>
<td>10 (3.9)</td>
</tr>
<tr>
<td>Corpus callosum anomaly</td>
<td>9 (3.5)</td>
</tr>
<tr>
<td>Other brain anomaly</td>
<td>8 (3.1)</td>
</tr>
</tbody>
</table>
eTable 2. Conditional Survival Probabilities for Children With Trisomy 13 and 18 With 95% Confidence Intervals

These probabilities show the likelihood of survival to the next time point (column) among children surviving to the current time point (row). For example, a child with trisomy 13 who is alive at one week (2nd row) has a 75% likelihood of surviving to one month (2nd row, 2nd column) and a 23% likelihood of surviving to 10 years (2nd row, 5th column).

<table>
<thead>
<tr>
<th>Ages</th>
<th>1 week</th>
<th>1 month</th>
<th>1 year</th>
<th>5 years</th>
<th>10 years</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Trisomy 13</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Birth</td>
<td>53% (45-60%)</td>
<td>42% (35-49%)</td>
<td>20% (14-26%)</td>
<td>15% (10-21%)</td>
<td>13% (8-19%)</td>
</tr>
<tr>
<td>1 week</td>
<td>75% (65-83%)</td>
<td>36% (26-45%)</td>
<td>35% (25-46%)</td>
<td>23% (15-32%)</td>
<td></td>
</tr>
<tr>
<td>1 month</td>
<td>47% (35-57%)</td>
<td>59% (44-73%)</td>
<td>76% (58-87%)</td>
<td>65% (46-79%)</td>
<td></td>
</tr>
<tr>
<td>6 months</td>
<td>77% (64-88%)</td>
<td>76% (58-87%)</td>
<td>86% (62-95%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Trisomy 18</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Birth</td>
<td>50% (44-56%)</td>
<td>35% (29-41%)</td>
<td>13% (9-17%)</td>
<td>11% (8-16%)</td>
<td>10% (6-14%)</td>
</tr>
<tr>
<td>1 week</td>
<td>67% (58-74%)</td>
<td>25% (17-32%)</td>
<td>22% (15-30%)</td>
<td>19% (13-26%)</td>
<td></td>
</tr>
<tr>
<td>1 month</td>
<td>36% (26-46%)</td>
<td>32% (23-42%)</td>
<td>28% (19-38%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 months</td>
<td>78% (63-89%)</td>
<td>90% (71-97%)</td>
<td>86% (63-95%)</td>
<td>77% (56-89%)</td>
<td>60% (44-75%)</td>
</tr>
<tr>
<td>1 year</td>
<td>70% (54-83%)</td>
<td>90% (71-97%)</td>
<td>77% (56-89%)</td>
<td>60% (44-75%)</td>
<td></td>
</tr>
<tr>
<td>5 years</td>
<td>90% (71-97%)</td>
<td>86% (63-95%)</td>
<td>77% (56-89%)</td>
<td>60% (44-75%)</td>
<td></td>
</tr>
</tbody>
</table>
**eTable 3A. Comparison of Children With Trisomy 13 (N=92) Who Have Shorter and Longer Survival Times**

This table excludes children who die within the first week of life. *Cytogenetic status unavailable before 2010. Includes organ systems in which more than 5 children have diagnoses. An individual child may have diagnoses in more than one category.*

<table>
<thead>
<tr>
<th></th>
<th>Children who survived between 7 days and 1 year (N, %)</th>
<th>Children who survived ≥1 year (N, %)</th>
<th>Difference between proportions/means/medians in column 1 and 2 (95% CI)</th>
<th>p-value for difference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total number</strong></td>
<td>58</td>
<td>34</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gender, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>37 (63.8)</td>
<td>20 (58.8)</td>
<td>5.0 (4.7-5.2)</td>
<td>0.64</td>
</tr>
<tr>
<td>Male</td>
<td>21 (36.2)</td>
<td>14 (41.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Birth weight, kg; mean (SD)</strong></td>
<td>2.6 (0.53)</td>
<td>2.8 (0.77)</td>
<td>-0.20 (-0.50 to 0.11)</td>
<td>0.20</td>
</tr>
<tr>
<td><em><em>Cytogenetic status</em>, n (%)</em>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not specified</td>
<td>&gt;52 (&gt;89.7)</td>
<td>25 (73.5)</td>
<td>19.6 (19.4-19.8)</td>
<td>0.01</td>
</tr>
<tr>
<td>Mosaic or translocation</td>
<td>&lt;6 (&lt;10.3)</td>
<td>9 (26.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Family income quintile, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1st or 2nd (lower)</td>
<td>31 (53.5)</td>
<td>15 (45.5)</td>
<td>6.4 (6.2-6.6)</td>
<td>0.46</td>
</tr>
<tr>
<td>3rd, 4th or 5th (higher)</td>
<td>27 (46.6)</td>
<td>18 (54.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Children with congenital anomaly diagnoses</strong>, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiac</td>
<td>17 (29.3)</td>
<td>10 (29.4)</td>
<td>0.1 (-0.1-0.3)</td>
<td>0.99</td>
</tr>
<tr>
<td>Neurologic</td>
<td>8 (13.8)</td>
<td>10 (29.4)</td>
<td>15.6 (15.4-15.8)</td>
<td>0.07</td>
</tr>
<tr>
<td>HEENT</td>
<td>16 (27.6)</td>
<td>10 (29.4)</td>
<td>1.8 (1.6-2.0)</td>
<td>0.85</td>
</tr>
<tr>
<td><strong>Number of organ systems with congenital anomaly diagnoses per child, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None or 1</td>
<td>36 (62.1)</td>
<td>20 (58.8)</td>
<td>3.2 (3-3.5)</td>
<td>0.62</td>
</tr>
<tr>
<td>2 or 3</td>
<td>13 (22.4)</td>
<td>7 (20.6)</td>
<td>1.8 (1.6-2.0)</td>
<td></td>
</tr>
<tr>
<td>4 or more</td>
<td>9 (15.5)</td>
<td>7 (20.6)</td>
<td>-5.1 (-5.3 to -4.9)</td>
<td></td>
</tr>
<tr>
<td><strong>Admissions in first year of life, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>12 (20.7)</td>
<td>8 (23.5)</td>
<td>-2.8 (-3.0 to -2.6)</td>
<td>0.39</td>
</tr>
<tr>
<td>2 or 3</td>
<td>27 (46.6)</td>
<td>11 (32.4)</td>
<td>14.2 (14.0-14.4)</td>
<td></td>
</tr>
<tr>
<td>&gt;4</td>
<td>19 (32.8)</td>
<td>15 (44.1)</td>
<td>-11 (-12 to -11)</td>
<td></td>
</tr>
<tr>
<td><strong>Length of stay during admissions in first year of life, days; median (IQR)</strong></td>
<td>6 (1-12)</td>
<td>6 (2-18)</td>
<td>-1 (-2 to 0)</td>
<td>0.17</td>
</tr>
</tbody>
</table>

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**eTable 3B. Comparison of Children With Trisomy 18 (N=128) Who Have Shorter and Longer Survival Times**

This table excludes children who die within the first week of life. *Cytogenetic status unavailable before 2010. **Includes organ systems in which more than 5 children have diagnoses. An individual child may have diagnoses in more than one category.*

<table>
<thead>
<tr>
<th></th>
<th>Children who survived between 7 days and 1 year (N, %)</th>
<th>Children who survived ≥1 year (N, %)</th>
<th>Difference between proportions/means/medians in column 1 and 2 (95% CI)</th>
<th>p-value for difference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total number</strong></td>
<td>97</td>
<td>31</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gender, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>78 (80.4)</td>
<td>18 (58.1)</td>
<td>22.3 (22.1-22.6)</td>
<td>0.01</td>
</tr>
<tr>
<td>Male</td>
<td>19 (19.6)</td>
<td>13 (41.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Birth weight, kg; mean (SD)</strong></td>
<td>2.0 (0.48)</td>
<td>2.5 (0.65)</td>
<td>-0.43 (-0.69 to -0.17)</td>
<td>0.002</td>
</tr>
<tr>
<td><em><em>Cytogenetic status</em>, n (%)</em>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not specified</td>
<td>&gt;91 (&gt;93.8)</td>
<td>24 (77.4)</td>
<td>21.5 (21.4-21.7)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Mosaic or translocation</td>
<td>&lt;6 (&lt;6.2)</td>
<td>7 (22.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Family income quintile, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1st or 2nd (lower)</td>
<td>48 (49.5)</td>
<td>17 (56.7)</td>
<td>-8.6 (-8.8 to -8.4)</td>
<td>0.49</td>
</tr>
<tr>
<td>3rd, 4th or 5th (higher)</td>
<td>49 (50.5)</td>
<td>13 (43.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Children with congenital anomaly diagnoses</strong>, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiac</td>
<td>45 (46.4)</td>
<td>13 (41.9)</td>
<td>-4.5 (-4.7 to -4.2)</td>
<td>0.66</td>
</tr>
<tr>
<td>Neurologic</td>
<td>8 (8.3)</td>
<td>7 (22.6)</td>
<td>14.3 (14.2-14.5)</td>
<td>0.03</td>
</tr>
<tr>
<td><strong>Number of organ systems with congenital anomaly diagnoses per child, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None or 1</td>
<td>68 (70.1)</td>
<td>18 (58.1)</td>
<td>12.0 (11.8-12.3)</td>
<td>0.30</td>
</tr>
<tr>
<td>2 or more</td>
<td>29 (29.9)</td>
<td>13 (41.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Admissions in first year of life, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>33 (34.0)</td>
<td>&lt;6 (&lt;19.4)</td>
<td>24.3 (24.2-24.5)</td>
<td>0.02</td>
</tr>
<tr>
<td>2 or 3</td>
<td>44 (45.4)</td>
<td>&gt;13 (&gt;41.9)</td>
<td>-6.3 (-6.5 to -6.0)</td>
<td></td>
</tr>
<tr>
<td>&gt;4</td>
<td>20 (20.6)</td>
<td>12 (38.7)</td>
<td>-18 (-18 to -18)</td>
<td></td>
</tr>
<tr>
<td><strong>Length of stay during admissions in first year of life, days; median (IQR)</strong></td>
<td>5 (1-14)</td>
<td>5 (2-10)</td>
<td>0 (-1 to 1)</td>
<td>0.95</td>
</tr>
</tbody>
</table>

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### eTable 4A. Surgeries Performed on Children With Trisomy 13 (See Table 2a)

<table>
<thead>
<tr>
<th>Organ system</th>
<th>Trisomy 13</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cardiac</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Major (n=10)</strong></td>
<td></td>
</tr>
<tr>
<td>Hemi-Fontan</td>
<td></td>
</tr>
<tr>
<td>Pulmonary artery transfer</td>
<td></td>
</tr>
<tr>
<td>Pulmonary artery occlusion</td>
<td></td>
</tr>
<tr>
<td>Thoracic vessel occlusion</td>
<td></td>
</tr>
<tr>
<td>Closed pulmonary valve repair</td>
<td></td>
</tr>
<tr>
<td>Atrial septal defect repair</td>
<td></td>
</tr>
<tr>
<td>Ventricular septal defect repair</td>
<td></td>
</tr>
<tr>
<td><strong>Gastrointestinal and genitourinary</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Major and intermediate (n=9)</strong></td>
<td></td>
</tr>
<tr>
<td>Large intestine resection</td>
<td></td>
</tr>
<tr>
<td>Large intestine reattachment</td>
<td></td>
</tr>
<tr>
<td>Colostomy revision</td>
<td></td>
</tr>
<tr>
<td>Repair of anus</td>
<td></td>
</tr>
<tr>
<td>Liver biopsy, open</td>
<td></td>
</tr>
<tr>
<td>Excision of appendix</td>
<td></td>
</tr>
<tr>
<td>Bladder neck repair</td>
<td></td>
</tr>
<tr>
<td>Hypospadias repair</td>
<td></td>
</tr>
<tr>
<td><strong>Minor (n=7)</strong></td>
<td></td>
</tr>
<tr>
<td>Testicular excision</td>
<td></td>
</tr>
<tr>
<td>Orchiopey</td>
<td></td>
</tr>
<tr>
<td>Division of penile adhesions</td>
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</tr>
<tr>
<td><strong>Ears, nose, and throat</strong></td>
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</tr>
<tr>
<td><strong>Major/intermediate (n=28)</strong></td>
<td></td>
</tr>
<tr>
<td>Maxillary reconstruction</td>
<td></td>
</tr>
<tr>
<td>Cleft palate repair</td>
<td></td>
</tr>
<tr>
<td>Mastoid autograft procurement and placement</td>
<td></td>
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<tr>
<td>Lip flap</td>
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<tr>
<td>Tonsillectomy and adenoidectomy</td>
<td></td>
</tr>
<tr>
<td>Adenoidectomy</td>
<td></td>
</tr>
<tr>
<td>Closure fistula of nose</td>
<td></td>
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<tr>
<td>Nasal repair</td>
<td></td>
</tr>
<tr>
<td>Rhinoplasty</td>
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</tr>
<tr>
<td><strong>Minor (n=15)</strong></td>
<td></td>
</tr>
<tr>
<td>Middle ear incision</td>
<td></td>
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<tr>
<td>Myringotomy with tube placement</td>
<td></td>
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<tr>
<td><strong>Respiratory and neurologic</strong></td>
<td></td>
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<tr>
<td><strong>Major (n=13)</strong></td>
<td></td>
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<tr>
<td>Tracheal fistula repair</td>
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<tr>
<td>Spinal cord release</td>
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<tr>
<td>Tracheostomy</td>
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<tr>
<td>Diaphragmatic repair</td>
<td></td>
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<tr>
<td>Ventriculoperitoneal shunt placement</td>
<td></td>
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<tr>
<td>Ventriculoperitoneal shunt replacement</td>
<td></td>
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<tr>
<td>Ventriculoperitoneal shunt management</td>
<td></td>
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<tr>
<td>Tracheal dilation</td>
<td></td>
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<tr>
<td>Revision of tracheostomy</td>
<td></td>
</tr>
<tr>
<td><strong>Minor (n&lt;6)(^a)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Technology</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Major/intermediate (n=21)</strong></td>
<td></td>
</tr>
<tr>
<td>Jejunostomy tube placement</td>
<td></td>
</tr>
<tr>
<td>Gastrostomy tube placement</td>
<td></td>
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<tr>
<td><strong>Minor (n&lt;6)(^a)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Musculoskeletal</strong></td>
<td></td>
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<tr>
<td><strong>Major/intermediate (n=14)</strong></td>
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<tr>
<td>Pelvic repair with autograft</td>
<td></td>
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<tr>
<td>Muscle repair, abdominal wall</td>
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<tr>
<td>Muscle release, legs</td>
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</tr>
<tr>
<td>Partial bone excision, hand</td>
<td></td>
</tr>
<tr>
<td>Joint repair, knee endoscopic</td>
<td></td>
</tr>
<tr>
<td><strong>Minor (n&lt;6)(^a)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Ophthalmologic</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Minor (n=12)(^a)</strong></td>
<td></td>
</tr>
</tbody>
</table>

\(^a\)Fewer than 6 children underwent this category of surgery, so surgical types are not reported.
eTable 4B. Surgeries Performed on children With Trisomy 18
See Table 2b.

<table>
<thead>
<tr>
<th>Trisomy 18</th>
<th>Cardiac</th>
<th>Gastrointestinal and genitourinary</th>
<th>Ears, nose, throat, respiratory and neurologic</th>
<th>Technology</th>
<th>Musculoskeletal and dermatologic</th>
<th>Ophthalmologic</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cardiac</strong></td>
<td><strong>Major (n=10)</strong></td>
<td><strong>Major (n=8)</strong></td>
<td><strong>Major/intermediate (n=10)</strong></td>
<td><strong>Major/intermediate (n=21)</strong></td>
<td><strong>Major/intermediate (n=12)</strong></td>
<td><strong>Minor (n&lt;6)</strong></td>
</tr>
<tr>
<td>Systemic to pulmonary artery shunt</td>
<td></td>
<td>Gastrochisis repair</td>
<td>Laryngeal repair</td>
<td>Jejunostomy tube placement</td>
<td>Spinal fusion</td>
<td></td>
</tr>
<tr>
<td>Pulmonary artery occlusion</td>
<td></td>
<td>Esophageal reconstruction</td>
<td>Meningocele repair</td>
<td>Gastrostomy tube placement</td>
<td>Internal fixation, foot</td>
<td></td>
</tr>
<tr>
<td>Thoracic vessel occlusion</td>
<td></td>
<td>Esophageal reinforcement</td>
<td>Diaphragmatic repair</td>
<td></td>
<td>Surgical bone repair, leg</td>
<td></td>
</tr>
<tr>
<td>Vena cava plication</td>
<td></td>
<td>Small intestine resection</td>
<td>Tracheal dilation</td>
<td></td>
<td>Surgical bone repair</td>
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<td></td>
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<td></td>
<td>Lip flap</td>
<td></td>
<td>Abdominal wall repair</td>
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<td></td>
<td>Tonsillectomy and adenoidectomy</td>
<td></td>
<td>Muscle lengthening</td>
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<td></td>
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<td></td>
<td>Ear reconstruction</td>
<td></td>
<td>Joint repair, knee endoscopic</td>
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<td></td>
<td>Hearing aid implantation</td>
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<tr>
<td><strong>Gastrointestinal and genitourinary</strong></td>
<td><strong>Major (n=8)</strong></td>
<td><strong>Minor (n&lt;6)</strong></td>
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<tr>
<td>Gastroschisis repair</td>
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<td>Esophageal reconstruction</td>
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<td>Small intestine resection</td>
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<tr>
<td>Pyloroplasty</td>
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<td>Pyloromyotomy</td>
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<tr>
<td><strong>Ears, nose, throat, respiratory and neurologic</strong></td>
<td><strong>Major/intermediate (n=10)</strong></td>
<td><strong>Minor (n=15)</strong></td>
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<tr>
<td>Laryngeal repair</td>
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<tr>
<td>Meningocele repair</td>
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<tr>
<td>Diaphragmatic repair</td>
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<td>Tracheal dilation</td>
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<tr>
<td>Tonsillectomy and adenoidectomy</td>
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<td>Ear reconstruction</td>
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<tr>
<td><strong>Technology</strong></td>
<td><strong>Major/intermediate (n=21)</strong></td>
<td><strong>Minor (n&lt;6)</strong></td>
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<tr>
<td>Jejunostomy tube placement</td>
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<td>Gastrostomy tube placement</td>
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<tr>
<td><strong>Musculoskeletal and dermatologic</strong></td>
<td><strong>Major/intermediate (n=12)</strong></td>
<td><strong>Minor (n=6)</strong></td>
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<td>Spinal fusion</td>
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<tr>
<td>Internal fixation, foot</td>
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<tr>
<td>Surgical bone repair, leg</td>
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<tr>
<td>Surgical bone repair</td>
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<tr>
<td>Abdominal wall repair</td>
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<tr>
<td>Muscle lengthening</td>
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<tr>
<td>Joint repair, knee endoscopic</td>
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<tr>
<td><strong>Ophthalmologic</strong></td>
<td></td>
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</tr>
</tbody>
</table>

*a Fewer than 6 children underwent this category of surgery, so surgical types are not reported.*
**eTable 5.** Results From Negative Binomial Model Testing Intervention Rates for Trisomy 13 and 18 Over Time Adjusted for Age Distribution of Children at Risk

<table>
<thead>
<tr>
<th></th>
<th>Adjusted beta coefficient (95% CI), log-person-day at risk</th>
<th>Test statistic (DF)</th>
<th>p-value</th>
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</thead>
<tbody>
<tr>
<td><strong>Trisomy 13</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Likelihood ratio omnibus test</td>
<td>-2179.3 (9)</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Fiscal year</td>
<td>0.032 (-0.01 to 0.07)</td>
<td></td>
<td>0.11</td>
</tr>
<tr>
<td>Age category 1 (0-90 days)</td>
<td>2.9 (2.0-3.7)</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Age category 2 (91-180 days)</td>
<td>2.6 (1.6-3.5)</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Age category 3 (181-270 days)</td>
<td>2.3 (1.3-3.4)</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Age category 4 (271-365 days)</td>
<td>3.0 (2.1-4.0)</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Age category 5 (1-2 years)</td>
<td>1.8 (0.9-2.7)</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Age category 6 (2-4 years)</td>
<td>1.3 (0.4-2.2)</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Age category 7 (4-7 years)</td>
<td>1.0 (0.2-1.9)</td>
<td></td>
<td>0.02</td>
</tr>
<tr>
<td>Age category 8 (&gt;7 years)</td>
<td>0 (0-0)</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td><strong>Trisomy 18</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Likelihood ratio omnibus test</td>
<td>-1021.0 (9)</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Fiscal year</td>
<td>0.036 (-0.01 to 0.08)</td>
<td></td>
<td>0.11</td>
</tr>
<tr>
<td>Age category 1 (0-90 days)</td>
<td>2.4 (1.5-3.3)</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Age category 2 (91-180 days)</td>
<td>1.6 (0.4-2.8)</td>
<td></td>
<td>0.01</td>
</tr>
<tr>
<td>Age category 3 (181-270 days)</td>
<td>2.4 (1.4-3.5)</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Age category 4 (271-365 days)</td>
<td>1.7 (0.4-2.9)</td>
<td></td>
<td>0.01</td>
</tr>
<tr>
<td>Age category 5 (1-2 years)</td>
<td>1.7 (0.7-2.6)</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Age category 6 (2-4 years)</td>
<td>0.9 (-0.1 to 1.8)</td>
<td></td>
<td>0.8</td>
</tr>
<tr>
<td>Age category 7 (4-7 years)</td>
<td>0.9 (0-1.8)</td>
<td></td>
<td>0.05</td>
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<tr>
<td>Age category 8 (&gt;7 years)</td>
<td>0 (0-0)</td>
<td></td>
<td>-</td>
</tr>
</tbody>
</table>
### eTable 6. Survival Data From 12 of the Largest Population-Based Studies of Children With Trisomy 13 or 18

*Children with mosaicism excluded from survival analysis. KM=Kaplan-Meier. NR=Not reported.*

<table>
<thead>
<tr>
<th>Study</th>
<th>Location (study years)</th>
<th>Trisomy 13</th>
<th>Trisomy 18</th>
<th>Data source; case ascertainment</th>
<th>Study approach to censoring and cytogenetic status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goldstein, 1988&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Denmark (1977-1986)</td>
<td>N=19</td>
<td>No. surviving to age 1 (KM estimate) 0 (0%)*, Median survival time (variability) 2.5 days (NR)</td>
<td>Danish Central Cytogenetic Register; data based on reports from all cytogenetic labs in Denmark; additionally, access to files from cytogenetic labs directly, pediatrics departments, and two vital statistics registries</td>
<td>Children without death data were censored at end of follow-up. Excluded children with mosaicism from analysis.</td>
</tr>
<tr>
<td>Root, 1994&lt;sup&gt;2&lt;/sup&gt;</td>
<td>Utah (1979-1988)</td>
<td>No. surviving to age 1 (KM estimate) 0 (0%)*, Median survival time (variability) 6 days (NR)</td>
<td>Data from the two cytogenetic labs in Utah that perform all chromosomal studies.</td>
<td>Followed-up all patient statuses. Cytogenetic status not discussed.</td>
<td></td>
</tr>
<tr>
<td>Nembhard, 2001&lt;sup&gt;3&lt;/sup&gt;</td>
<td>Texas (1995-1997)</td>
<td>N=27</td>
<td>No. surviving to age 1 (KM estimate) 2 (7.4%), Median survival time (variability) NR (NR)</td>
<td>Texas Birth Defects Monitoring Division registry; no information on ascertainment</td>
<td>Did not examine survival beyond one year; children without death certificate during first year presumed alive. Cytogenetic status not discussed.</td>
</tr>
<tr>
<td>Brewer, 2002&lt;sup&gt;3&lt;/sup&gt;</td>
<td>Scotland (1974-1997)</td>
<td>N=32</td>
<td>No. surviving to age 1 (KM estimate) 1 (3.0%), Median survival time (variability) 8.5 days (range: 1-412)</td>
<td>Glasgow Register of Congenital Anomalies (1974-1989); registry staff verified cases for which notification was received; Scottish Trisomy Register (1989-1997);</td>
<td>Reported maximum survival (412 days in trisomy 13 and 975 days in trisomy 18), so presumably had confirmation of death for entire cohort. Excluded children with mosaicism from analysis.</td>
</tr>
</tbody>
</table>
**eTable 6. Survival Data From 12 of the Largest Population-Based Studies of Children With Trisomy 13 or 18**

*Children with mosaicism excluded from survival analysis. KM=Kaplan-Meier. NR=Not reported.*

<table>
<thead>
<tr>
<th>Study</th>
<th>Location (study years)</th>
<th>No. surviving to age 1 (KM estimate)</th>
<th>Median survival time (variability)</th>
<th>No. surviving to age 1 (KM estimate)</th>
<th>Median survival time (variability)</th>
<th>Data source; case ascertainment</th>
<th>Study approach to censoring and cytogenetic status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rasmussen 2003[^5]</td>
<td>Atlanta registry (1968-1999)</td>
<td>70 (8.6%)*</td>
<td>7 days (95% CI: 3-15)</td>
<td>114 (8.4%)*</td>
<td>14.5 days (95% CI: 8-28)</td>
<td>Metropolitan Atlanta Congenital Defects Program; registry abstractors obtain data from medical charts and cytogenetic labs</td>
<td>Assumed patients without death data to be living at study end. Excluded children with mosaicism from analysis.</td>
</tr>
<tr>
<td>United States death files data (1979-1997)</td>
<td>United States (1979-1997)</td>
<td>5515 (5.6%)</td>
<td>10 days (IQR: 1-30)</td>
<td>8750 (5.6%)</td>
<td>10 days (IQR: 2-60)</td>
<td>Multiple-Cause Mortality Files; data abstracted from US death certificates</td>
<td>Ascertainment based on death, not birth; prevalence estimates were higher than in prior birth-based studies. Children with mosaicism included in analysis.</td>
</tr>
<tr>
<td>Vendola, 2010[^7]</td>
<td>Texas (1999-2003)</td>
<td>130 (3.0%)*</td>
<td>4.5 days (NR)</td>
<td>184 (3.0%)*</td>
<td>7 days (NR)</td>
<td>Texas Birth Defects Registry; registry staff visit medical facilities routinely to identify infants with birth defects</td>
<td>Cases without death data excluded from survival analysis. If excluded cases had survived 1 year, survival probabilities would have been 10% and 11% for trisomy 13 and 18, respectively. Did not describe survival beyond 1 year.</td>
</tr>
</tbody>
</table>
### eTable 6. Survival Data From 12 of the Largest Population-Based Studies of Children With Trisomy 13 or 18

*Children with mosaicism excluded from survival analysis. KM=Kaplan-Meier. NR=Not reported.*

<table>
<thead>
<tr>
<th>Study</th>
<th>Location (study years)</th>
<th>Trisomy 13</th>
<th>Trisomy 18</th>
<th>Data source; case ascertainment</th>
<th>Study approach to censoring and cytogenetic status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Irving, 2011*</td>
<td>England (1985-2007)</td>
<td>NR</td>
<td>NR</td>
<td>Northern Congenital Abnormality Survey; survey completed by ultrasonographers, physicians, cytogeneticists</td>
<td>Did not describe details of survival data except that it was available to one year. Excluded children with mosaicism from analysis.</td>
</tr>
<tr>
<td>Wang, 2011*</td>
<td>New York (1983-2006)</td>
<td>NR</td>
<td>NR</td>
<td>Congenital Malformations Registry of the New York State Department of Health; hospitals required to report children diagnosed up to age two, and additional cases are identified through record and on-site audits.</td>
<td>Assumed children without New York state death certificates were alive at end of follow-up. Cytogenetic status not discussed.</td>
</tr>
<tr>
<td>Wu, England</td>
<td>120 10 10 days</td>
<td>309 (7.8%)*</td>
<td>14 days</td>
<td>National Down</td>
<td>Excluded 31 cases of</td>
</tr>
</tbody>
</table>
**eTable 6. Survival Data From 12 of the Largest Population-Based Studies of Children With Trisomy 13 or 18**
*Children with mosaicism excluded from survival analysis. KM=Kaplan-Meier. NR=Not reported.*

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<tr>
<th>Study</th>
<th>Location (study years)</th>
<th>Trisomy 13</th>
<th>Trisomy 18</th>
<th>Data source; case ascertainment</th>
<th>Study approach to censoring and cytogenetic status</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>No. surviving to age 1</td>
<td>Median survival time</td>
<td>No. surviving to age 1</td>
<td>Median survival time</td>
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<tr>
<td></td>
<td></td>
<td>(KM estimate) (variability)</td>
<td></td>
<td>(KM estimate) (variability)</td>
<td></td>
</tr>
</tbody>
</table>
**eTable 6. Survival Data From 12 of the Largest Population-Based Studies of Children With Trisomy 13 or 18**

*Children with mosaicism excluded from survival analysis. KM=Kaplan-Meier. NR=Not reported.*


525 children meeting study inclusion criteria:
- Valid encoded health card number
- ICD code for trisomy on hospital record during first year of life
- Admission for trisomy between April 1, 1991 and March 31, 2012

97 children excluded from the study:
- 49 were not Ontario residents
- 6 did not have a birth or hospitalization record in first seven days of life or had listed birth date occurring after discharge date
- 7 had an uncertain genetic diagnosis due to equal numbers of hospital admissions with diagnosis codes for trisomy 13 and 18
- 35 had a discharge diagnosis code for trisomy 21 on a hospital record

428 children included in the study:
- 174 children with trisomy 13
- 254 children with trisomy 18
Figure 2. Birth Prevalence of Trisomy 13 and 18 Over Time

The lines are loess curves.

**Trisomy 13 birth prevalence over time**

- Rate per 100,000 live births
- Fiscal year

**Trisomy 18 birth prevalence over time**

- Rate per 100,000 live births
- Fiscal year
eFigure 3. Survival Duration Histograms for Children With Trisomy 13 and 18

**Survival duration of children with trisomy 13**

- Days of survival: <=7, 8-30, 31-90, 91-180, 181-364, >=365
- Percent of cohort: 0, 10, 20, 30, 40, 50, 60

**Survival duration of children with trisomy 18**

- Days of survival: <=7, 8-30, 31-90, 91-180, 181-364, >=365
- Percent of cohort: 0, 10, 20, 30, 40, 50
eAppendix. Procedure Hierarchy

TRISOMY 13
Cardiac procedures
- **Major**
  - Hemi-Fontan
  - Pulmonary artery transfer
  - Pulmonary artery occlusion
  - Thoracic vessel occlusion
  - Closed pulmonary valve repair
  - Atrial septal defect repair
  - Ventricular septal defect repair
Gastrointestinal procedures
- **Major**
  - Large intestine resection
  - Large intestine reattachment
  - Colectomy revision
  - Repair of anus
  - Liver biopsy, open
- **Intermediate**
  - Excision of appendix
- **Minor**
  - Umbilical hernia repair
  - Paracentesis with tube placement, open
  - Operative inspection of abdomen
Genitourinary procedures
- **Major**
  - Bladder neck repair
  - Hypospadias repair
- **Minor**
  - Testicular excision
  - Orchiopexy
  - Division of penile adhesions
Ear, nose and throat procedures
- **Major**
  - Maxillary reconstruction
  - Cleft palate repair
  - Mastoid autograft procurement and placement
  - Lip flap
  - Tonsillectomy and adenoidectomy
  - Adenoidectomy
  - Closure fistula of nose
  - Nasal repair
  - Rhinoplasty
- **Minor**
  - Middle ear incision
  - Myringotomy with tube placement
Musculoskeletal procedures
- **Major**
  - Pelvic repair with autograft
- **Intermediate**
  - Muscle repair, abdominal wall
  - Muscle release, legs
  - Partial bone excision, hand
  - Joint repair, knee endoscopic
  - **Minor (not reported because <6)**
Ophthalmological procedures
- **Minor (not reported because <6)**
Respiratory and neurologic procedures
- **Major**
  - Tracheal fistula repair
  - Spinal cord release
  - Tracheostomy
  - Diaphragmatic repair
  - Ventriculoperitoneal shunt placement
  - Ventriculoperitoneal shunt replacement
  - Ventriculoperitoneal shunt management
- **Intermediate**
  - Tracheal dilation
  - Revision of tracheostomy
  - **Minor (not reported because <6)**
Technology
- **Major**
  - Jejunostomy tube placement
- **Intermediate**
  - Gastrostomy tube placement
  - **Minor (not reported because <6)**
TRISOMY 18
Cardiac procedures
- **Major**
  - Systemic to pulmonary artery shunt
  - Pulmonary artery occlusion
  - Thoracic vessel occlusion
  - Vena cava plication
Gastrointestinal and genitourinary procedures
- **Major**
  - Gastroschisis repair
  - Esophageal reconstruction
  - Esophageal reinforcement
  - Small intestine resection
  - Pyloroplasty
  - Pyloromyotomy
- **Minor (not reported because <6)**
HEENT, neurologic, and respiratory procedures
- **Major**
  - Laryngeal repair
  - Meningocele repair
  - Diaphragmatic repair
- **Intermediate**
  - Tracheal dilation
  - Lip flap
  - Tonsillectomy and adenoidectomy
  - Ear reconstruction
### Hearing Aid Implantation

- **Minor (not reported because <6)**

### Musculoskeletal and Ophthalmologic Procedures

#### Major
- Spinal fusion
- Internal fixation, foot
- Surgical bone repair, leg

#### Intermediate
- Surgical bone repair
- Muscle repair, abdominal wall
- Muscle lengthening
- Joint repair, knee endoscopic

#### Technology

#### Major
- Jejunostomy tube placement

#### Intermediate
- Gastrostomy tube placement
- Gastrostomy tube placement for suction

#### Minor (not reported because <6)

### Ophthalmological Procedures

#### Minor (not reported because <6)