SUPPLEMENTARY MATERIAL

Health care utilization and expenditures of parents of children with and without hemophilia A

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Supplementary Table 1. Hemophilia A-related Drug and Procedure Codes

<table>
<thead>
<tr>
<th>HA-related drug code (NDC)</th>
<th>Generic drug name begins with “Antihem-”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>C9136, C9137, C9140, C9141, C9267, J2597, J7170, J7182, J7183, J7184, J7185, J7186, J7187, J7188, J7189, J7190, J7191, J7192, J7198, J7199, J7205, J7207, J7208, J7209, J7210, J7211, Q9975, Q9995</td>
</tr>
</tbody>
</table>

Supplementary Table 2. Diagnosis Codes for Charlson Comorbidity Index
<table>
<thead>
<tr>
<th>Comorbidities</th>
<th>Deyo's ICD-9-CM</th>
<th>ICD-10 *</th>
<th>Enhanced ICD-9-CM *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Myocardial infarction</td>
<td>410.x, 412.x</td>
<td>I21.x, I22.x, I25.2</td>
<td>410.x, 412.x</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>428.x</td>
<td>I09.9, I11.0, I13.0, I13.2, I25.5, I42.0, I42.5-I42.9, I43.x, I50.x, P29.0</td>
<td>398.91, 402.01, 402.11, 402.91, 404.01, 404.03, 404.11, 404.13, 404.91, 404.93, 425.4-425.9, 428.x</td>
</tr>
<tr>
<td>Peripheral vascular disease</td>
<td>443.9, 441.x, 785.4, V43.4 Procedure 38.48</td>
<td>I70.x, I71.x, I73.1, I73.8, I73.9, I77.1, I79.0, I79.2, K55.1, K55.8, K55.9, Z95.8, Z95.9</td>
<td>093.0, 437.3, 440.x, 441.x, 443.1-443.9, 447.1, 557.1, 557.9, V43.4</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>430.x-438.x</td>
<td>G45.x, G46.x, H34.0, I60.x-I69.x</td>
<td>362.34, 430.x-438.x</td>
</tr>
<tr>
<td>Dementia</td>
<td>290.x</td>
<td>F00.x-F03.x, F05.1, G30.x, G31.1</td>
<td>290.x, 294.1, 331.2</td>
</tr>
<tr>
<td>Chronic pulmonary disease</td>
<td>490.x-505.x, 506.4</td>
<td>I27.8, I27.9, J40.x-J47.x, J60.x-J67.x, J68.4, J70.1, J70.3</td>
<td>416.8, 416.9, 490.x-505.x, 506.4, 508.1, 508.8</td>
</tr>
<tr>
<td>Rheumatic disease</td>
<td>710.0, 710.1, 710.4, 714.0-714.2, 714.81, 725.x</td>
<td>M05.x, M06.x, M31.5, M32.x-M34.x, M35.1, M35.3, M36.0</td>
<td>446.5, 710.0-710.4, 714.0-714.2, 714.8, 725.x</td>
</tr>
<tr>
<td>Peptic ulcer disease</td>
<td>531.x-534.x</td>
<td>K25.x-K28.x</td>
<td>531.x-534.x</td>
</tr>
<tr>
<td>Mild liver disease</td>
<td>571.2, 571.4-571.6</td>
<td>B18.x, K70.0-K70.3, K70.9, K71.3-K71.5, K71.7, K73.x, K74.x,</td>
<td>070.22, 070.23, 070.32, 070.33, 070.44, 070.54, 070.6, 070.9,</td>
</tr>
<tr>
<td>Condition</td>
<td>ICD-10 Codes</td>
<td>Additional Codes</td>
<td>Notes</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>--------------</td>
<td>------------------</td>
<td>----------------------------</td>
</tr>
<tr>
<td>Diabetes without chronic complication</td>
<td>250.0-250.3, 250.7</td>
<td>E10.0, E10.1, E10.6, E10.8, E10.9, E11.0, E11.1, E11.6, E11.8, E11.9, E12.0, E12.1, E12.6, E12.8, E12.9, E13.0, E13.1, E13.6, E13.8, E13.9, E14.0, E14.1, E14.6, E14.8, E14.9</td>
<td>250.0-250.3, 250.8, 250.9</td>
</tr>
<tr>
<td>Hemiplegia or paraplegia</td>
<td>344.1, 342.x</td>
<td>G04.1, G11.4, G80.1, G80.2, G81.x, G82.x, G83.0-G83.4, G83.9</td>
<td>334.1, 342.x, 343.x, 344.0-344.6, 344.9</td>
</tr>
<tr>
<td>Renal disease</td>
<td>582.x, 583-583.7, 585.x, 586.x, 588.x</td>
<td>I12.0, I13.1, N03.2-N03.7, N05.2-N05.7, N18.x, N19.x, N25.0, Z49.0-Z49.2, Z94.0, Z99.2</td>
<td>403.01, 403.11, 403.91, 404.02, 404.03, 404.12, 404.13, 404.92, 404.93, 582.x, 583.0-583.7, 585.x, 586.x, 587.3, 570.x, 571.x, 573.3, 573.4, 573.8, 573.9, V42.7</td>
</tr>
<tr>
<td>Condition</td>
<td>ICD Codes</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>--------------------</td>
<td>----------------------------------</td>
<td></td>
</tr>
<tr>
<td>Any malignancy, including lymphoma and leukemia, except malignant neoplasm of skin</td>
<td>140.x-172.x, 174.x-195.8, 200.x-208.x</td>
<td>588.0, V42.0, V45.1, V56.x</td>
<td></td>
</tr>
<tr>
<td>Moderate or severe liver disease</td>
<td>456.0-456.21, 572.2-572.8</td>
<td>456.0-456.2, 572.2-572.8</td>
<td></td>
</tr>
<tr>
<td>Metastatic solid tumor</td>
<td>196.x-199.1</td>
<td>196.x-199.x</td>
<td></td>
</tr>
<tr>
<td>AIDS/HIV</td>
<td>042.x-044.x</td>
<td>042.x-044.x</td>
<td></td>
</tr>
</tbody>
</table>

**Sources:**


Supplementary Table 3. Attrition of Parents of Children with HA

<table>
<thead>
<tr>
<th>Description</th>
<th>N</th>
<th>% of Prior Step</th>
</tr>
</thead>
<tbody>
<tr>
<td>MarketScan enrollees (2011-2018)</td>
<td>305,799,312</td>
<td></td>
</tr>
<tr>
<td>Enrollees with ≥1 encounter with HA diagnosis code</td>
<td>29,487</td>
<td>0.01%</td>
</tr>
<tr>
<td>Male, age &lt;18, child/dependent beneficiary status</td>
<td>6,854</td>
<td>23.2%</td>
</tr>
<tr>
<td>HA-related drug or procedure</td>
<td>3,725</td>
<td>54.3%</td>
</tr>
<tr>
<td>Unique across all years (randomly selected claim)</td>
<td>1,580</td>
<td>42.4%</td>
</tr>
<tr>
<td>Parents matched by family ID</td>
<td>2,246</td>
<td>--</td>
</tr>
<tr>
<td>Continuous enrollment 1-year post-index</td>
<td>1,332</td>
<td>59.3%</td>
</tr>
<tr>
<td>Unique parents (allow only 1 HA child per family)</td>
<td>1,270</td>
<td>95.3%</td>
</tr>
<tr>
<td>Data available to calculate CCI and number of children</td>
<td>1,127</td>
<td>88.7%</td>
</tr>
<tr>
<td>Random selection of parents across years</td>
<td>1,087</td>
<td>96.5%</td>
</tr>
<tr>
<td>Matched parents</td>
<td>1,068</td>
<td>98.3%</td>
</tr>
</tbody>
</table>

CCI=Charlson Comorbidity Index; HA=hemophilia A.
Supplementary Figure 1. Mean 1-Year Cost for Nonmental Health Claims By Parent Policy Holder Type

![Bar chart showing mean costs for nonmental health claims by parent policy holder type.](image-url)
Supplementary Figure 2. Mean 1-Year Costs for Mental Health Claims By Parent Policy Holder Type
Primary policy holders (n=1,770) mean cost for mental health claims: $195
Secondary policy holders (n=1,420) mean cost for mental health claims:
- Parents of children with HA: $213
- Control parents: $274

1-Year Cost for Mental Health Claims

Mean Cost

$350
$300
$250
$200
$150
$100
$50
$0

Parent Beneficiary Type
- Parents of children with HA
- Control parents
Supplementary Table 4. Sensitivity Analysis Results for Likelihood of Incurring Health Care Costs

<table>
<thead>
<tr>
<th>Non-Mental Health Cost</th>
<th>Odds Ratio</th>
<th>Standard Error</th>
<th>95% CI</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parameter</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent of HA child</td>
<td>1.12</td>
<td>0.18</td>
<td>0.82, 1.56</td>
<td>0.478</td>
</tr>
<tr>
<td>Age</td>
<td>1.06</td>
<td>0.01</td>
<td>1.04, 1.08</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Female</td>
<td>2.36</td>
<td>0.32</td>
<td>1.81, 3.09</td>
<td>&lt;0.001</td>
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<tr>
<td>Secondary beneficiary</td>
<td>1.12</td>
<td>0.16</td>
<td>0.86, 1.47</td>
<td>0.415</td>
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<tr>
<td>Child’s age</td>
<td>0.99</td>
<td>0.01</td>
<td>0.96, 1.02</td>
<td>0.409</td>
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<tr>
<td>Number of children</td>
<td>0.99</td>
<td>0.03</td>
<td>0.93, 1.05</td>
<td>0.718</td>
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<tr>
<td>Index month</td>
<td>0.94</td>
<td>0.02</td>
<td>0.90, 0.97</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Insurance type, HMO*</td>
<td>1.76</td>
<td>0.41</td>
<td>1.14, 2.85</td>
<td>0.016</td>
</tr>
<tr>
<td>Insurance type, other*</td>
<td>1.25</td>
<td>0.18</td>
<td>0.95, 1.68</td>
<td>0.120</td>
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<tr>
<td>CCI</td>
<td>2.24</td>
<td>0.49</td>
<td>1.51, 3.60</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Region, north central=</td>
<td>0.79</td>
<td>0.15</td>
<td>0.54, 1.14</td>
<td>0.213</td>
</tr>
<tr>
<td>Region, south=</td>
<td>1.15</td>
<td>0.21</td>
<td>0.79, 1.65</td>
<td>0.451</td>
</tr>
<tr>
<td>Region, west=</td>
<td>0.87</td>
<td>0.18</td>
<td>0.58, 1.30</td>
<td>0.501</td>
</tr>
<tr>
<td>Region, unknown=</td>
<td>0.41</td>
<td>0.17</td>
<td>0.19, 0.99</td>
<td>0.032</td>
</tr>
<tr>
<td>Parameter</td>
<td>Odds Ratio</td>
<td>Standard Error</td>
<td>95% CI</td>
<td>P value</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>------------</td>
<td>----------------</td>
<td>-----------</td>
<td>---------</td>
</tr>
<tr>
<td>Parent of HA child</td>
<td>1.20</td>
<td>0.09</td>
<td>1.03, 1.40</td>
<td>0.018</td>
</tr>
<tr>
<td>Age</td>
<td>1.00</td>
<td>5.33e-03</td>
<td>0.99, 1.01</td>
<td>0.550</td>
</tr>
<tr>
<td>Female</td>
<td>1.72</td>
<td>0.12</td>
<td>1.50, 1.98</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Secondary beneficiary</td>
<td>1.04</td>
<td>0.07</td>
<td>0.91, 1.19</td>
<td>0.597</td>
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<tr>
<td>Child’s age</td>
<td>1.00</td>
<td>7.45e-03</td>
<td>0.99, 1.02</td>
<td>0.524</td>
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<tr>
<td>Number of children</td>
<td>1.01</td>
<td>0.02</td>
<td>0.98, 1.04</td>
<td>0.740</td>
</tr>
<tr>
<td>Index month</td>
<td>1.00</td>
<td>9.35e-03</td>
<td>0.98, 1.02</td>
<td>0.753</td>
</tr>
<tr>
<td>Insurance type, HMO*</td>
<td>0.86</td>
<td>0.09</td>
<td>0.70, 1.05</td>
<td>0.134</td>
</tr>
<tr>
<td>Insurance type, other*</td>
<td>0.84</td>
<td>0.06</td>
<td>0.72, 0.97</td>
<td>0.018</td>
</tr>
<tr>
<td>CCI</td>
<td>1.13</td>
<td>0.05</td>
<td>1.03, 1.23</td>
<td>0.008</td>
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<tr>
<td>Region, north central=</td>
<td>1.39</td>
<td>0.14</td>
<td>1.15, 1.70</td>
<td>&lt;0.001</td>
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<tr>
<td>Region, south=</td>
<td>1.22</td>
<td>0.11</td>
<td>1.02, 1.47</td>
<td>0.030</td>
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<tr>
<td>Region, west=</td>
<td>1.13</td>
<td>0.12</td>
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<td>0.249</td>
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<tr>
<td>Region, unknown=</td>
<td>1.00</td>
<td>0.29</td>
<td>0.54, 1.74</td>
<td>0.998</td>
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<tr>
<td>Full-time employment≠</td>
<td>1.23</td>
<td>0.09</td>
<td>1.07, 1.42</td>
<td>0.004</td>
</tr>
<tr>
<td>Index year</td>
<td>1.01</td>
<td>0.01</td>
<td>0.98, 1.04</td>
<td>0.451</td>
</tr>
</tbody>
</table>

CCI=Charlson Comorbidity Index; CI=confidence interval; HA=hemophilia A; HMO=health maintenance organization.

*Reference group = preferred provider organization

≡Reference group = northeast region

≠Reference group = not full-time employment