
Table S1. EMBASE Search
Table S2. MEDLINE Search Strategy
Table S3. PICOS Criteria

This supplementary material has been provided by the authors to give readers additional information about their work.
## Table S1. EMBASE Search Strategy

<table>
<thead>
<tr>
<th>No.</th>
<th>Search Terms*</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>exp wilsons disease/</td>
<td>10 289</td>
</tr>
<tr>
<td>2</td>
<td>(wilsons disease or Wilson disease or Wilson's disease).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]</td>
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<tr>
<td>3</td>
<td>hepatolenticular degeneration.mp.</td>
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</tr>
<tr>
<td>5</td>
<td>copper storage disease.mp.</td>
<td>38</td>
</tr>
<tr>
<td>6</td>
<td>or/1-5</td>
<td>11 741</td>
</tr>
<tr>
<td>7</td>
<td>socioeconomics/</td>
<td>145 802</td>
</tr>
<tr>
<td>8</td>
<td>exp quality of life/</td>
<td>534 461</td>
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<tr>
<td>9</td>
<td>quality of life.ab,ti,kw.</td>
<td>493 850</td>
</tr>
<tr>
<td>10</td>
<td>(instrument or instruments) adj.3 quality of life).ab.</td>
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<td>11</td>
<td>quality-adjusted life year/</td>
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<td>12</td>
<td>quality adjusted life.ti,ab,kw.</td>
<td>21 977</td>
</tr>
<tr>
<td>13</td>
<td>(qaly* or qald* or qale* or qtime* or life year or life years).ti,ab,kw.</td>
<td>36 662</td>
</tr>
<tr>
<td>14</td>
<td>disability adjusted life.ti,ab,kw.</td>
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<td>23</td>
<td>(hqe or hqes).ti,ab,kw.</td>
<td>146</td>
</tr>
<tr>
<td>24</td>
<td>(health* adj.2 year* adj.2 equivalent*).ti,ab,kw.</td>
<td>55</td>
</tr>
<tr>
<td>25</td>
<td>(pqol or qsl).ti,ab,kw.</td>
<td>668</td>
</tr>
<tr>
<td>26</td>
<td>(quality of wellbeing or quality of well being or index of wellbeing or index of well being or qwb).ti,ab,kw.</td>
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</tr>
<tr>
<td>27</td>
<td>nottingham health profile*.ti,ab,kw.</td>
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</tr>
<tr>
<td>28</td>
<td>nottingham health profile/</td>
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<td>29</td>
<td>sickness impact profile.ti,ab,kw.</td>
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<tr>
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<td>sickness impact profile/</td>
<td>2 351</td>
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<tr>
<td>31</td>
<td>health status indicator/</td>
<td>3 177</td>
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<tr>
<td>32</td>
<td>(health adj.3 (utilit* or status)).ti,ab,kw.</td>
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<tr>
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<tr>
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<tr>
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Table S1. EMBASE Search Strategy, cont’d

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<th>No.</th>
<th>Search Terms*</th>
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<td>38</td>
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<td>duke health profile.ti,ab,kw.</td>
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<td>functional status questionnaire.ti,ab,kw.</td>
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<td>46</td>
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Table S2. MEDLINE Search Strategy

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* Databases include Ovid MEDLINE® and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions*, 1946–July 24, 2021.

### Table S3. PICOS Criteria

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<th>Criteria</th>
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<tr>
<td>Population</td>
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<td>Interventions</td>
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<td>Comparators</td>
<td>Not restricted</td>
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<tr>
<td>Outcomes</td>
<td>Patient/Physician/Caregiver</td>
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<tr>
<td></td>
<td>• Generic quality of life</td>
</tr>
<tr>
<td></td>
<td>• Disease-specific quality of life</td>
</tr>
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<td></td>
<td>• Generic health-related quality of life</td>
</tr>
<tr>
<td></td>
<td>• Disease-specific health-related quality of life</td>
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<tr>
<td>Study design</td>
<td>• Randomized controlled trials and non-randomized clinical trials</td>
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<tr>
<td></td>
<td>• Observational studies reporting health-related quality of life/utility (e.g. controlled before-and-after studies, interrupted time series studies, historically controlled studies, prospective and retrospective cohort studies, case-control studies, cross-sectional studies, controlled and uncontrolled longitudinal studies)</td>
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<tr>
<td>Language</td>
<td>• Studies published in English will be included</td>
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