APPENDIX 9

DATA EXTRACTION FORM
How to assess the prevalence in Europe of each rare disease
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How to assess the prevalence in Europe of each rare disease

Part 1: COVERSHEET

<table>
<thead>
<tr>
<th>Article Title:</th>
<th>First Author:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Journal:</td>
<td>Notes:</td>
</tr>
</tbody>
</table>

Part 2: STUDY CHARACTERISTICS

<table>
<thead>
<tr>
<th>Publication Year:</th>
<th>Country of study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study design:</td>
<td>Data source:</td>
</tr>
<tr>
<td>□ cross-sectional</td>
<td>□ medical record</td>
</tr>
<tr>
<td>□ case-report</td>
<td>□ special survey</td>
</tr>
<tr>
<td>□ other __________</td>
<td>□ multiple source</td>
</tr>
<tr>
<td></td>
<td>□ surveillance</td>
</tr>
<tr>
<td></td>
<td>□ registries</td>
</tr>
<tr>
<td>Population study:</td>
<td>Age groups included (describe):</td>
</tr>
<tr>
<td>□ total population</td>
<td>□ Male</td>
</tr>
<tr>
<td>□ specific group population</td>
<td>□ Female</td>
</tr>
<tr>
<td>□ other __________</td>
<td>□ Both</td>
</tr>
</tbody>
</table>

Part 3: STUDY QUALITY

Circle the appropriate study design that is being assessed.

**Cross-Sectional Studies**

**SELECTION BIAS**

Was the survey conducted in some form of a probabilistic sample of the community?
□ Yes
□ No
□ Unable to tell

What was the non-response rate?

**INFORMATION BIAS**

How was the disease diagnosed? (only clinically, only biological, no description)

Was ascertainment of the disease assessed in the same way for entire study population?
□ Yes
□ No
□ Unable to tell

Was the definition of a disease case adequate?
□ Yes
□ No
□ Unable to tell

**CONFOUNDING**

List the major confounders (age, gender etc) adjusted in the analysis or design?
□ Yes
□ No
□ Unable to tell

**MOST IMPORTANT DESIGN FLAWS:**
### Part 4: RESULTS

**What is the outcome measure in this analysis (describe):**
- [ ] Absolute numbers
- [ ] Point prevalence
- [ ] Periodic prevalence

**Measure of the prevalence**
- [ ] Crude Measure
- [ ] Adjusted measure

If **adjusted** what factors were adjusted for in this study (list):

**Estimate of measure of the prevalence and 95% CI (by considering it to be the mean of a Poisson distribution):**

**Other comments:**