What is the prevalence of cerebral palsy (CP) in Norway?

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Background
The prevalence of cerebral palsy (CP) in Norway has varied in recently published studies using different data sources:

<table>
<thead>
<tr>
<th>Prevalence</th>
<th>Data Source</th>
<th>Birth Years</th>
<th>Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.8 per 1000 live births</td>
<td>The Norwegian Social Insurance Scheme</td>
<td>1967-2002</td>
<td>Tollånes et al. 2014</td>
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<tr>
<td>3.0 per 1000 residing in Norway</td>
<td>The Norwegian Patient Register (NPR)</td>
<td>1999-2010</td>
<td>Surén et al. 2012</td>
</tr>
<tr>
<td>2.1 per 1000 live births</td>
<td>The Cerebral Palsy Register of Norway (CPRN)</td>
<td>1996-1998</td>
<td>Andersen et al. 2008</td>
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</tbody>
</table>

Objective
To determine the “true” prevalence of CP in Norway through scrutinizing all cases of CP in the NPR and the CPRN.

Study Participants/Setting
• The NPR is a compulsory health register that receives a standardized set of individual patient data from all hospital and outpatient clinic consultations (specialists) in Norway
• The CPRN is a consent-based national medical quality register that collects detailed clinical data and summative information from all habilitation centers in Norway

Methods
11-digit national ID numbers were used to identify children with CP born 1996-2007, that were registered in both registers. Children recorded in both registers were considered to have CP. The hospital records of children not recorded in the CPRN were reviewed by two experienced Child Neurologists for the purpose of validation. To estimate prevalence, live birth data from The Medical Birth Registry of Norway was used.

Results
Among the 780 scrutinized cases:
• 464 (59.5%) were correctly coded with CP
• 302 (38.7%) did not have CP
• 14 (1.8%) could not be classified

Thus:
• 1,784 children (of the 2,224 recorded in NPR) had CP
• “True” prevalence: 2.5 (95% CI: 2.4-2.7) per 1000 live births

The most common diagnoses among those who did not have CP were:
• 53 (12.3%) Epilepsy
• 55 (12.7%) Mental and behavioral disorders
• 53 (12.3%) Congenital malformations, deformations and chromosomal abnormalities

Conclusions
• A more accurate prevalence of CP can only be obtained by combining various sources and scrutinizing individual cases
• Hospital-based registers are liable to over-diagnosing, whereas informed consent-based registers relying on voluntarily reporting of cases are liable to underreporting
• Caution is needed when differences in prevalence rates from different sources and populations are interpreted and compared