Does the internet provide accurate and valid health information regarding disorders of sex development?

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Background

- Understanding disorders/differences of sex development (DSD), can be difficult for patients and their families due to their complexity and low prevalence.
- Increasingly, families are turning to the internet to access health information including for DSD.
- However, the quality, validity and accuracy of the information available online regarding DSD has not been formally assessed before.

Aim: To assess the quality, validity and accuracy of website health information concerning commonly searched terms related to DSD

Methods

- Families of children with DSD were consulted to generate 5 search terms: “Disorders of Sex Development OR Differences of Sex Development”, “Congenital Adrenal Hyperplasia” (CAH), “Ambiguous Genitalia OR Atypical Genitalia”, “Cliteromegaly OR Citoromegaly” and “Micropenis”.
- Top 20 Google search results were scored by two independent reviewers using the validated QUality Evaluation Scoring Tool (QUEST)
- The tool scored 6 domains (authorship attribution, conflict of interest, currency, complementarity and tone), with a maximum score of 28 (figure 1).
- Website inclusion criteria: article-information-like leaflet format, in English, no payment/login required, and articles considering aetiology/diagnosis/treatment of disorder

RESULTS

- Thirty per cent of Google search results did not satisfy inclusion criteria, leaving a total 70 webpages for analysis.
- There was substantial inter-rater agreement across all domains, except ‘Tone’ where there was moderate agreement.
- There was no evidence that average QUEST score varied between chosen search terms, or Google rank.
- Micropenis’ demonstrated the most variable results (SD 7.4), ‘CAH’ had the least variable results (SD 3.4)

Table 1. Category of website per search term in Top 20 Google hits **reason for exclusion

<table>
<thead>
<tr>
<th>Search Term</th>
<th>Hospital</th>
<th>Charity</th>
<th>Personal Information</th>
<th>Health Information</th>
<th>Educational Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>'CAH'</td>
<td>0.63</td>
<td>0.72</td>
<td>0.75</td>
<td>0.71</td>
<td>0.85</td>
</tr>
<tr>
<td>'Clitoromegaly'</td>
<td>0.09</td>
<td>0.08</td>
<td>0.09</td>
<td>0.12</td>
<td>0.13</td>
</tr>
<tr>
<td>'Congenital Hyperplasia'</td>
<td>0.09</td>
<td>0.07</td>
<td>0.09</td>
<td>0.13</td>
<td>0.13</td>
</tr>
<tr>
<td>'Ambiguous Genitalia'</td>
<td>0.09</td>
<td>0.11</td>
<td>0.09</td>
<td>0.12</td>
<td>0.12</td>
</tr>
</tbody>
</table>

Table 2. Assessment of inter-rater reliability across all 6 QUEST domains.

- There was no high proportion of articles in Google searches are either not accessible or are from tabloid sources.
- More colloquial terms e.g. micropenis have more variability in information quality.
- This study provides further validation of the QUEST score with near perfect inter-rater agreement across nearly all categories.
- The lowest quality information comes from hospital websites – often due to lack of clarity about who the author was, where the information comes from or they were promoting their own healthcare services (especially US sites).
- The highest quality information comes from peer reviewed publications.
- The main limitation of QUEST is there is no score of accessibility nor is there a clear cut-off of what score would be deemed acceptable or indeed ‘good’.

We would recommend professionals consider the quality criteria in the QUEST tool when designing health information websites for DSD.

Acknowledgements

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References: