SOCIAL MEDIA-BASED DATA: FACEBOOK GROUP EXAMPLE

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SPAIN

Evidence Based Advocacy 1 - Generating the evidence
#CMLHZ18
Generating the Evidence: Why? Objective?
Generating the Evidence: What kind of data and how?

### Side effects, Quality of life

<table>
<thead>
<tr>
<th>Symptom Severity</th>
<th>Patient graded higher</th>
<th>Physician graded higher</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdominal discomfort</td>
<td>4%</td>
<td>14%</td>
</tr>
<tr>
<td>Nausea</td>
<td>8%</td>
<td>16%</td>
</tr>
<tr>
<td>Headache</td>
<td>8%</td>
<td>28%</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>9%</td>
<td>23%</td>
</tr>
<tr>
<td>Edema</td>
<td>12%</td>
<td>26%</td>
</tr>
<tr>
<td>Skin problems</td>
<td>15%</td>
<td>39%</td>
</tr>
<tr>
<td>Musculoskeletal pain</td>
<td>15%</td>
<td>27%</td>
</tr>
<tr>
<td>Muscular cramps</td>
<td>12%</td>
<td>37%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>11%</td>
<td>39%</td>
</tr>
</tbody>
</table>

### Health status

| Overall health status | 6%                    | 36%                    | 41%                    | 26%                    |

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Generating the Evidence: Which tools?

- Draft
- Survey in Spanish
- Translate to English
- Share through FB and TW
- Store answers on database
Generating the Evidence: How analyse the data? Someone's help?
Generating the Evidence: How use the data? Publish the data?

SURVEY RESULTS:
https://goo.gl/YuFYVi

Facebook CML Horizons
Twitter EHA Meeting
Email ...

CML ADVOCATES Network

English
Total Clicks 2,204

Spanish
Total Clicks 763

Referrers
google.com 21.1% unknown 58.3% www.facebook.com 15.6%
m.facebook.com 4.0% not_attribution 0.5%

Referrers
google.com 27.1% unknown 29.9% www.facebook.com 37.7%
m.facebook.com 0.4% not_attribution 0.5%
Generating the Evidence: What did it cost?

If there's no money...

Ideas
+Patient Experience
+Patient Advocacy
+Collaboration
+Online Free Tools
+Time
= Results ➔ Evidence
Generating the Evidence: what would do differently next time?


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