Technical report

Prevalence, screening, diagnostic assessment and treatment of emotional wellbeing

International evidence-based guideline for the assessment and management of polycystic ovary syndrome 2018
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Evidence and GRADE framework with narrative reviews:

1) In women with PCOS (evidence): What is the prevalence and severity of reduced QoL? Should QoL be assessed as part of standard care?

2) In women with PCOS, what is the most effective tool/method to assess quality of life? (Narrative review)

3) In women with PCOS, what dimensions of QoL are most affected? (Narrative review)

Summary

As acknowledged in guideline development meetings, quality of life is not necessarily diagnosed and instead is assessed using tools that measure the level of impairment of quality of life. Therefore we are unable to determine the ‘prevalence’ of quality of life in women with PCOS as this would require evidence about the number of women diagnosed with impaired quality of life in those with and without PCOS.

Here we have compared the level/severity of impairment of quality of life in women with and without PCOS. Based on studies of low quality and certainty; and with some statistical heterogeneity, the evidence suggests that women with PCOS have lower quality of life compared to women without PCOS. This may suggest the value of quality of life assessment as part of standard care in order to address the aspects leading to reduced quality of life.

No evidence was identified by our search to determine the most effective tool to assess quality of life. A clinical expert recommendation may be made about tools used in the general population such as SF-36 and WHOQOL or the PCOS specific, PCOSQ.

Characteristics of included studies (Question 1)

<table>
<thead>
<tr>
<th>Study ID</th>
<th>ROB</th>
<th>Design</th>
<th>Setting</th>
<th>N</th>
<th>PCOS criteria</th>
<th>Age (years)</th>
<th>BMI (kg/m²)</th>
<th>Hirsutism (FGI/S)</th>
<th>Acne</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acmaz 2013</td>
<td>Mod</td>
<td>CS</td>
<td>Hospital, Turkey</td>
<td>C: 47</td>
<td>P: 22</td>
<td>27.77 ± 6.49</td>
<td>23.37 ± 3.13</td>
<td>0%</td>
<td>6.4%</td>
<td>SF-36</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>P/I: 22</td>
<td>P/W: 24.32 ± 4.59</td>
<td>24.32 ± 4.59</td>
<td>24.35 ± 3.48</td>
<td>36.4%</td>
<td>40.9%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>P/W: 29</td>
<td>P/W: 26.00 ± 6.58</td>
<td>26.00 ± 6.58</td>
<td>33.59 ± 2.61</td>
<td>37.9%</td>
<td>49.2%</td>
<td></td>
</tr>
<tr>
<td>Benetti-Pinto 2015</td>
<td>Mod</td>
<td>CS</td>
<td>Uni O&amp;G dep, Brazil</td>
<td>C: 102</td>
<td>P: 52</td>
<td>35.6 ± 7.3</td>
<td>28.5 ± 5.4</td>
<td>FGI: 10.4 ± 4.5 (85.7%)</td>
<td>NR</td>
<td>WHOQOL-BREF</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>P: 26.9 ± 4.9</td>
<td>P: 31.9 ± 8.5</td>
<td>5.4</td>
<td>85.7%</td>
<td>4.5</td>
<td>49.2%</td>
<td></td>
</tr>
<tr>
<td>Benson 2008</td>
<td>Mod</td>
<td>CS</td>
<td>Uni clinics, private</td>
<td>C: 28</td>
<td>P: 57</td>
<td>29.9 ± 1.2</td>
<td>23.6 ± 0.7</td>
<td>P: 10.2 ± 5.6 (SEM)</td>
<td>NR</td>
<td>SF-36</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>P: 28.9 ± 0.7</td>
<td>P: 29.6 ± 1</td>
<td>0.7</td>
<td>5.6</td>
<td>28.9</td>
<td>49.2%</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Type</td>
<td>Study Details</td>
<td>C: Mean ± SEM</td>
<td>P: Mean ± SEM</td>
<td>C: Mean ± SEM</td>
<td>P: Mean ± SEM</td>
<td>ROB</td>
<td>SF Scale</td>
<td></td>
</tr>
<tr>
<td>---------------</td>
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<td></td>
</tr>
<tr>
<td>Drosdzol 2007</td>
<td>Mod</td>
<td>CS</td>
<td>Uni O&amp;G/GE clinics, Poland</td>
<td>C: 40 P: 50</td>
<td>PSE &amp; ESHRE</td>
<td>C: 30.5 ± 5.3</td>
<td>P: 28.9 ± 5.6</td>
<td>2.7 ± 2.1</td>
<td>SF-36</td>
<td></td>
</tr>
<tr>
<td>Elsenbruch 2003</td>
<td>Mod</td>
<td>CC</td>
<td>Uni clinic &amp; employees, Germany</td>
<td>C: 50 P: 50</td>
<td>NIH</td>
<td>C: 29.9 ± 5.7</td>
<td>P: 28.4 ± 5.0</td>
<td>3 ± 2</td>
<td>German</td>
<td></td>
</tr>
<tr>
<td>Hahn 2005</td>
<td>Mod</td>
<td>CC</td>
<td>Uni dep clinics, public ads, Germany</td>
<td>C: 120 P: 50</td>
<td>NIH</td>
<td>C: 30 ± 5.7</td>
<td>P: 29 ± 5.4</td>
<td>3.0 ± 2.0</td>
<td>SF-36</td>
<td></td>
</tr>
<tr>
<td>Kumarapeli 2011</td>
<td>Low</td>
<td>CC</td>
<td>Community in a district, Sri Lanka</td>
<td>C: 170 P: 146</td>
<td>Rott</td>
<td>C: 27.0 ± 7.1</td>
<td>P: 25.6 ± 7.1</td>
<td>NR</td>
<td>WHOQOL-BREF, GHQ30</td>
<td></td>
</tr>
<tr>
<td>Ozcan Dag 2015 &amp; 2016</td>
<td>Mod</td>
<td>CS</td>
<td>Uni clinic, Turkey</td>
<td>C: 38 P: 53</td>
<td>Rott</td>
<td>C: 21.34 ± 2.12</td>
<td>P: 22.69 ± 4.54</td>
<td>NR</td>
<td>SF-36</td>
<td></td>
</tr>
<tr>
<td>Ramos 2016</td>
<td>Mod</td>
<td>CC</td>
<td>Uni hospital clinic, Brazil</td>
<td>C: 51 P: 43</td>
<td>Rott</td>
<td>C: 29.74 ± 5.26</td>
<td>P: 27.8 ± 5.34</td>
<td>NR</td>
<td>SF-36</td>
<td></td>
</tr>
<tr>
<td>Shafti 2016</td>
<td>High</td>
<td>CC</td>
<td>Hospital, infertility clinics and public, Iran</td>
<td>C: 125 P: 129</td>
<td>Med verified</td>
<td>C: 32.79 SD NR</td>
<td>P: 30.10 SD NR</td>
<td>NR</td>
<td>WHOQOL</td>
<td></td>
</tr>
<tr>
<td>Shishehgar 2016</td>
<td>Mod</td>
<td>CC</td>
<td>Uni and clinics, Iran</td>
<td>C: 140 P: 142</td>
<td>AES</td>
<td>C: 29.0 ± 5.8</td>
<td>P: 28.6 ± 4.9</td>
<td>C: 0 (0-1)</td>
<td>SF-36</td>
<td></td>
</tr>
<tr>
<td>Trent 2002</td>
<td>Mod</td>
<td>CS</td>
<td>Primary care clinics, USA</td>
<td>C: 186 P: 97</td>
<td>Zawadski 1992</td>
<td>C: 17 ± 2.4</td>
<td>P: 16.9 ± 2</td>
<td>C: 1.8 ± 3.2</td>
<td>CHQ-CF87</td>
<td></td>
</tr>
</tbody>
</table>

Mod, moderate; CC, case control; CS, cross-sectional; P, PCOS; C, control; Rott, Rotterdam; FGI, Ferriman Gallway index; ROB, risk of bias (low risk, moderate risk and high risk); P/I, women with PCOS who came to the clinic in relation to infertility; P/OH, women with PCOS who came to the clinic in relation to excess facial and body hair (hirsutism), acne and irregular menstrual cycles (oligomenorrhea); P/W, women with PCOS who came to the clinic in relation to being overweight or obese; PSE, Polish Society of Endocrinology; The Child Health Questionnaire–Child Self-Report Form, CHQ-CF87
### Results of individual studies in meta-analyses of quality of life in women with and without PCOS using SF-36

<table>
<thead>
<tr>
<th>Study ID</th>
<th>Vitality</th>
<th>Physical functioning</th>
<th>Bodily pain</th>
<th>General health perceptions</th>
<th>Physical role functioning</th>
<th>Emotional role functioning</th>
<th>Social role functioning</th>
<th>Mental health</th>
<th>Physical sum</th>
<th>Psychological sum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acmaz 2013</td>
<td>Medians only*</td>
<td>Medians only</td>
<td>Medians only</td>
<td>Medians only</td>
<td>C: 90.7±1.9 P/OH: 70.8±7.4 P/I: 73.5±8.0 P/W: 79.8±5.4</td>
<td>C: 95.1±2.3 P/OH: 75.2±10.7 P/I: 79.0±8.8 P/W: 79.6±8.0</td>
<td>Medians only</td>
<td>C: 79.8±4.2 P/OH: 58.2±8.9 P/I: 61.0±6.9 P/W: 66.9±5.6</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Benson 2008</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>C: 57.1±3.7 P: 48.9±15.1</td>
<td>C: 45.4±10.6 P: 39.9±12.1</td>
</tr>
<tr>
<td>Drosdzol 2007</td>
<td>C: 71.2±17.7 P: 57.3±16.4</td>
<td>C: 93.7±8.1 P: 89.9±11.1</td>
<td>C: 72.6±19.8 P: 64.8±25.1</td>
<td>C: 60.1±18.9 P: 46.3±15.9</td>
<td>C: 87.5±22.6 P: 73.5±30.8</td>
<td>C: 95.8±11.4 P: 67.7±28.6</td>
<td>C: 82.6±17.8 P: 70.6±21.5</td>
<td>C: 69.9±15.1 P: 57.5±17.9</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Ozcan Dag 2015 &amp; 2016</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>C: 79.6±11.8 P: 67.3±12.9</td>
<td>C: 62.6±20.6 P: 52.7±15.3</td>
</tr>
<tr>
<td>Ramos 2016</td>
<td>C: 65.5±19.6 P: 59.5±18.4</td>
<td>C: 87.2±13.4 P: 86.9±13</td>
<td>C: 67.6±21.6 P: 68.6±23.2</td>
<td>C: 70.6±20.8 P: 58.5±17.8</td>
<td>C: 77.9±31.5 P: 75.6±26.4</td>
<td>C: 69.3±38.8 P: 72.8±31.1</td>
<td>C: 75±24.6 P: 76.2±24.8</td>
<td>C: 68.2±20.5 P: 68.4±23.9</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Shishehgar 2016</td>
<td>C: 64.6±1.7 P: 52.2±1.3</td>
<td>C: 82.4±1.9 P: 80.3±1.9</td>
<td>C: 77.5±2.1 P: 70.9±2.1</td>
<td>C: 68.7±1.6 P: 63.0±1.5</td>
<td>C: 76.2±2.8 P: 71.7±2.8</td>
<td>C: 71.3±2.8 P: 66.8±2.8</td>
<td>C: 79.4±2.1 P: 70.9±2.1</td>
<td>C: 68.8±1.9 P: 55.0±1.9</td>
<td>C: 76.2±1.4 P: 71.4±1.4</td>
<td>C: 71.0±1.5 P: 61.2±1.5</td>
</tr>
</tbody>
</table>

*Note: Higher scores on the SF-36 indicate better QoL.* Mean±SD. NR, not reported. *For medians, see evidence tables.
Meta-analyses of quality of life in women with and without PCOS using SF-36

a. Vitality $P < 0.00001; I^2 = 32%$

b. Physical functioning $P < 0.02; I^2 = 64%$

c. Bodily pain $P < 0.00001; I^2 = 12%$

d. General health perceptions $P < 0.004; I^2 = 71%$

e. Physical role functioning $P < 0.008; I^2 = 62%$

f. Emotional role functioning $P < 0.02; I^2 = 94%$

g. Social role functioning $P < 0.00001; I^2 = 34%$

h. Mental health $P < 0.00001; I^2 = 60%$
Quality of life

i. Physical summary \( P < 0.0004; I^2 = 81\% \)

<table>
<thead>
<tr>
<th>Study ID</th>
<th>Physical health</th>
<th>Psychological health</th>
<th>Social relationships</th>
<th>Environment</th>
<th>QoL in general</th>
<th>Health in general</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benetti-Pinto 2015</td>
<td>C: 73.1±15.3</td>
<td>P: 72.9±18.4</td>
<td>C: 66.6±16.7</td>
<td>C: 59.9±13.3</td>
<td>C: 72.3±17.9</td>
<td>C: 63.7±23.5</td>
</tr>
<tr>
<td>Kumarapeli 2011</td>
<td>C: 69.4±15.4</td>
<td>P: 64.8±16.2</td>
<td>C: 68.8±14.4</td>
<td>C: 63.4±15.0</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Shafti 2016</td>
<td>C: 26.98±3.74</td>
<td>P: 25.37±3.94</td>
<td>C: 22.79±2.88</td>
<td>C: 28.77±3.90</td>
<td>NR</td>
<td>NR</td>
</tr>
</tbody>
</table>

Note: Higher scores on the WHOQOL indicate better QoL. Mean±SD. NR, not reported.

Results of individual studies in meta-analyses of quality of life in women with and without PCOS using WHOQOL (26-item, see Appendix 2 for details of each domain)

j. Psychological summary \( P < 0.00001; I^2 = 28\% \)

<table>
<thead>
<tr>
<th>Study ID</th>
<th>Physical health</th>
<th>Psychological health</th>
<th>Social relationships</th>
<th>Environment</th>
<th>QoL in general</th>
<th>Health in general</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benetti-Pinto 2015</td>
<td>62.4±19.2</td>
<td>66.6±16.7</td>
<td>69.5±20.5</td>
<td>59.9±13.3</td>
<td>72.3±17.9</td>
<td>63.7±23.5</td>
</tr>
<tr>
<td>Kumarapeli 2011</td>
<td>64.9±17.2</td>
<td>68.8±14.4</td>
<td>60.5±21.4</td>
<td>63.8±15.0</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Shafti 2016</td>
<td>21.59±3.41</td>
<td>11.24±2.19</td>
<td>27.61±5.37</td>
<td>28.77±3.90</td>
<td>NR</td>
<td>NR</td>
</tr>
</tbody>
</table>

Meta-analyses of quality of life in women with and without PCOS using WHOQOL (26-item)

a. Physical health \( P < 0.03; I^2 = 31\% \)

b. Psychological health \( P < 0.04; I^2 = 34\% \)

c. Social relationships \( P < 0.23; I^2 = 63\% \)
d. Environment  $P < 0.04$; $I^2 = 0\%$

Results of the individual study measuring quality of life in adolescents with and without PCOS using the Child Health Questionnaire – Child Self-Report Form (CHQ-CF87)

<table>
<thead>
<tr>
<th>Study ID: Trent 2002</th>
<th>PCOS</th>
<th>CONTROL</th>
<th>$P$ value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in health in the last year</td>
<td>2.8±1.1</td>
<td>2.5±1.0</td>
<td>0.04</td>
</tr>
<tr>
<td>General health perceptions</td>
<td>68.6±16.1</td>
<td>76.3±15.3</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>91.2±12.2</td>
<td>94.8±7.8</td>
<td>0.001</td>
</tr>
<tr>
<td>Mental health</td>
<td>66.5±16.9</td>
<td>70.3±14.3</td>
<td>0.07</td>
</tr>
<tr>
<td>Family activities</td>
<td>77.2±21.3</td>
<td>81.8±18.9</td>
<td>0.03</td>
</tr>
<tr>
<td>Behaviour</td>
<td>93.9±12.7</td>
<td>94.8±11.7</td>
<td>0.04</td>
</tr>
<tr>
<td>Role/social emotional</td>
<td>87.3±19.8</td>
<td>88.7±18.5</td>
<td>0.57</td>
</tr>
<tr>
<td>Role/social behavioural</td>
<td>93.9±12.7</td>
<td>94.8±11.7</td>
<td>0.43</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>70.4±19.5</td>
<td>73.4±19.2</td>
<td>0.23</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>73.9±14.8</td>
<td>77.7±15.3</td>
<td>0.19</td>
</tr>
<tr>
<td>Role/social physical</td>
<td>94.3±13.6</td>
<td>97.0±10.7</td>
<td>0.15</td>
</tr>
<tr>
<td>Family cohesion</td>
<td>61.2±29.0</td>
<td>65.2±29.4</td>
<td>0.28</td>
</tr>
</tbody>
</table>

*Note: Higher scores on the CHQ-CF87 indicate better QoL*
<table>
<thead>
<tr>
<th>Outcome</th>
<th>Study results and measurements</th>
<th>Effect estimates comparing QOL in women with and without PCOS</th>
<th>Certainty (Quality of evidence)</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>QoL - vitality</td>
<td>Measured by: SF 36 Scale: - High better Based on data from 733 patients in 5 studies Follow up NA</td>
<td><strong>Difference: MD 13.01 lower</strong> (CI 95% 15.68 lower - 10.33 lower)</td>
<td><strong>Low</strong> Due to serious risk of bias</td>
<td>With a P&lt;0.00001 and heterogeneity of 32%, evidence suggests that the SF-36 quality of life domain of vitality is lower in women with PCOS compared with women without PCOS.</td>
</tr>
<tr>
<td>QoL - physical functioning</td>
<td>Measured by: SF-36 Scale: - High better Based on data from 733 patients in 5 studies Follow up NA</td>
<td><strong>Difference: MD 3.97 lower</strong> (CI 95% 7.23 lower - 0.71 lower)</td>
<td><strong>Low</strong> Due to serious risk of bias</td>
<td>With a P&lt;0.02 and heterogeneity of 64%, evidence suggests that while the SF-36 quality of life domain of physical functioning is lower in women with PCOS compared with women without PCOS, high heterogeneity means the results should be interpreted with caution.</td>
</tr>
<tr>
<td>QoL - bodily pain</td>
<td>Measured by: SF-36 Scale: - High better Based on data from 733 patients in 5 studies Follow up NA</td>
<td><strong>Difference: MD 6.72 lower</strong> (CI 95% 8.98 lower - 4.47 lower)</td>
<td><strong>Low</strong> Due to serious risk of bias</td>
<td>With a P&lt;0.00001 and heterogeneity of 12%, evidence suggests that the SF-36 quality of life domain of bodily pain is lower in women with PCOS compared with women without PCOS.</td>
</tr>
<tr>
<td>QoL - general health perceptions</td>
<td>Measured by: SF-36 Scale: - High better Based on data from 633 patients in 4 studies Follow up NA</td>
<td><strong>Difference: MD 7.16 lower</strong> (CI 95% 12.01 lower - 2.32 lower)</td>
<td><strong>Low</strong> Due to serious risk of bias</td>
<td>With a P&lt;0.004 and heterogeneity of 71%, evidence suggests that while the SF-36 quality of life domain of general health perceptions is lower in women with PCOS compared with women without PCOS, high heterogeneity means the results should be interpreted with caution.</td>
</tr>
<tr>
<td>QoL - physical role functioning</td>
<td>Measured by: SF-36 Scale: - High better Based on data from 633 patients in 4 studies Follow up NA</td>
<td><strong>Difference:</strong> MD 8.16 lower (CI 95% 14.18 lower - 2.14 lower)</td>
<td><strong>Low</strong> Due to serious risk of bias</td>
<td>With a P&lt;0.008 and heterogeneity of 62%, evidence suggests that while the SF-36 quality of life domain of physical role functioning is lower in women with PCOS compared with women without PCOS, high heterogeneity means the results should be interpreted with caution.</td>
</tr>
<tr>
<td>QoL - emotional role functioning</td>
<td>Measured by: SF-36 Scale: - High better Based on data from 733 patients in 5 studies Follow up NA</td>
<td><strong>Difference:</strong> MD 18.24 lower (CI 95% 32.95 lower - 3.52 lower)</td>
<td><strong>Low</strong> Due to serious risk of bias</td>
<td>With a P&lt;0.02 and heterogeneity of 94%, evidence suggests that while the SF-36 quality of life domain of emotional role functioning is lower in women with PCOS compared with women without PCOS, high heterogeneity means the results should be interpreted with caution.</td>
</tr>
<tr>
<td>QoL - social role functioning</td>
<td>Measured by: SF-36 Scale: - High better Based on data from 733 patients in 5 studies Follow up NA</td>
<td><strong>Difference:</strong> MD 9.13 lower (CI 95% 12.65 lower - 5.61 lower)</td>
<td><strong>Low</strong> Due to serious risk of bias</td>
<td>With a P&lt;0.0001 and heterogeneity of 34%, evidence suggests that the SF-36 quality of life domain of social role functioning is lower in women with PCOS compared with women without PCOS.</td>
</tr>
<tr>
<td>QoL - mental health</td>
<td>Measured by: SF-36 Scale: - High better Based on data from 733 patients in 5 studies Follow up NA</td>
<td><strong>Difference:</strong> MD 12.25 lower (CI 95% 16.08 lower - 8.42 lower)</td>
<td><strong>Low</strong> Due to serious risk of bias</td>
<td>With a P&lt;0.00001 and heterogeneity of 60%, evidence suggests that while the SF-36 quality of life domain of mental health is lower in women with PCOS compared with women without PCOS, high heterogeneity means the results should be interpreted with caution.</td>
</tr>
<tr>
<td>QoL - physical summary</td>
<td>Measured by: SF-36 Scale: - High better Based on data from 458 patients in 3 studies Follow up NA</td>
<td><strong>Difference:</strong> MD 7.88 lower (CI 95% 12.25 lower - 3.51 lower)</td>
<td><strong>Low</strong> Due to serious risk of bias</td>
<td>With a P&lt;0.0004 and heterogeneity of 81%, evidence suggests that while the SF-36 physical summary of quality of life is lower in women with PCOS compared with women without PCOS, high heterogeneity means the results should be interpreted with caution.</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------</td>
<td>---------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>QoL - psychological summary</td>
<td>Measured by: SF-36 Scale: - High better Based on data from 458 patients in 3 studies Follow up NA</td>
<td><strong>Difference:</strong> MD 9.09 lower (CI 95% 11.42 lower - 6.76 lower)</td>
<td><strong>Low</strong> Due to serious risk of bias</td>
<td>With a P&lt;0.00001 and heterogeneity of 28%, evidence suggests that the SF-36 psychological summary of quality of life is lower in women with PCOS compared with women without PCOS.</td>
</tr>
<tr>
<td>QoL - physical health</td>
<td>Measured by: WHOQOL Scale: - High better Based on data from 728 patients in 3 studies Follow up NA</td>
<td><strong>Difference:</strong> MD 2.12 lower (CI 95% 4.02 lower - 0.22 lower)</td>
<td><strong>Low</strong> Due to serious risk of bias</td>
<td>With a P&lt;0.03 and heterogeneity of 31%, evidence suggests that the WHOQOL quality of life domain of physical health is lower in women with PCOS compared with women without PCOS.</td>
</tr>
<tr>
<td>QoL - psychological health</td>
<td>Measured by: WHOQOL Scale: - High better Based on data from 728 patients in 3 studies Follow up NA</td>
<td><strong>Difference:</strong> MD 2.07 lower (CI 95% 4.02 lower - 0.12 lower)</td>
<td><strong>Low</strong> Due to serious risk of bias</td>
<td>With a P&lt;0.04 and heterogeneity of 34%, evidence suggests that the WHOQOL quality of life domain of psychological health is lower in women with PCOS compared with women without PCOS.</td>
</tr>
<tr>
<td>Quality of life</td>
<td>Measured by: WHOQOL Scale: - High better</td>
<td>Difference: MD 2.16 lower (CI 95% 5.69 lower - 1.37 lower)</td>
<td>Low Due to serious risk of bias</td>
<td>With a P&lt;0.23 and heterogeneity of 63%, evidence suggests that there is no difference in the WHOQOL quality of life domain of social relationships between women with and without PCOS.</td>
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<td>----------------</td>
<td>------------------------------------------</td>
<td>----------------------------------------------------------</td>
<td>--------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>QoL - social relationships</td>
<td>Based on data from 728 patients in 3 studies Follow up NA</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>QoL - environment</td>
<td>Measured by: WHOQOL Scale: - High better</td>
<td>Difference: MD 1.13 lower (CI 95% 2.2 lower - 0.07 lower)</td>
<td>Low Due to serious risk of bias</td>
<td>With a P&lt;0.04 and heterogeneity of 0%, evidence suggests that the WHOQOL quality of life domain of environment is lower in women with PCOS compared with women without PCOS.</td>
</tr>
<tr>
<td>Based on data from 728 patients in 3 studies Follow up NA</td>
<td></td>
<td></td>
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</tbody>
</table>
Quality of life

GRADE framework

Interactive Evidence to Decision Framework

1) In women with PCOS, what is the prevalence and severity of reduced QoL and should QoL be assessed as part of standard care?
Evidence review

2) In women with PCOS, what dimensions of QoL are most affected?
Narrative review

3) In women with PCOS, what is the most effective tool/method to assess quality of life (QoL)?
Evidence/narrative review

QUESTION

Question details

Problem: Women with PCOS have lower quality of life than women without PCOS, capturing patient reported impact of their condition is important, however assessment of QoL in PCOS can be challenging

Option: Is QoL reduced in PCOS and should assessment be part of standard care in women with PCOS

Comparison: NA

Main outcomes: Quality of life

Setting: Primary care, PCOS models of care and in clinical research

Perspective: Health care provider

Background

Health Related Quality of life (HRQoL) is a well-recognised and important health outcome, especially in chronic disease and relates to the patient reported physical, social and emotional effects of a condition and its associated treatments. HRQoL is patient reported subjective perception of wellbeing, has multiple dimensions and is time dependent. Assessment is based on patient reported outcomes and can be measured through a variety of tools. Commonly used generic tools for screening HRQoL such as the Short Form -36 (SF-36) and WHO- BREF are limited by specificity for PCOS features and are not ideal for PCOS overall as they have a significant focus on unrelated health issues such as mobility,
impact on work, pain, environment and propensity to infective illnesses. They also do not measure the impact of key dimensions of PCOS such as infertility and hirsutism. However the use of these tools is the only way to assess QoL across women with PCOS and women without PCOS.

Condition specific tools have therefore been developed which in PCOS include the PCOSQ and modified PCOSQ (MPCOSQ). The PCOSQ has 26 items, measuring emotions (8 items), body hair (5 items), weight (5 items), infertility difficulties (4 items) and menstrual problems (4 items). Each item is graded with a seven-point scale ranging from 1 (maximum impairment) to 7 (no problems or difficulties). The MPCOSQ is similar to the PCOSQ and in addition to four more items on acne. Studies in PCOS increasingly use the PCOSQ and the MPCOSQ which have also been adapted and tested in different ethnic populations including in China. However these tools cannot be used to show QoL in PCOS differs to non PCOS women.

Subgroups

Subgroup name: Adults
Description: Women with and without PCOS

Subgroup name: Adolescents
Description: Adolescents with and without PCOS

ASSESSMENT

Problem

Is the problem a priority?
Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>No</th>
<th>Probably No</th>
<th>Probably Yes</th>
<th>Yes</th>
</tr>
</thead>
</table>

Research evidence

Meta-analysis of five studies using SF-36 and three studies using WHO-BREF in adult women, all of which were low quality and low certainty, suggests that women with PCOS have lower quality of life compared to women without PCOS. Statistical heterogeneity was present in meta-analysis for six out of the ten domains in SF-36 and in one out of four domains in the WHO-BREF.

Additional considerations
The application of generic poorly tailored QoL tools that include features unrelated to the condition such as immobility, pain, risk of infections and environment have limited relevance in assessment of QoL in PCOS however they are the only tools that can compare across women with PCOS and those without the condition. Given the generic nature of these tools, and the specific features of PCOS, the results are consistent with the clinical features of PCOS with lower QoL primarily related to emotional role, functioning, psychological features, vitality and mental health. Physical impacts were less remarkable as expected. Also as PCOS is a diverse condition with variable expression of each of the features, that also vary by ethnicity are dynamic overtime and are influenced by individual patient perspectives heterogeneity is to be expected.

In this case, the evidence captured in this evidence review is not greatly helpful in addressing the question on which tools should be used and should QoL be assessed in routine care. Instead this question is best answered armed with the awareness that QoL is reduced and that there is a need for increasing awareness and understanding of the need to treat to patient reported and meaningful outcomes. Clinically a detailed history remains important to capture and treat to patient prioritised outcomes when partnering with women with PCOS in their care. These outcomes can be captured in QoL tools and the availability of more appropriate and condition specific QoL assessment tools (PCOSQ and MPCOSQ) outlined in the narrative review could be useful in targeting treatment to areas of greatest QoL impact, although burden of administration is noted.

In the research setting, whilst the expert GDG acknowledge that there is a need to determine clinical meaningful differences in QoL scores and to validate the tools for change over time, based on a range of evidence sources, clinical expertise and patient perspectives it was considered important to formally measure QoL in clinical research studies with condition specific tools.

Panel discussion
All in agreement for judgement.

Desirable effects

How substantial are the desirable anticipated effects?

Judgement

<table>
<thead>
<tr>
<th></th>
<th>Don't know</th>
<th>Varies</th>
<th>Trivial</th>
<th>Small</th>
<th>Moderate</th>
<th>Large</th>
</tr>
</thead>
</table>

Research evidence

No evidence was identified about the effects of assessing quality of life or which tool/method is most effective in women with PCOS.

Additional considerations

Addressing patient reported and prioritised outcomes is important in improving QoL and optimising health in any chronic condition. This is based on evidence from literature of patient reported outcome measures (PROMS) and patient reported experience measures (PREMS) internationally. If patient reported priorities and outcomes were recognised as front and centre of holistic care, this would be a substantive step forward in addressing key gaps in care and significant dissatisfaction expressed by women internationally with PCOS.

If formal QoL assessment tools were applied in standard care it brings patient and provider burden and individual benefit is more difficult to determine.

If application of QoL assessment were applied in clinical research this would significantly advance understanding of the usefulness and comparative effectiveness of treatments from the patients perspective.
Panel discussion
All in agreement for judgement. In recommending treatment or developing and improving services, ultimately patient priorities and QoL is a key consideration and desirable effects on QoL should inform therapeutic decisions for both patients and health professionals.

**Undesirable effects**
How substantial are the undesirable anticipated effects?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Large</th>
<th>Moderate</th>
<th>Small</th>
<th>Trivial</th>
</tr>
</thead>
</table>

Research evidence
See above in ‘Desirable effects’.

Additional considerations
None.

Panel discussion
All in agreement for judgement.

**Certainty of the evidence (for question 1 only)**
What is the overall certainty of the evidence of effects?

Judgement

<table>
<thead>
<tr>
<th>No included studies</th>
<th>Very low</th>
<th>Low</th>
<th>Moderate</th>
<th>High</th>
</tr>
</thead>
</table>

Research evidence
See above in ‘Desirable effects’.

Additional considerations
None.

Panel discussion
All in agreement for judgement. Evidence of value in standard care is lacking at present.
Values
Is there important uncertainty about, or variability in, how much people value the main outcomes?

Judgement

<table>
<thead>
<tr>
<th>Important uncertainty or variability</th>
<th>Possibly important uncertainty or variability</th>
<th>Probably no important uncertainty or variability</th>
<th>No important uncertainty or variability</th>
</tr>
</thead>
</table>

Research evidence
Evidence not sought.

Additional considerations
This is uncertain. However in recent years, there has been an increased focus on placing patients at the center of health care research and evaluating clinical care in order to improve their experience and ensure that research is both robust and of maximum value for the use of treatments and health services. Patients’ involvement in clinical research and service evaluation is now recognised as fundamental and encompasses patient-reported outcomes (PROs) and patient-reported outcome measures (PROMs), patient-reported experiences measures (PREMs) and patient and public involvement (PPI) for including patients in the research and in service development and improvement. Generic evidence in this area suggests value from the assessment on patient prioritised outcomes in clinical research and also underpins the notion of patient centred care in clinical practice. Based on reduced QoL in PCOS and patient dissatisfaction with current care, it would appear to be of value to apply PCOS specific assessment tools in clinical research and to potentially consider them if time allows for application in clinical care, with the caveat that clinically meaningful differences in scores need to be determined with urgency.

Health Serv Insights. 2013; 6: 61–68. Published online 2013 Aug 4. doi: 10.4137/HSI.S11093 PatientReported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs) Theresa Weldring and Sheree M.S. Smith

Panel discussion
All in agreement for judgement.

Balance of effects
Does the balance between desirable and undesirable effects favour the option or the comparison?

Judgement

| Don't know | Varies | Favours the comparison | Probably favours the comparison | Does not favour either the option or the comparison | Probably favours the option | Favours the option |
Research evidence
See above in ‘Desirable effects’.

Additional considerations
None.

Panel discussion
All in agreement for judgement.

Resources required
How large are the resource requirements (costs)?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Large costs</th>
<th>Moderate costs</th>
<th>Negligible costs or savings</th>
<th>Moderate savings</th>
<th>Large savings</th>
</tr>
</thead>
</table>

Research evidence
No evidence was identified about the effects or resource requirements of assessing quality of life in women with PCOS.

Additional considerations
Overall the costs of implementing the recommendations to understand and focus on patient priorities including taking a targeted history and considering patient prioritised outcomes may increase consultation times, yet may make treatments more targeted and beneficial to patients.

If structured tools are to be used in practice, these can be completed outside contact time, costs are minimal and relate to health professional time to score and explain the tools. However the resource requirements here on a larger scale are significant.

Costs of self administration of QoL assessment tools in clinical research studies are nominal. These relate to staff time to distribute the tools and enter and analyse the date only.

Panel discussion
Moderate potential savings by targeting appropriate most meaningful priorities for patients.

Certainty of evidence of required resources
What is the certainty of the evidence of resource requirements (costs)?

Judgement
Quality of life

Research evidence
No evidence was identified about the effects or resource requirements of assessing quality of life in women with PCOS.

Additional considerations
There is no relevant evidence to guide resource needs, however this is a simple short survey and logistics are minimal.

Panel discussion
All in agreement for judgement.

Cost-effectiveness

Does the cost-effectiveness of the option favour the option or the comparison?

Judgement

Research evidence
No evidence was identified about the effects or cost effectiveness of assessing quality of life in women with PCOS.

Additional considerations
Overall the costs of implementing the recommendations to understand and focus on patient priorities including taking a targeted history and considering patient prioritised outcomes may increase consultation times, yet benefits are likely to outweigh disadvantages of treatment without considering a woman’s perspectives.

If considering implementing the formal QoL tool into routine care the burden of administration is likely unreasonable in clinical care but important and appropriate in research in capturing the benefits of new treatments or health services on QoL and in this setting the balance favors application of the tools yet in standard care it is not possible to assess the balance at this time.

Panel discussion
All in agreement for judgement.

Equity
What would be the impact on health equity?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Reduced</th>
<th>Probably reduced</th>
<th>Probably no impact</th>
<th>Probably increased</th>
<th>Increased</th>
</tr>
</thead>
</table>

Research evidence

No evidence was identified about the impact on health equity associated with assessing quality of life in women with PCOS.

Additional considerations

None

Panel discussion

Improving active patient and health professional participation will increase the effectiveness of this strategy.

Acceptability

Is the option acceptable to key stakeholders?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>No</th>
<th>Probably No</th>
<th>Probably Yes</th>
<th>Yes</th>
</tr>
</thead>
</table>

Research evidence

No evidence to inform this criterion.

Additional considerations

In clinical research this would be acceptable to stakeholders, however in standard care application of the assessment tools in unlikely to be acceptable at this time

Panel discussion

In certain cultures, health systems and contexts, patient driven prioritisation may be less acceptable. At the current time assessment of QoL in standard care is unlikely to be acceptable to providers given inadequate evidence of benefit and time limitations

Feasibility

Is the option feasible to implement?

Judgement
Quality of life

Don't know

Varies

No

Probably No

Probably Yes

Yes

Research evidence
No evidence was identified about assessing quality of life in women with PCOS.

Additional considerations
Feasibility challenge in clinical care, but feasible in research settings.

Panel discussion
This requires a degree of change in practice towards partnership in care internationally. As per acceptability, feasibility in clinical research is relatively simple but in practice is limited at this time

CONCLUSIONS

Consensus recommendations
All health professionals should be aware of the adverse impact of PCOS on quality of life.
Capturing patient perceptions of their symptoms, impact on their quality of life and priorities must be considered in standard care to improve patient outcomes.

Judgement

Practice point
If it is clinical or patient preference to use a structured tool to elicit patient priorities, the PCOSQ or the MPCOSQ may be of use.

Justification
QoL is reduced in PCOS. PCOS is a diverse and dynamic condition and patient experience, perceptions and priorities in terms of the impact of different dimensions of PCOS on QoL are important. This diverse condition, varies across the lifespan and across ethnicities, key gaps in patient satisfaction have been demonstrated in this context, eliciting patient priorities to guide management are very important here.
Whilst QoL is vital in individual patient standard care, the lack of evidence on degree of difference that constitutes meaningful changes over time and lack of longitudinal data as well as patient and provider burden and likely lack of acceptability and feasibility would suggest that implementation of formal QoL assessment into standard care is not recommended at this time.

QoL is an important outcomes in research to inform treatment or service benefit and patient value.

**Subgroup considerations**

Ethnic, linguistic, cultural and lifestage considerations impact on the dimensions most impaired by PCOS. In research the PCOSQ and MPCOSQ have been tested and validated across ethnicities.

**Implementation considerations**

Implementation can include letters to the editors of key PCOS journals around QoL tool application in research as well as communication through the 32 international societies involved in the PCOS guideline.

**Monitoring and evaluation**

Patient surveys could assess whether clinical practice takes note of patient priorities in clinical care.

Evaluation of QoL reporting in PCOS research can be simply completed and reported to ascertain effective guideline recommendation implementation.

**Research priorities**

Quality of life should be measured using the PCOSQ or MPCOSQ in all clinical research studies.

Determination of the clinical meaningful differences in QoL scores should be undertaken with urgency and validation of the use of the QoL assessment tools over time should be completed, acknowledging that PCOS is a dynamic condition that changes over time.

QoL assessment with the MPCOSQ should be included in all clinical, health services and population health research in PCOS.

When comparing women with PCOS and those without PCOS, consideration should be given to using broader tools capturing psychosocial dimensions of QoL such as the AQoL.
List of included studies


## Appendix I: Methods

### PICO/selection criteria – question 1

<table>
<thead>
<tr>
<th>RANK: 3</th>
<th>In women with PCOS:</th>
</tr>
</thead>
<tbody>
<tr>
<td>a.</td>
<td>What is the prevalence and severity of reduced QoL?</td>
</tr>
<tr>
<td>b.</td>
<td>Should QoL be assessed as part of standard care?</td>
</tr>
</tbody>
</table>

### Participants (P)

- Females of any age, ethnicity and weight.
  - Subgroups:
    - Adolescents
    - Ethnicity
    - Phenotype

### Intervention (I)

- Quality of life measured in women with PCOS (diagnosed by Rotterdam, NIH or AES – phenotypes will be captured).
- Refer Table 2 for possible tools.
- If no evidence in PCOS, relevant evidence will be sought narratively by key contact (not searched by evidence team).

### Comparison (C)

- Quality of life measured in a non-PCOS group.
- Same QoL tool as that used in women with PCOS must be used.

### Outcomes (O)

- Prevalence and severity of impaired quality of life.

### Study type

- Evidence based guidelines, systematic reviews, comparative prospective cohort studies and comparative cross sectional studies.

### Limits

- English language.
- New search.

### Exclusion criteria

- NA

- Non-evidence based guidelines or any study lower than a comparative cross sectional study.
<table>
<thead>
<tr>
<th>PICO/selection criteria – question 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>RANK: 3</td>
</tr>
<tr>
<td><strong>Participants (P)</strong></td>
</tr>
<tr>
<td><strong>Intervention (I)</strong></td>
</tr>
<tr>
<td>Females with PCOS (diagnosed by Rotterdam, NIH or AES) of any age, ethnicity and weight. Subgroups: • Adolescents • Ethnicity • Phenotype</td>
</tr>
<tr>
<td>Tool to screen for quality of life. REFER TABLE 2 FOR POSSIBLE TOOLS</td>
</tr>
<tr>
<td><strong>Outcomes (O)</strong></td>
</tr>
<tr>
<td><strong>Study type</strong></td>
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<tr>
<td><strong>Exclusion criteria</strong></td>
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<tr>
<td>Females without PCOS.</td>
</tr>
<tr>
<td>All other tools.</td>
</tr>
<tr>
<td>All other tools.</td>
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<tr>
<td><strong>Outcomes (O)</strong></td>
</tr>
<tr>
<td><strong>Study type</strong></td>
</tr>
<tr>
<td>Pearson or Spearman correlations and odds ratios</td>
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### Database search results

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Duplicates removed over total 131

Screened 473

Excluded based on T & A 420

Excluded based on full text 40

Unable to retrieve full text 0

Included Question 1 13

Included Question 2 0

Thirteen studies were identified to answer question 1 and evidence synthesis has been conducted.

No studies were identified to answer question 2 and a narrative review has been prepared by the key contacts.
### Appendix II - WHOQOL-BREF domains

<table>
<thead>
<tr>
<th>Domain</th>
<th>Facets incorporated within domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physical health</td>
<td>Activities of daily living&lt;br&gt;Dependence on medicinal substances and medical aids&lt;br&gt;Energy and fatigue&lt;br&gt;Mobility&lt;br&gt;Pain and discomfort&lt;br&gt;Sleep and rest&lt;br&gt;Work Capacity</td>
</tr>
<tr>
<td>2. Psychological health</td>
<td>Bodily image and appearance&lt;br&gt;Negative feelings&lt;br&gt;Positive feelings&lt;br&gt;Self-esteem&lt;br&gt;Spirituality / Religion / Personal beliefs&lt;br&gt;Thinking, learning, memory and concentration</td>
</tr>
<tr>
<td>3. Social relationships</td>
<td>Personal relationships&lt;br&gt;Social support&lt;br&gt;Sexual activity</td>
</tr>
<tr>
<td>4. Environment Financial resources</td>
<td>Freedom, physical safety and security&lt;br&gt;Health and social care: accessibility and quality&lt;br&gt;Home environment&lt;br&gt;Opportunities for acquiring new information and skills&lt;br&gt;Participation in and opportunities for recreation / leisure activities&lt;br&gt;Physical environment (pollution / noise / traffic / climate)&lt;br&gt;Transport</td>
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NARRATIVE REVIEW: In women with PCOS, what is the prevalence and severity of depression and anxiety and should they be screened?

Prevalence and problem
Depression and anxiety are exceptionally common throughout the world and represent a major public health problem. Several studies have shown that women with PCOS are more likely to have depressive symptoms or clinical depression and anxiety symptoms than their healthy counterparts.

Clinical practice gap – need for guidance
Despite an awareness of the high prevalence of depressive and anxiety symptoms there are no uniform recommendations to screen women with PCOS routinely. The Australian PCOS guidelines state that depression and anxiety should be routinely screened and assessed by all appropriately qualified health professionals in women with PCOS. If a woman with PCOS is positive on screening, the practitioner should further assess for depression/anxiety. If detected, appropriate management should be offered. Despite these recommendations surveys of women with PCOS in North America, Europe and Australia show that less than 10% were satisfied with information regarding long term complications associated with PCOS and less than 5% were satisfied with emotional support and counselling offered.

Summary of key information

Depression
The most commonly reported symptoms of depression were daily fatigue, sleep disturbances and diminished interest [1]. A meta-analysis of 10 studies including 522 women with PCOS and 475 controls from 8 countries reported increased depression scores in 44% women in the PCOS group (14-67%) versus 17% in controls (2-35%) (OR: 4.03, 95% CI: 2.96-5.5, p<0.01) [2]. Interestingly, the risk of having an abnormal depression score was still 4-fold increased when PCOS and control groups were matched for BMI (number of studies = 5) suggesting that this risk is independent of obesity. This meta-analysis reported no evidence of heterogeneity between the included studies. Another meta-analysis with several overlapping studies included 910 women with PCOS and 1347 controls and reported a standardized mean difference (SMD) of depression scores between the two groups of 0.82 (95% CI: 0.73-0.92), suggesting a higher risk of depression in PCOS [3]. Included studies did not show a significant heterogeneity in this meta-analysis however, it was not clear if the depression scores were clinically significant. A meta-analysis of 26 studies including 4716 participants from 14 different countries was published in 2012 [4]. This paper reported SMD of 0.60 for depression scores between PCOS and control groups (95% CI: 0.47-0.73) however, the authors emphasized that scores for women with PCOS were not in a clinically significant range in half of the studies whereas mild depression was reported in the remaining studies. Further, there was significant heterogeneity between studies (I2-73%, p<0.001). The most recent meta-analysis including 23 studies was conducted with rigorous inclusion criteria including diagnosis of PCOS by a physician and not self-reported, and inclusion of studies that provided prevalence of abnormal depression scores in the study population [5]. This meta-analysis showed the odds ratio of moderate/severe depressive symptoms was 4.18 in women with PCOS (95% CI: 2.68-6.52). The median prevalence of depression was 36.6% (IQR: 22.3, 50.0%) in the PCOS group and 14.2% (IQR: 10.7, 22.2%) in the control group. This meta-analysis also confirmed that the increased risk of depressive symptoms was independent of obesity. Sensitivity analyses showed that both clinic and community recruits had higher depressive scores compared to matched controls. There are some limitations to most studies included in the above meta-analyses including relatively small sample sizes of individual studies and limited confirmation of the diagnosis of depression. For example, in only 3 studies, depression was confirmed with further clinical assessment in individuals who had abnormal screening test scores. Nevertheless, two out of those 3 studies reported increased rates of clinically diagnosed depression in women with PCOS.

A large population-based study using national health registries in Sweden, examined the association between PCOS and psychiatric disorders, as well as risks for psychiatric disorders in female and male siblings of women with PCOS [6]. This study reported a significantly increased adjusted risk of depression in women with PCOS of 1.25 (1.19-1.31). In another large hospital database in Western Australia, the incidence of depression in women with PCOS (9.8%) was...
Depressive and anxiety symptoms, screening and treatment_ prevalence and screening significantly higher compared to women who did not have a diagnosis of PCOS (4.6%) [7]. Overall these studies confirm that women with PCOS have a higher prevalence of clinically significant depressive symptoms indicating a chronic condition and not episodic events.

Anxiety
Symptoms of anxiety and anxiety disorders are more common in women with PCOS. One meta-analysis published in 2011 including 6 studies and another including 11 studies reported that women with PCOS had significantly higher anxiety scores compared to controls [3, 4]. Another meta-analysis in the same time period including 4 studies reported a sevenfold increase in the risk of abnormal anxiety scores among PCOS subjects [8]. However, there was significant heterogeneity amongst included studies in all three meta-analysis. A recent rigorous meta-analysis identified 10 studies that included prevalence of anxiety symptoms in women with well-defined PCOS diagnosed by physicians using validated screening tools [5]. This study shows an increased odds of high anxiety symptoms compared with controls (OR: 5.62; 95% CI: 3.22, 9.80) and also an increased odds of moderate and severe anxiety symptoms (OR: 5.38; 95% CI: 2.28, 12.67). The median prevalence of anxiety was 41.9% (IQR: 13.6, 52.0%) in the PCOS group and 8.5% (IQR: 3.3, 12.0%) in the control group. There was however, increased heterogeneity amongst studies. In a large population-based study in Sweden, including 24,385 women diagnosed with PCOS matched for sex, year of birth, and county of residence to ten individuals randomly selected from the general population showed an increased adjusted OR for anxiety disorder (1.37, CI: 1.32, 1.43) [6]. Further, sisters of women with PCOS also had higher adjusted OR for anxiety disorder (1.15, CI: 1.07, 1.25). In another large hospital database in Western Australia mentioned in the depression section, the incidence of anxiety in women with PCOS (14%) was significantly higher compared to women who did not have a diagnosis of PCOS (5.9%) [7]. Collectively these studies indicate increased anxiety symptoms and anxiety disorders in women with PCOS, across diverse ethnic groups.

Recommendations

<table>
<thead>
<tr>
<th>CONSENSUS RECOMMENDATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Given the high prevalence, we recommend that depression should be routinely screened and assessed in all women with PCOS at diagnosis. Simple screening tools validated in the region of practice may be utilized.</td>
</tr>
<tr>
<td>• If a woman with PCOS has a positive screen, practitioners should further assess, refer to appropriate specialists or offer treatment. If a woman with PCOS has a negative screen, repeated screening is suggested in high risk women such as those with anxiety, obesity, diabetes, family history of depression and postpartum period.</td>
</tr>
<tr>
<td>• Given the high prevalence, we recommend that anxiety should be routinely screened and assessed in all women with PCOS. Simple screening tools validated in the region of practice may be utilized.</td>
</tr>
<tr>
<td>• If a woman with PCOS has a positive screen, practitioners should further assess, refer to appropriate specialists or offer treatment. If a woman with PCOS has a negative screen, repeated screening should be suggested in high risk women such as those with depression and obesity.</td>
</tr>
</tbody>
</table>
In women with PCOS, what is the prevalence and severity of symptoms of depression and anxiety and should they be screened?

CONSIDERATIONS

Background
Systematic reviews, meta-analyses, registries and health service datasets collectively indicate that women with PCOS have a higher prevalence of clinically significant symptoms of depression and anxiety. Identification of mental health disorders is important for supporting women’s overall health, wellbeing and quality of life by facilitating appropriate referral and care. In the context of PCOS, identification of mental health disorders is also crucial for optimising women’s ability to engage with lifestyle management and other preventive strategies at the core of PCOS care. Therefore, we recommend routine mental health screening for women with PCOS.

We did not identify any evidence in women with PCOS for an evidence based recommendation about screening tools and therefore a clinical consensus recommendation has been made based on key relevant sources of evidence-based information for the general population and the clinical expertise of the multidisciplinary guideline development group.

ASSESSMENT

Problem
Is the problem a priority?

Judgement

| 1 | Don't know  |  |  | 3 | Probably Yes | 5 | Yes |

Research evidence
Women with PCOS are at increased risk of experiencing symptoms of depression and anxiety compared to women without PCOS. Past systematic reviews report that both prevalence and odds of depression and anxiety symptoms in women with PCOS are higher than in women without PCOS [1,2]. Further moderate and severe symptoms are increased in women with PCOS. Few studies indicate that clinically diagnosed depression is also increased in women with PCOS.

Additional considerations
Despite an awareness of the high prevalence of depressive and anxiety symptoms there are no uniform recommendations to screen women with PCOS routinely. The Australian PCOS guidelines state that depression and anxiety should be routinely screened and assessed by all appropriately qualified health professionals in women with polycystic ovary syndrome. If a woman with polycystic ovary syndrome is positive on screening, the practitioner should further assess for depression/anxiety. If detected, appropriate management should be offered. Also, the endocrine society guidelines recommend screening women with PCOS for depression and anxiety. Despite these recommendations surveys of women with PCOS in North America, Europe and Australia show that less than 10% were satisfied with information regarding long term complications associated with PCOS and less than 5% were satisfied with emotional support and counselling offered.

Panel discussion
All in agreement for judgement.

Resources required
Depressive and anxiety symptoms, screening and treatment_ prevalence and screening

How large are the resource requirements (costs)?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Large costs</th>
<th>Moderate costs</th>
<th>Negligible costs or savings</th>
<th>Moderate savings</th>
<th>Large savings</th>
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Research evidence
Evidence not sought.

Additional considerations
In many countries it is not usual practice to screen women with PCOS for depression and/or anxiety symptoms and doing so may identify affected patients who would otherwise be missed. Screening may have resource implications such as an impact on length of consultation, however this can be reduced by the use of the screening tools recommended here. If depression and/or anxiety symptoms are detected, intervention may require referral to other health practitioners. Additional time with the patient may also be required to complete an appropriate care plan. Access to appropriately trained and experienced health professionals will be required. It is the responsibility of all health professionals to understand the impact of PCOS on psychological health and to screen for and manage these disorders.

Panel discussion
Complex because resources sit across screening, referral and treatment and there is no evidence to assess the balance. Primary resource required is clinical time. Regional resources and training and health system are relevant.

Cost-effectiveness

Does the cost-effectiveness of the intervention favour the intervention or the comparison?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Favours the comparison</th>
<th>Probably favours the comparison</th>
<th>Does not favour either the intervention or the comparison</th>
<th>3</th>
<th>Favours the intervention</th>
</tr>
</thead>
</table>

Research evidence
Evidence not sought.

Additional considerations
None.

Panel discussion
The GDG did have different perspectives on this issue.

Equity

What would be the impact on health equity?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Reduced</th>
<th>Probably reduced</th>
<th>Probably no impact</th>
<th>Probably increased</th>
<th>Increased</th>
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</thead>
</table>

Research evidence
Depressive and anxiety symptoms, screening and treatment _ prevalence and screening

The life stage of a woman should also be considered when screening for mental health disorders as risk factors and life events may differ. Specific screening tools for risk factors and symptomatology exist for adolescents, the antenatal and postnatal periods and for older adults. Consider issues around religion and sexual orientation.

The cultural identity and preferred language of a woman are also important considerations. Be aware of possible variations in presentation of mental health disorders and conduct screening in a culturally sensitive manner. Consider using screening tools that have been translated and cross-culturally validated [13]. For example, culturally validated assessment tools for Aboriginal and Torres Strait Islander women are available and should be used in a context of culturally competent care [11].

Additional considerations
None

Panel discussion
Cultural and linguistic workforce training, health system, stigma and resources considered.

Acceptability

Is the intervention acceptable to key stakeholders?
Judgement

![Don't know](square) ![Varies](square) ![No](square) ![Probably No](square) ![Probably Yes](square) ![Yes](square)

Research evidence
Evidence not sought.

Additional considerations
None

Panel discussion
Cultural and linguistic workforce training, health system, stigma and resources.

Feasibility

Is the intervention feasible to implement?
Judgement

![Don't know](square) ![Varies](square) ![No](square) ![Probably No](square) ![Probably Yes](square) ![Yes](square)

Research evidence
Based on consultation of the key sources of evidence-based information for the general population [3,4,5,6,7,8,9,10,11] and the clinical expertise of the multidisciplinary guideline development group we suggest a stepped screening process and the use of tools outlined in the recommendation to increase feasibility.

Screening for mental health disorders comprises three parts: assessment of risk factors, assessment of symptoms, and assessment of risk of deliberate self-harm or suicidal intent. Screening can be separated into two levels depending on the competence of the practitioner.

Step 1: The following questions could be asked [12]:
Over the last 2 weeks, how often have you been bothered by the following problems?
1) Feeling down, depressed, or hopeless?
2) Little interest or pleasure in doing things?
3) Feeling nervous, anxious or on edge?
Depressive and anxiety symptoms, screening and treatment — prevalence and screening

4) Not being able to stop or control worrying?

**Step 2:** If any of the responses are positive, further screening should involve either:

A) Referral to an appropriate professional to perform a further mental health assessment. If this is not the patient’s usual GP, inform the GP of the referral.

OR

B) Completing the following assessments:

1) **Assess psychosocial risk factors with or without a structured tool:**

Where appropriate, respectfully elicit a history of any past or current mental health disorder or chronic physical illness, domestic violence, sexual abuse or past traumatic events, past response to treatments, past experience of mood elevation, family history of mental illness. Enquire about current living conditions, financial security, quality of interpersonal relationships, social isolation, employment, immigration status, alcohol and drug use.

Structured tools to assist with risk factor assessment exist and an appropriate tool should be selected based on the woman’s circumstances such as age, ethnicity and life-stage.

2) **Assess symptoms using one or more of the following general screening tools:**

Many of these tools are available in different lengths and have been widely translated. Exercise clinical judgement to select the appropriate tool or combination of tools.

- **Patient Health Questionnaire (PHQ)** (self-administered)
- **Brief Psychiatric Rating Scale (BPRS)** (clinician-administered)
- **Hospital Anxiety and Depression Scale (HADS)** (self-administered)
- **Depression Anxiety Stress Scale (DASS)** (self-administered)

If further testing is required then the more specific or comprehensive screening tools listed below can be used:

- **Generalised Anxiety Disorder Scale (GAD7)** (self-administered)
- **Hamilton Depression Rating Scale (HAM-D)** (clinician-administered)
- **Hamilton Anxiety Rating Scale (HAM-A)** (clinician-administered)
- **Beck Depression Inventory (BDI)** (self-administered)
- **Beck Anxiety Inventory (BAI)** (self-administered)
- **Zanarini Rating Scale (ZAN-BPD)** (clinician-administered to diagnose Borderline Personality Disorder)

3) **Assess suicidal ideation, intent and deliberate self-harm.**

The tools marked * contain questions for asking about suicidal thoughts or intentions, and thoughts or acts of self-harm.

Use clinical judgement and the information gained from all three assessments to decide whether referral to a psychiatrist or psychologist is required for a clinical interview to establish a mental health diagnosis.

**Additional considerations**

The optimal timing and interval for screening is unknown. A pragmatic approach may be to screen all women and adolescents at the time of PCOS diagnosis and where appropriate, at the time of their regular physical health checks for PCOS. Use clinical judgment considering an individual woman’s risk factors to inform if additional screening is warranted. Align timing and interval of screening during the antenatal and postnatal periods with the regional clinical practice guidelines.

**Panel discussion**

Cultural and linguistic workforce training, health system, stigma and resources.
CONCLUSIONS

Consensus recommendations

- All health professionals must be aware of the high prevalence of moderate to severe anxiety and depressive symptoms in adolescents and adults with PCOS.
- Anxiety and depressive symptoms should be routinely screened in all adolescents and adults with PCOS at diagnosis.
- If a woman with PCOS has a positive screen, practitioners should further assess and/or refer for assessment.
- If treatment is warranted, psychological therapy and/or pharmacological treatment should be offered, informed by regional clinical practice guidelines.

Judgement

<table>
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<th>Recommendation</th>
<th>Strong recommendation against the option</th>
<th>Conditional recommendation against the option</th>
<th>Conditional recommendation for either the option or the comparison</th>
<th>Conditional recommendation for the option</th>
<th>Strong recommendation for the option</th>
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</table>

Practice points

- The optimal interval for screening is not known. A pragmatic approach could include repeat screening using clinical judgment, considering risk factors, comorbidities and life events.
- If using pharmacological treatment, avoid agents that exacerbate PCOS symptoms including weight gain.

Justification

High prevalence in PCOS and impact of treatment on better engagement in PCOS related treatments.

Subgroup considerations

Adolescents and different PCOS phenotypes should be considered.

Implementation considerations

The life stage of a woman should also be considered when screening for mental health disorders as risk factors and life events may differ. Consider issues around culture and sexual orientation.

The cultural identity and preferred language of a woman are also important considerations. Be aware of possible variations in presentation of mental health disorders and conduct screening in a culturally sensitive manner.

In many countries it is not usual practice to screen women with PCOS for depression and/or anxiety symptoms and doing so may identify affected patients who would otherwise be missed. Screening may have resource implications such as an impact on length of consultation, however this can be reduced by the use of the PCOS emotional wellbeing general screening tool and other tools recommended here.

If depression and/or anxiety symptoms are detected, intervention may require referral to other health practitioners. Additional time with the patient may also be required to complete an appropriate care plan. Access to appropriately trained and experienced health professionals will be required. It is the responsibility of all health professionals to understand the impact of PCOS on psychological health and to screen for and manage these disorders.

Monitoring and evaluation

Ongoing monitoring of women with depressive and anxiety symptoms is important. Change in symptoms with initiation of PCOS related therapies should be monitored. The guideline translation, including these recommendations, will need to be evaluated.
Depressive and anxiety symptoms, screening and treatment: prevalence and screening

Research priorities
Validation of screening tools in the PCOS population.
Longitudinal follow up to determine frequency of screening for depressive and anxiety symptoms.
Prevalence of depressive and anxiety symptoms in PCOS phenotypes, populations and across different life stages.
Prevalence of mental health disorders diagnosed by clinical interview.
Elucidate the cause of depressive and anxiety symptoms.

References


EVIDENCE AND NARRATIVE REVIEW: In women with PCOS, what is the most effective tool/method to assess depression and/or anxiety?

(No studies identified by the search so key contacts prepared a narrative review)

Narrative synthesis

Clinical need for the question

Women with PCOS are at increased risk of experiencing symptoms of depression and anxiety compared to women without PCOS. Past systematic reviews report that both prevalence and odds of depression and anxiety symptoms in women with PCOS are higher than in women without PCOS [1, 2]. Identification of mental health disorders is important for supporting women’s overall health, wellbeing and quality of life by facilitating appropriate referral and care. In the context of PCOS, identification of mental health disorders is also crucial for optimising women’s ability to engage with lifestyle management and other preventive strategies at the core of PCOS care.

With routine screening recommended for women with PCOS, guidance for how to identify possible mental health disorders is needed.

Evidence to answer the question

We did not identify any evidence in women with PCOS to answer the question and therefore a clinical consensus recommendation has been made based on key relevant sources of evidence-based information for the general population and the clinical expertise of the multidisciplinary guideline development group. The following resources and guidelines were consulted:

The treatment and management of depression in adults with chronic physical health problems, NICE, 2009 [3].

Common mental health problems: identification and pathways to care, NICE, 2011 [4].

Antenatal and postnatal mental health: clinical management and service guidance, NICE, 2014 [5].

Screening for Depression in Adults: US Preventive Services Task Force Recommendation Statement, 2016 [6].

Screening for Depression in Children and Adolescents: U.S. Preventive Services Task Force Recommendation Statement, 2016 [7].

Screening for and Treatment of Suicide Risk Relevant to Primary Care: A Systematic Review for the U.S. Preventive Services Task Force, 2014 [8].

Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines for Mood Disorders, 2015 [9].


Recommendation

**CLINICAL CONSENSUS RECOMMENDATION**
Mental health disorders should be routinely screened and assessed by appropriately qualified health professionals in all women with polycystic ovary syndrome. If symptoms of a mental health disorder are present, further assessment by clinical interview should be conducted. If a mental health disorder is detected, appropriate management should be offered.

**CLINICAL PRACTICE POINT**
Screening for mental health disorders comprises three parts: assessment of risk factors, assessment of symptoms, and assessment of risk of deliberate self-harm or suicidal intent. Screening can be separated into two levels depending on the competence of the practitioner.

**Step 1:** The following questions could be asked [12]:
Over the last 2 weeks, how often have you been bothered by the following problems?
1) Feeling down, depressed, or hopeless?
2) Little interest or pleasure in doing things?
3) Feeling nervous, anxious or on edge?
4) Not being able to stop or control worrying?

**Step 2:** If any of the responses are positive, further screening should involve either:
A) Referral to an appropriate professional to perform a further mental health assessment. If this is not the patient's usual GP, inform the GP of the referral.

OR

B) Completing the following assessments:
1) **Assess psychosocial risk factors with or without a structured tool:**
Where appropriate, respectfully elicit a history of any past or current mental health disorder or chronic physical illness, domestic violence, sexual abuse or past traumatic events, past response to treatments, past experience of mood elevation, family history of mental illness. Enquire about current living conditions, financial security, quality of interpersonal relationships, social isolation, employment, immigration status, alcohol and drug use.

Structured tools to assist with risk factor assessment exist and an appropriate tool should be selected based on the woman’s circumstances such as age, ethnicity and life-stage.

2) Assess symptoms using one or more of the following general screening tools:

Many of these tools are available in different lengths and have been widely translated. Exercise clinical judgement to select the appropriate tool or combination of tools.

- Patient Health Questionnaire (PHQ)* (self-administered)
- Brief Psychiatric Rating Scale (BPRS)* (clinician-administered)
- Hospital Anxiety and Depression Scale (HADS) (self-administered)
- Depression Anxiety Stress Scale (DASS) (self-administered)

If further testing is required then the more specific or comprehensive screening tools listed below can be used:

- Generalised Anxiety Disorder scale (GAD7) (self-administered)
- Hamilton Depression Rating Scale (HAM-D)* (clinician-administered)
- Hamilton Anxiety Rating Scale (HAM-A) (clinician-administered)
- Beck Depression Inventory (BDI)* (self-administered)
- Beck Anxiety Inventory (BAI) (self-administered)
- Zanarini Rating Scale (ZAN-BPD)* (clinician-administered to diagnose Borderline Personality Disorder)

3) Assess suicidal ideation, intent and deliberate self-harm.

The tools marked * contain questions for asking about suicidal thoughts or intentions, and thoughts or acts of self-harm.

Use clinical judgement and the information gained from all three assessments to decide whether referral to a psychiatrist or psychologist is required for a clinical interview to establish a mental health diagnosis.
Screening Timing and Interval

The optimal timing and interval for screening is unknown. A pragmatic approach may be to screen all women and adolescents at the time of PCOS diagnosis and at the time of their regular physical health checks for PCOS. Use clinical judgment considering an individual woman’s risk factors to inform if additional screening is warranted. Align timing and interval of screening during the antenatal and postnatal periods with the national clinical practice guidelines.

Specific Populations

The life stage of a woman should also be considered when screening for mental health disorders as risk factors and life events may differ. Specific screening tools for risk factors and symptomatology exist for adolescents (e.g. PHQ-A, BDI-PC), the antenatal and postnatal periods (e.g. EPDS) and for older adults (e.g. Geriatric Depression Scale). Consider issues around religion and sexual orientation.

The cultural identity and preferred language of a woman are also important considerations. Be aware of possible variations in presentation of mental health disorders and conduct screening in a culturally sensitive manner. Consider using screening tools that have been translated and cross-culturally validated [13]. Culturally validated assessment tools for Aboriginal and Torres Strait Islander women are available and should be used in a context of culturally competent care [11].

Clinical impact of the recommendation: Very large

In many countries it is not usual practice to screen women with PCOS for depression and/or anxiety symptoms and doing so may identify affected patients who would otherwise be missed. Screening may have resource implications such as an impact on length of consultation, however this can be reduced by the use of tools recommended here. If depression and/or anxiety symptoms are detected, intervention may require referral to other health practitioners. Additional time with the patient may also be required to complete an appropriate care plan. It is important to note that all tools mentioned are free to use in clinical practice, research and education. Access to appropriately trained and experienced health professionals will be required. It is the responsibility of all health professionals to understand the impact of PCOS on psychological health and to screen for and manage or refer for management of these disorders.
In women with PCOS, what is the most effective tool/method to screen for symptoms of depression and anxiety?

**Background**

Systematic reviews, meta-analyses, registries and health service datasets collectively indicate that women with PCOS have a higher prevalence of clinically significant symptoms of depression and anxiety and of related symptoms.

Identification of mental health disorders is important for supporting women’s overall health, wellbeing and quality of life by facilitating appropriate referral and care. In the context of PCOS, identification of mental health disorders is also crucial for optimising women’s ability to engage with lifestyle management and other preventive strategies at the core of PCOS care. Therefore, we recommend routine mental health screening for women with PCOS.

We did not identify any evidence in women with PCOS for an evidence based recommendation about screening tools and therefore a clinical consensus recommendation has been made based on key relevant sources of evidence-based information for the general population and the clinical expertise of the multidisciplinary guideline development group.

**Subgroups**

**Subgroup name:** Depression  
**Description:** High levels of depressive symptoms present in PCOS women

**Subgroup name:** Anxiety  
**Description:** High levels of anxiety symptoms in women with PCOS
Depressive and anxiety symptoms, screening and treatment. Assessment tools

**Problem**

Is the problem a priority?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>No</th>
<th>Probably No</th>
<th>Probably Yes</th>
<th>Yes</th>
</tr>
</thead>
</table>

Research evidence

Women with PCOS are at increased risk of experiencing symptoms of depression and anxiety compared to women without PCOS. Past systematic reviews report that both prevalence and odds of depression and anxiety symptoms in women with PCOS are higher than in women without PCOS [1,2].

Additional considerations

Despite an awareness of the high prevalence of depressive and anxiety symptoms there are no uniform recommendations to screen women with PCOS routinely. The Australian PCOS guidelines state that depression and anxiety should be routinely screened and assessed by all appropriately qualified health professionals in women with PCOS. If a woman with PCOS is positive on screening, the practitioner should further assess for depression/anxiety. If detected, appropriate management should be offered. Despite these recommendations surveys of women with PCOS in North America, Europe and Australia show that less than 10% were satisfied with information regarding long term complications associated with PCOS and less than 5% were satisfied with emotional support and counselling offered.

High quality research using diagnostic interviews is required to establish the prevalence of clinical depression, anxiety and other mental health disorders in PCOS. Other mental health conditions, including Borderline Personality Disorder, may also be increased in PCOS (15). Other priority areas for research include prevalence studies in different PCOS phenotypes and longitudinal studies to determine optimal timing and frequency of screening.

Panel discussion

High prevalence of depressive and anxiety symptoms in the PCOS population. All in agreement for judgement.

**Desirable effects**

How substantial are the desirable anticipated effects?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Trivial</th>
<th>Small</th>
<th>Moderate</th>
<th>Large</th>
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</table>

Research evidence

The systematic search did not identify any evidence to address this criterion.
Additional considerations

Identification of mental health disorders is important for supporting women’s overall health, wellbeing and quality of life by facilitating appropriate referral and care. In the context of PCOS, identification of mental health disorders is also crucial for optimising women’s ability to engage with lifestyle management and other preventive strategies at the core of PCOS care.

Anxiety and depressive symptoms should be routinely screened and assessed by appropriately qualified health professionals in all women with polycystic ovary syndrome.

If symptoms of a mental health disorder are present, further assessment by clinical interview should be conducted.

If a mental health disorder is detected, appropriate management should be offered.

With routine screening recommended for women with PCOS, guidance for how to identify possible mental health disorders is needed. In many countries it is not usual practice to screen women with PCOS for depression and/or anxiety symptoms and doing so may identify affected patients who would otherwise be missed.

Panel discussion

All in agreement for judgement.

Undesirable effects

How substantial are the undesirable anticipated effects?

Judgement

<table>
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<tr>
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<th>Moderate</th>
<th>Small</th>
<th>Trivial</th>
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Research evidence

See above in ‘Desirable effects’.

Additional considerations

None

Panel discussion

Untreated depressive and anxiety symptoms can affect overall health and specifically weight loss efforts in obese women with PCOS. Need to consider the possibility of over-diagnosis and burdening women already distress by PCOS with another stigmatising diagnosis. Evidence from diabetes research suggests that depression/anxiety are over-estimated by screening questionnaires and that diabetes-specific distress explains a large amount of the variance in depressive/anxiety symptom scores, indicating that we need clinicians supporting people with diabetes to be sensitive to the distress associated specifically with living with and managing diabetes. This may well be true also in PCOS but needs to be researched thoroughly.

Also, problems associated with screening, identifying the disorder(s), and then not being able to offer effective treatment.
**Certainty of the evidence**

What is the overall certainty of the evidence of effects?

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<td>High</td>
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</table>

Research evidence
See above in ‘Desirable effects’.

Additional considerations
See above in ‘Desirable effects’.

Panel discussion
See above.

**Values**

Is there important uncertainty about, or variability in, how much people value the main outcomes?

<table>
<thead>
<tr>
<th>Judgement</th>
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<th>25%</th>
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<tr>
<td>No important uncertainty or variability</td>
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Research evidence
Evidence not sought.

Additional considerations
A study in North America, Europe and Australia show that less than 10% of women with PCOS were satisfied with information regarding long term complications associated with PCOS and less than 5% were satisfied with emotional support and counselling offered [14].
Depressive and anxiety symptoms, screening and treatment _ assessment tools

National guidelines for the USA and the UK recommend routine screening for common mental health disorders for all adults and adolescents, particularly those with chronic physical health problems and during the perinatal period [3,4,5,6,7]. The USA guidelines specifically conclude a moderate net benefit of screening for depression in the general adult population [6]. Australian guidelines for the general population do not recommend routine screening, except during the perinatal period [9,10].

Panel discussion
Women with PCOS have expressed a very low level of satisfaction with the emotional support and counselling they currently receive after PCOS diagnosis. All in agreement for judgement.

**Balance of effects**

Does the balance between desirable and undesirable effects favour the intervention or the comparison?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Favours the comparison</th>
<th>Probably favours the comparison</th>
<th>Does not favour either the intervention or the comparison</th>
<th>Probably favours the intervention</th>
<th>Favours the intervention</th>
</tr>
</thead>
</table>

Research evidence
See above.

Additional considerations
See above.

Panel discussion
National guidelines for the USA and the UK recommend routine screening for common mental health disorders for all adults and adolescents, particularly those with chronic physical health problems and during the perinatal period. All in agreement for judgement.

**Resources required**

How large are the resource requirements (costs)?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Large costs</th>
<th>Moderate costs</th>
<th>Negligible costs or savings</th>
<th>Moderate savings</th>
<th>Large savings</th>
</tr>
</thead>
</table>
Depressive and anxiety symptoms, screening and treatment__ assessment tools

Research evidence
Evidence not sought for this criterion.

Additional considerations
In many countries it is not usual practice to screen women with PCOS for depression and/or anxiety symptoms and doing so may identify affected patients who would otherwise be missed. Screening may have resource implications such as an impact on length of consultation, however this can be reduced by the use of the PCOS emotional wellbeing general screening tool and other tools recommended here. If depression and/or anxiety symptoms are detected, intervention may require referral to other health practitioners. Additional time with the patient may also be required to complete an appropriate care plan. Access to appropriately trained and experienced health professionals will be required. It is the responsibility of all health professionals to understand the impact of PCOS on psychological health and to screen for and manage these disorders.

Panel discussion
Don't know the best screening tool in PCOS specifically.

Certainty of evidence of required resources
What is the certainty of the evidence of resource requirements (costs)?

Judgement

<table>
<thead>
<tr>
<th>Research evidence</th>
<th>Evidence not sought for this criterion.</th>
</tr>
</thead>
<tbody>
<tr>
<td>No included studies</td>
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<tr>
<td>Low</td>
<td>Moderate</td>
</tr>
</tbody>
</table>

Certainty of evidence of required resources
What is the certainty of the evidence of resource requirements (costs)?

Judgement

Research evidence
Evidence not sought for this criterion.

Additional considerations
Screening Timing and Interval
The optimal timing and interval for screening is unknown. A pragmatic approach may be to screen all women and adolescents at the time of PCOS diagnosis and at the time of their regular physical health checks for PCOS. Use clinical judgment considering an individual woman’s risk factors to inform if additional screening is warranted. Align timing and interval of screening during the antenatal and postnatal periods with the national clinical practice guidelines.

Panel discussion
All in agreement for judgement.

Cost-effectiveness
Does the cost-effectiveness of the intervention favour the intervention or the comparison?
Depressive and anxiety symptoms, screening and treatment—assessment tools

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Favours the comparison</th>
<th>Probably favours the comparison</th>
<th>Does not favour either the intervention or the comparison</th>
<th>Probably favours the intervention</th>
<th>Favours the intervention</th>
</tr>
</thead>
</table>

Research evidence

Evidence not sought for this criterion.

Additional considerations

Cost effectiveness of any screening tool depends on the prevalence of the condition and both depressive and anxiety symptoms have a high prevalence in women with PCOS.

Panel discussion

All in agreement for judgement.

Equity

What would be the impact on health equity?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Reduced</th>
<th>Probably reduced</th>
<th>Probably no impact</th>
<th>Probably increased</th>
<th>Increased</th>
</tr>
</thead>
</table>

Research evidence

The life stage of a woman should also be considered when screening for mental health disorders as risk factors and life events may differ. Specific screening tools for risk factors and symptomatology exist for adolescents (e.g. PHQ-A, BDI-PC), the antenatal and postnatal periods (e.g. EPDS) and for older adults (e.g. Geriatric Depression Scale). Consider issues around religion and sexual orientation.

The cultural identity and preferred language of a woman are also important considerations. Be aware of possible variations in presentation of mental health disorders and conduct screening in a culturally sensitive manner. Consider using screening tools that have been translated and cross-culturally validated [13]. Culturally validated assessment tools, for example in Aboriginal and Torres Strait Islander women, are available and should be used in a context of culturally competent care [11].

Additional considerations

None.

Panel discussion

All in agreement for judgement.
**Acceptability**

Is the intervention acceptable to key stakeholders?

<table>
<thead>
<tr>
<th>Judgement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know</td>
</tr>
</tbody>
</table>

**Research evidence**

Evidence not sought for this criterion.

**Additional considerations**

A study in North America, Europe and Australia show that less than 10% of women with PCOS were satisfied with information regarding long term complications associated with PCOS and less than 5% were satisfied with emotional support and counselling offered [14].

**Panel discussion**

Evidence from diabetes suggests that screening for emotional distress would be acceptable to women with PCOS, as they are likely to want to be able to share this burden and have someone to talk with, who they perceive as 'on their side'. However, we need to be careful about whether depression/anxiety measures are the right route, and generate new evidence to determine whether a new measure of 'PCOS-related distress' would be useful.

**Feasibility**

Is the intervention feasible to implement?

<table>
<thead>
<tr>
<th>Judgement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know</td>
</tr>
</tbody>
</table>

**Research evidence**

Based on consultation of the key sources of evidence-based information for the general population [3,4,5,6,7,8,9,10,11] and the clinical expertise of the multidisciplinary guideline development group we suggest a stepped screening process and the following tools to increase feasibility.

Screening for mental health disorders comprises three parts: assessment of risk factors, assessment of symptoms, and assessment of risk of deliberate self-harm or suicidal intent. Screening can be separated into two levels depending on the competence of the practitioner.

**Step 1:** The following questions could be asked [12]:

...
Over the last 2 weeks, how often have you been bothered by the following problems?
1) Feeling down, depressed, or hopeless?
2) Little interest or pleasure in doing things?
3) Feeling nervous, anxious or on edge?
4) Not being able to stop or control worrying?

**Step 2:** If any of the responses are positive, further screening should involve either:

A) Referral to an appropriate professional to perform a further mental health assessment. If this is not the patient’s usual GP, inform the GP of the referral.

OR

B) Completing the following assessments:

1) **Assess psychosocial risk factors with or without a structured tool:**

   Respectfully elicit a history of any past or current mental health disorder or chronic physical illness, domestic violence, sexual abuse or past traumatic events, past response to treatments, past experience of mood elevation, family history of mental illness. Enquire about current living conditions, financial security, quality of interpersonal relationships, social isolation, employment, immigration status, alcohol and drug use.

   Structured tools to assist with risk factor assessment exist and an appropriate tool should be selected based on the woman’s circumstances such as age, ethnicity and life-stage.

2) **Assess symptoms using one or more of the following general screening tools:**

   Many of these tools are available in different lengths and have been widely translated. Exercise clinical judgement to select the appropriate tool or combination of tools.

   - **Patient Health Questionnaire (PHQ)** (self-administered)
   - **Brief Psychiatric Rating Scale (BPRS)** (clinician-administered)
   - **Hospital Anxiety and Depression Scale (HADS)** (self-administered)
   - **Depression Anxiety Stress Scale (DASS)** (self-administered)

   If further testing is required then the more specific or comprehensive screening tools listed below can be used:

   - **Generalised Anxiety Disorder scale (GAD7)** (self-administered)
   - **Hamilton Depression Rating Scale (HAM-D)** (clinician-administered)
   - **Hamilton Anxiety Rating Scale (HAM-A)** (clinician-administered)
   - **Beck Depression Inventory (BDI)** (self-administered)
   - **Beck Anxiety Inventory (BAI)** (self-administered)
   - **Zanarini Rating Scale (ZAN-BPD)** (clinician-administered to diagnose Borderline Personality Disorder)
3) Assess suicidal ideation, intent and deliberate self-harm.

The tools marked * contain questions for asking about suicidal thoughts or intentions, and thoughts or acts of self-harm.

Use clinical judgement and the information gained from all three assessments to decide whether referral to a psychiatrist or psychologist is required for a clinical interview to establish a mental health diagnosis.

**Additional considerations**

None

**Panel discussion**

Short screening tools validated in the general population are available. It is feasible to use emotional health screening tools in clinical practice in other chronic conditions. USPTF also recommends screening all adults in the US for depression.

**CONCLUSIONS**

**Consensus recommendation**

Anxiety and depressive symptoms should be routinely screened and assessed by appropriately qualified health professionals in all women with polycystic ovary syndrome.

If symptoms of a mental health disorder are present, further assessment by clinical interview should be conducted.

If a mental health disorder is detected, appropriate management should be offered.

**Judgement**

- [ ] Strong recommendation against the intervention
- [ ] Conditional recommendation against the intervention
- [ ] Conditional recommendation for either the intervention or the comparison
- [ ] Conditional recommendation for the intervention
- [x] Strong recommendation for the intervention

**Clinical practice point**

Depression and/or anxiety can be screened using a stepped approach.

**Step 1:** The following questions could be asked [12]:

Over the last 2 weeks, how often have you been bothered by the following problems?

1) Feeling down, depressed, or hopeless?
2) Little interest or pleasure in doing things?
3) Feeling nervous, anxious or on edge?
4) Not being able to stop or control worrying?

**Step 2:** If any of the responses are positive, further screening should involve:

A) Assessment of risk factors and symptoms using age, culturally and regionally appropriate tools, such as the PHQ9 and GAD7.

OR

B) Referral to an appropriate professional to perform a further mental health assessment. If this is not the patient’s usual healthcare provider, inform the primary care physician

**Justification**

Anxiety and depressive symptoms should be routinely screened and assessed by appropriately qualified health professionals in all women with polycystic ovary syndrome. While the optimal timing and interval for screening is unknown a pragmatic approach may be to screen all women and adolescents at the time of PCOS diagnosis. Frequency of screening is unclear and some assessment at the time of their regular physical health checks for PCOS may be warranted. Use clinical judgement considering an individual woman’s risk factors to inform if additional screening is warranted. Align timing and interval of screening during the antenatal and postnatal periods with clinical practice guidelines.

Recommendations are aligned with international, broadly validated, screening approaches for general populations.

**Subgroup considerations**

Adolescents, different PCOS phenotypes and culturally and linguistically diverse groups should be considered.

**Implementation considerations**

The life stage of a woman should also be considered when screening for mental health disorders as risk factors and life events may differ.

Specific screening tools for risk factors and symptomatology exist for adolescents (e.g. PHQ-A, BDI-PC), the antenatal and postnatal periods (e.g. EPDS) and for older adults (e.g. Geriatric Depression Scale). Consider issues around religion and sexual orientation.

The cultural identity and preferred language of a woman are also important considerations. Be aware of possible variations in presentation of mental health disorders and conduct screening in a culturally sensitive manner. Consider using screening tools that have been translated and cross-culturally validated [13]. Culturally validated assessment tools for Aboriginal and Torres Strait Islander women are available and should be used in a context of culturally competent care [11].
Depressive and anxiety symptoms, screening and treatment_ assessment tools

In many countries it is not usual practice to screen women with PCOS for depression and/or anxiety symptoms and doing so may identify affected patients who would otherwise be missed. Screening may have resource implications such as an impact on length of consultation, however this can be reduced by the use of stepped approach to screening recommended here. If depression and/or anxiety symptoms are detected, intervention may require referral to other health practitioners. Additional time with the patient may also be required to complete an appropriate care plan. Access to appropriately trained and experienced health professionals will be required. It is the responsibility of all health professionals to understand the impact of PCOS on psychological health and to screen for and manage these disorders.

Monitoring and evaluation
Surveys of consumers and health professionals on adherence to the guideline is recommended.

Research priorities
Validation of screening tools in diverse PCOS populations.
Relationships of mental health symptoms with PCOS features and the concept of PCOS-related distress.
Longitudinal follow up to determine frequency of screening for depressive and anxiety symptoms.
Prevalence of depressive and anxiety symptoms in different PCOS phenotypes.
Prevalence of mental health disorders, including borderline personality disorders, diagnosed by clinical interview.
References


### Appendix I: Methods

### PICO/selection criteria

<table>
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<tr>
<th>RANK: 5</th>
<th>In women with PCOS, what is the most effective tool/method to assess depression and/or anxiety?</th>
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</thead>
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<td><strong>Inclusion criteria</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Participants (P)</strong></td>
<td>Females with PCOS (diagnosed by Rotterdam, NIH or AES) of any age, ethnicity and weight. Subgroups: • Adolescents • Ethnicity • Phenotype If no evidence in PCOS, relevant evidence will be sought narratively by key contact (not searched by evidence team).</td>
</tr>
<tr>
<td><strong>Intervention (I)</strong></td>
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<tr>
<td><strong>Comparison (C)</strong></td>
<td></td>
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<tr>
<td><strong>Outcomes (O)</strong></td>
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3 poly-cystic ovar*.mp. (13)
4 PCO*.mp. (24502)
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6 anovulation/ (2224)
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8 oligo-ovulat*.mp. (79)
9 oligoovulat*.mp. (43)
10 (ovar* adj5 (sclerocystic or polycystic or poly-cystic or degenerat* or hyperandrogen* or hyper-androgen*)).mp. (15787)
11 or/1-10 (36142)
12 exp Depression/ (102503)
13 exp Depressive Disorder/ (102647)
14 exp Depression, Postpartum/ (4888)
15 exp Depressive Disorder, Major/ (27170)
16 exp Dysthymic Disorder/ (1209)
17 exp Mood Disorders/ (114933)
18 exp Seasonal Affective Disorder/ (1204)
19 exp Adjustment Disorders/ (4210)
20 exp Bipolar Disorder/ (38558)
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22 ((agitated or psychosis or involutional or masked or organic or postoperative or

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25 exp Anxiety Disorders/ (76077)
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### Database search results

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<td>ALL EBM</td>
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<td>CINAHL</td>
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- Duplicates removed over total: 322
- Screened: 1153
- Excluded based on T & A: 1151
- Excluded based on full text: 2
- Unable to retrieve full text: 0
- Included: 0
### Appendix II: Tools to accept when screening search results (relevant to depression and anxiety)

<table>
<thead>
<tr>
<th>Depression &amp; anxiety tools</th>
<th>Tools</th>
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<tbody>
<tr>
<td>Comprehensive Psychopathological Rating Scale for Affective Syndromes (CPRS-S-A). Can derive:</td>
<td>Schedule for Affective Disorders and Schizophrenia (SADS)</td>
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<tr>
<td>• Brief Scale for Anxiety (BSA-S) and</td>
<td>Depression Anxiety Stress Scale (DASS-21)</td>
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<tr>
<td>• Montgomery Åsberg Depression Rating Scale (MADRS)</td>
<td>Structured Clinical Interview for DSM Disorders (SCID)</td>
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<tr>
<td>Kessler Psychological Distress Scale 5 (K-5), 6 (K-6) &amp; 10 (K-10)</td>
<td>Mini-international neuropsychiatric interview (MINI)</td>
</tr>
<tr>
<td>Beck Depression Inventory 1A (BDI-I) &amp; II (BDI-II) &amp; Short Form (BDI-SF)</td>
<td>World Health Organisation Composite International Diagnostic Interview (CIDI)</td>
</tr>
<tr>
<td>The Goldberg Depression Questionnaire</td>
<td>Schedules for Clinical Assessment in Neuropsychiatry (SCAN)</td>
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<tr>
<td>Hospital Anxiety and Depression Scale (HADS)</td>
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<td>Spielberger State-Trait Anxiety Inventory (STAI)</td>
<td>Diagnostic Interview for Genetic Studies (DIGS)</td>
</tr>
<tr>
<td>Inventory of Depressive Symptomatology (IDS)</td>
<td>Chinese Classification of Mental Disorders (CCMD)</td>
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<tr>
<td>Quick Inventory of Depressive Symptomatology (QIDS)</td>
<td>Beck Hopelessness Scale</td>
</tr>
<tr>
<td>Generalised Anxiety Disorder Tool (GAD-7)</td>
<td>Panic and Agoraphobia Scale (PAS)</td>
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<td>Zung Self-Rating Depression Scale</td>
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<td>Carroll Rating Scale for Depression</td>
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<td>SPHERE</td>
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<tr>
<td>Inventory of Depression and Anxiety Symptoms (IDAS)</td>
<td>Depression in the Medically Ill.</td>
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<tr>
<td>Patient Health Questionnaire 2 (PHQ-2) &amp; 4 (PHQ-4)</td>
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<tr>
<td>The Hamilton Rating Scale for Depression (HRSD)</td>
<td>The Strengths and Difficulties Questionnaire (SDQ) (adolescents)</td>
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<td>Major Depression Inventory (MDI)</td>
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<td>Zung Self-Rating Anxiety Scale</td>
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<td>General Health Questionnaire (GHQ28)</td>
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<td>Daily Assessment of Symptoms – Anxiety</td>
<td>Kutcher Adolescent Depression Scale (KADS)</td>
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<tr>
<td>Hamilton Anxiety Rating Scale</td>
<td>The Mood and Feelings Questionnaire (MFQ)</td>
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</table>
Psychosexual dysfunction refers to sexual problems or difficulties that have a psychological origin based in cognitions and/or emotions such as depression, low self-esteem and negative body image [1]. The prevalence of psychosexual dysfunction varies from 13.3% to 62.5% in PCOS patients [2-5]. It appears that women with PCOS suffer from greater psychosexual dysfunction than women in the general population in most studies [6]. Whilst there is limited quality research in this area, studies [6-8] do show a correlation between PCOS and reduced QoL, sexual satisfaction and feminine identity. Physical PCOS symptoms such as hirsutism, obesity, menstrual irregularity and infertility may cause loss of feminine identity and a feeling of being unattractive which may impact on sexuality [6,7,9]. Women with PCOS also report less sexual satisfaction and lower sexual self-worth than women without PCOS and sexual dysfunction impacts more on relationships in women with PCOS [10]. Overall, psychosexual dysfunction appears to be more common in women with PCOS, may be an important issue for the individual woman and is likely to impact on QoL and relationships. Until now, there was only one study [3] published in 2013 showed that the prevalence of sexual dysfunction in the PCOS group was similar to general population (25% vs 19%; P=0.54), and no significant difference was found according to each domain score of female sexual function index (FSFI). Considering all the studies above, clinicians should be aware of potential psychosexual dysfunction in PCOS and screening and assessment should be considered. In this setting guidance on the most effective way to assess psychosexual dysfunction is needed. The female sexual function index (FSFI) [3] and Arizona Sexual Experience Scale (ASEX) [2] are usually be used to evaluate psychosexual dysfunction in PCOS patients.
Psychosexual function

GRADE framework

Interactive Evidence to Decision Framework

1) In women with PCOS what is the prevalence and severity of psychosexual dysfunction and should they be screened?

Narrative review

2) In women with PCOS, what is the most effective tool/method to assess psychosexual dysfunction?

Narrative review

ASSESSMENT

Problem

Is the problem a priority?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>No</th>
<th>Probably No</th>
<th>Probably Yes</th>
<th>Yes</th>
</tr>
</thead>
</table>

Research evidence

The prevalence of psychosexual dysfunction varies from 13.3% to 62.5% in PCOS patients [2-5]. It appears that women with PCOS suffer from greater psychosexual dysfunction than women in the general population in most studies [6-13]. Whilst there is limited quality research in this area, studies [6-8] do show a correlation between PCOS and reduced QoL, sexual satisfaction and feminine identity. Physical PCOS symptoms such as hirsutism, obesity, menstrual irregularity and infertility may cause loss of feminine identity and a feeling of being unattractive which may impact on sexuality [6,7,9]. Women with PCOS also report less sexual satisfaction and lower sexual self-worth than women without PCOS and sexual dysfunction impacts more on relationships in women with PCOS [10]. Overall, psychosexual dysfunction appears to be more common in women with PCOS, may be an important issue for the individual woman and is likely to impact on QoL and relationships. Until now, there was only two studies showed negative results,[2, 3] Veras’s study [2] published in 2011 showed the incidence of sexual dysfunction was verified (13.3%), and it was observed that the average (SD) ASEX score of 14.4 (3.7) was comparable with that of the population with no medical problems. Ercan’s study [3] published in 2013 showed that the prevalence of sexual dysfunction in the PCOS group was similar to general population (25% vs 19%; P=0.54), and no significant difference was found according to each domain score of female sexual function index (FSFI).

The screen methods were listed below:

<table>
<thead>
<tr>
<th>Method</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arizona Sexual Experiences Scale (ASEX)</td>
<td>Veras AB.2011</td>
</tr>
<tr>
<td>Female Sexual Function Index (FSFI)</td>
<td>Eftekhar.2014(Rotterdam criteria)</td>
</tr>
<tr>
<td></td>
<td>Dashti.2016(Rotterdam criteria)</td>
</tr>
<tr>
<td></td>
<td>Ercan.2013(Rotterdam criteria)</td>
</tr>
</tbody>
</table>
Psychosexual function

McCoy Female Sexuality Questionnaire (MFSQ) | Morotti E.2013
---|---
Index of Sexual Satisfaction (ISS) | Drosdzol A.2007
Visual Analog Scales (VASs) | Hahn. 2005(NIH)
Elsenbruch.2003(NIH)
Abstract | Janssen OE.2008
Not mention | Chen CH.2014
Manlove HA.2008

Additional considerations
None

Panel discussion
All in agreement for judgement.

**Desirable effects**

How substantial are the desirable anticipated effects?

Judgement

<table>
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<tr>
<th></th>
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<th></th>
<th></th>
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<td>Trivial</td>
<td>Small</td>
<td>Moderate</td>
<td>Large</td>
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</table>

Research evidence

Evidence not systematically sought for this criterion. In 2015, Bazarganipour et al. [Bazarganipour F, Taghavi SA, Montazeri A, et al. The impact of polycystic ovary syndrome on the health-related quality of life: A systematic review and meta-analysis. Iran J Reprod Med. 2015 Feb;13(2):61-70.] did a meta-analysis, which showed based on PCOSQ or modified version (MPCOSQ), the most affected domains in specific HRQoL in PCOS patients were hirsutism (3.81; 95% CI 3.26-4.35) and menstruation (3.84; 95% CI 3.63-4.04). The combine mean of emotional (4.40; 95% CI 3.77-5.04), infertility (4.13; 95% CI 3.81-4.45) and weight (3.88; 95% CI 2.33-5.42) dimensions were better.

Additional considerations

PCOS is a physical, psychological and social syndrome; therefore, it is necessary to taking a more holistic approach to patient care beyond treating physical symptoms. Therapy should focus on both the short and long-term reproductive, metabolic and psychological features. Given the aetiological role of insulin resistance and the impact of obesity on both hyperinsulinaemia and hyperandrogenism, multidisciplinary lifestyle improvement aimed at normalizing insulin resistance, improving androgen status and aiding weight management is recognized as a crucial initial treatment strategy. These treatments included lifestyle interventions and physical activity, acupuncture, medical treatment and cognitive – behavioral therapy.

Panel discussion
All in agreement for judgement.

**Undesirable effects**
How substantial are the undesirable anticipated effects?

Judgement

<table>
<thead>
<tr>
<th>☐ 3</th>
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<th>☐</th>
<th>Moderate</th>
<th>☐</th>
<th>Small</th>
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<th>Trivial</th>
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</thead>
</table>

Research evidence

See above in ‘Desirable effects’.

Additional considerations

See above in ‘Desirable effects’.

Panel discussion

All in agreement for judgement.

Values

Is there important uncertainty about, or variability in, how much people value the main outcomes?

Judgement

<table>
<thead>
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<th>☐ 1</th>
<th>Important uncertainty or variability</th>
<th>☐ 3</th>
<th>Possibly important uncertainty or variability</th>
<th>☐ 1</th>
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</tr>
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</table>

Research evidence

Evidence not sought.

Additional considerations

None

Panel discussion

All in agreement for judgement.

Balance of effects

Does the balance between desirable and undesirable effects favour the intervention or the comparison?

Judgement

<table>
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<th>Varies</th>
<th>☐</th>
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<th>☐</th>
<th>Probably favours the comparison</th>
<th>☐</th>
<th>Does not favour either the intervention or the comparison</th>
<th>☐</th>
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<th>☐</th>
<th>Favours the intervention</th>
</tr>
</thead>
</table>

Research evidence

See above in ‘Desirable effects’.
Psychosexual function

Additional considerations
See above in ‘Desirable effects’.

Panel discussion
All in agreement for judgement.

Resources required

How large are the resource requirements (costs)?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
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<th>Large costs</th>
<th>Moderate costs</th>
<th>Negligible costs or savings</th>
<th>Moderate savings</th>
<th>Large savings</th>
</tr>
</thead>
</table>

Research evidence

What tools are used to screen for sexual dysfunction in PCOS? Are these validated? What resources will be required?

Personal Experiences Screening Questionnaire (PESQ)

Female Sexual Function Index (FSFI)

Sexual Function Questionnaire (SFQ)

McCoy Female Sexuality Questionnaire (MFSQ)

Index of Sexual Satisfaction (ISS)

Sexual Distress Scale (SDS)

Sexual Quality of Life-Female (SQOL-F)

Derogatis Sexual Function Inventory (DSFI)

Arizona Sexual Experiences Scale (ASEX)

Visual analog scales (VASs)

Additional considerations

None

Panel discussion

Cost of awareness is negligible, cost of screening includes time and access to tools.

Cost-effectiveness

Does the cost-effectiveness of the intervention favour the intervention or the comparison?

Judgement
**Psychosexual function**

<table>
<thead>
<tr>
<th></th>
<th>Don't know</th>
<th>Varies</th>
<th>Favours the comparison</th>
<th>Probably favours the comparison</th>
<th>Does not favour either the intervention or the comparison</th>
<th>Probably favours the intervention</th>
<th>Favours the intervention</th>
</tr>
</thead>
</table>

Research evidence

Evidence not sought.

Additional considerations

None

Panel discussion

All in agreement for judgement.

---

**Equity**

What would be the impact on health equity?

Judgement

<table>
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<th>Probably no impact</th>
<th>Probably increased</th>
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Research evidence

Evidence not sought.

Additional considerations

None

Panel discussion

Sensitivities and cultural challenges around the topic of psychosexual dysfunction from patient and health professional perspective may present barriers to implementation.

---

**Acceptability**

Is the intervention acceptable to key stakeholders?

Judgement

<table>
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<th></th>
<th>Don't know</th>
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<th>No</th>
<th>Probably No</th>
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</table>

Research evidence

Evidence not sought.

Additional considerations

None
Sensitivities and cultural challenges around the topic of psychosexual dysfunction from patient and health professional perspective may present barriers to implementation.

Time and resources.

**Feasibility**

Is the intervention feasible to implement?

**Judgement**

<table>
<thead>
<tr>
<th></th>
<th>Don't know</th>
<th>Varies</th>
<th>No</th>
<th>Probably No</th>
<th>Probably Yes</th>
<th>Yes</th>
</tr>
</thead>
</table>

**Research evidence**

Evidence not sought.

**Additional considerations**

None

**Panel discussion**

Sensitivities and cultural challenges around the topic of psychosexual dysfunction from patient and health professional perspective may present barriers to implementation.

**CONCLUSIONS**

**Consensus recommendation**

All health professionals should be aware of the increased prevalence of psychosexual dysfunction in adults with PCOS.

Consider screening for psychosexual dysfunction in adults with PCOS.

If a woman with PCOS has suspected psychosexual dysfunction, further assess, refer or treat as appropriate.

**Judgement**

<table>
<thead>
<tr>
<th></th>
<th>Strong recommendation against the intervention</th>
<th>Conditional recommendation against the intervention</th>
<th>Conditional recommendation for either the intervention or the comparison</th>
<th>Conditional recommendation for the intervention</th>
<th>Strong recommendation for the intervention</th>
</tr>
</thead>
</table>

An upcoming meta-analysis was also discussed by the GDG. Key challenges involved variable use of scales and limited overall likely conclusions.

**Practice point**

Health professionals should be aware that obesity and infertility are also associated with psychosexual dysfunction.
Psychosexual function

Justification

GDG members were aware of a conference abstract about a meta-analysis that was underway and the group sought data directly from the authors who were also involved in the guideline.

Sensitivities and cultural challenges around the topic of psychosexual dysfunction from patient and health professional perspective may present barriers to implementation. However the international, multi-disciplinary guideline development group, including consumers, recommended that despite implementation challenges, the recommendation was warranted on the basis of prevalence data from a meta-analysis and on potential impact.

Subgroup considerations

Infertility and obesity.

Implementation considerations

Sensitivities and cultural challenges around the topic of psychosexual dysfunction from patient and health professional perspective may present barriers to implementation.

Time and resources for screening.

Monitoring and evaluation

Surveys to assess awareness among women and health professionals.

Research priorities

Guidance on the most effective way to assess psychosexual dysfunction in women with PCOS is needed.

Studies on prevalence of psychosexual dysfunction in PCOS

Association of PCOS features with psychosexual dysfunction.

References

Psychosexual function


NARRATIVE REVIEW: 1) In women with PCOS, what is the prevalence and severity of body image distress and should they be screened?

NARRATIVE REVIEW: 2) In women with PCOS, what is the most effective tool/method to assess body image distress?

Clinical need for the question

Body image is complex and is influenced by many factors. For the purpose of this clinical question, body image is defined as the way a person may feel, think and view their body including their appearance. Physical factors affecting appearance (excess weight and hirsutism), psychological factors (self-esteem) and sociocultural influences all appear to influence the way women think and feel about their bodies. Body image includes attitudes to physical appearance, understanding of health, physical fitness and body size, the mental picture that individuals form of their bodies, values and self-esteem. Assessment of body image includes measures of body dissatisfaction and disordered eating (1), body size estimation and weight (2).

Two thirds of women from the general population are dissatisfied with their body, yet negative body image has in some, but not all, studies been shown to be more prevalent in PCOS and impacts on thoughts and feelings of health, appearance, QoL, mood and physical fitness.

Clinical practice gap: need for guidance

There is no study investigating prevalence of body image distress in women with PCOS. One study demonstrated that women with PCOS, compared with control women, had a negative body image in 7 out of 10 subscales of the validated Multidimensional Body-Self Relations Questionnaire (3). Women with PCOS appear to feel less physically attractive, healthy or physically fit and are less satisfied with their body size and appearance than women without PCOS (4). Infertile women with PCOS have lower self-esteem and body satisfaction as measured with the Body Image Concern Inventory (BICI) than non-infertile women with PCOS (5). Further, hirsute women experienced lower self-esteem than non-hirsute women, and women with menstrual irregularities and higher BMI had more body dissatisfaction (5).

PCOS features, in particular hirsutism and increased weight, appear to impact negatively on body image and QoL (6, 7), and negative body image is strongly associated with depression in women with PCOS (8, 9), even after controlling for weight (9, 10).

However, some recent case-control studies did not find differences in body image satisfaction and self-esteem when comparing women with and without PCOS, and all women seem to idealize a slender body shape (11-13). However all studies are hampered by small sample size.

Given that negative body image in PCOS may result in increased depression and poorer health-related QoL, body image of women with PCOS should be considered as part of a comprehensive assessment and management plan. Recommendations for screening and assessment that are easy to use and widely applicable are needed in PCOS. If identified, addressing negative body and associated mood disorders may assist to improve emotional wellbeing and QoL in PCOS, although more research in this area is needed.

Summary of key information

We did not identify any evidence in women with PCOS to answer the questions and therefore a clinical consensus recommendation has been made based on key relevant sources of evidence-based information for the general population and the clinical expertise of the multidisciplinary guideline development group.
Recommendations

CLINICAL CONSENSUS RECOMMENDATION:
Negative body image should be *considered* in women with PCOS.
If a woman with PCOS is positive on screening, the practitioner should further assess for negative body image.
If negative body image is detected, appropriate management should be offered.

CLINICAL PRACTICE POINT:
To screen for negative body image, the following questions could be asked:
1) Do you worry a lot about the way you look and wish you could think about it less?
2) On a typical day, do you spend more than 1 hour per day worrying about your appearance? (More than 1 hour a day is considered excessive)
3) What specific concerns do you have about your appearance?
4) What effect does it have on your life?
5) Does it make it hard to do your work or be with your friends and family?

If an issue is identified, the practitioner could further assess negative body image by:
a) Identifying any focus of concern of the patient and respond appropriately
b) Assessing the level of depression and/or anxiety (if they have not done so already)
c) Identifying if there is any distortion of body image (e.g. presence of anorexia nervosa or body dysmorphic disorder)

Negative body image is increased in women with PCOS and is related to depression and reduced QoL, hence it is important and highly recommended that women with PCOS are screened and assessed for negative body image. It is not usual practice to screen and assess women with PCOS for negative body image. Detection of negative body image provides the opportunity to address both psychological aspects such as self-esteem and self-acceptance as well as working on the physical aspects of the condition such as hirsutism, overweight and acne if appropriate. As no relevant clinical evidence exists in relation to assessment of body image in women with PCOS, the guideline group have sought alternative key relevant sources of evidence based information and expertise. Consequently the guideline group have consulted the following key relevant Guidelines:
1) NICE Guideline 31 – Obsessive Compulsive Disorder: Core interventions in the treatment of obsessive compulsive disorder and body dysmorphic disorder. (14)
GRADE framework

Interactive Evidence to Decision Framework

1) In women with PCOS, what is the prevalence and severity of body image distress and should they be screened?
Narrative review

2) In women with PCOS, what is the most effective tool/method to assess body image distress?
Narrative review

QUESTION

Question details

Population: Women with PCOS
Option: Screening for body image distress
Main outcomes:
• Prevalence and severity of body image distress?
• What is the most effective tool/method to assess body image distress?
Setting: Primary care, PCOS models of care and in clinical research
Perspective: Patients and health professionals

Background
Body image is complex and is influenced by many factors. For the purpose of this clinical question, body image is defined as the way a person may feel, think and view their body including their appearance. Physical factors affecting appearance (excess weight and hirsutism), psychological factors (self-esteem) and sociocultural influences all appear to influence the way women think and feel about their bodies. Body image includes attitudes to physical appearance, understanding of health, physical fitness and body size, the mental picture that individuals form of their bodies, values and self-esteem. Assessment of body image includes measures of body dissatisfaction and disordered eating (1), body size estimation and weight (2).

Narrative reviews were prepared to answer these questions (evidence was not searched systematically). There were no studies in women with PCOS to answer the questions. The GDG decided not to make a recommendation based on clinical grounds and in the absence of evidence. Therefore, the GRADE criteria have not been specifically addressed and instead have been used to guide relevant clinical comment and practice points.

The guideline group have consulted the following key relevant Guidelines:

1. NICE Guideline 31 – Obsessive Compulsive Disorder: Core interventions in the treatment of obsessive compulsive disorder and body dysmorphic disorder. (14)

Subgroups

Subgroup name: Adult women with and without PCOS
Subgroup name: Adolescents with and without PCOS

ASSESSMENT

Problem

Is the problem a priority?
Two thirds of women from the general population are dissatisfied with their body, yet negative body image has in some, but not all, studies been shown to be more prevalent in PCOS and impacts on thoughts and feelings of health, appearance, QoL, mood and physical fitness.

There is no study investigating prevalence of body image distress in women with PCOS. One study demonstrated that women with PCOS, compared with control women, had a negative body image in 7 out of 10 subscales of the validated Multidimensional Body-Self Relations Questionnaire (3). Women with PCOS appear to feel less physically attractive, healthy or physically fit and are less satisfied with their body size and appearance than women without PCOS (4). Infertile women with PCOS have lower self-esteem and body satisfaction as measured with the Body Image Concern Inventory (BICI) than non-infertile women with PCOS (5). Further, hirsute women experienced lower self-esteem than non-hirsute women, and women with menstrual irregularities and higher BMI had more body dissatisfaction (5).

PCOS features, in particular hirsutism and increased weight, appear to impact negatively on body image and QoL (6, 7), and negative body image is strongly associated with depression in women with PCOS (8, 9), even after controlling for weight (9, 10).

However, some recent case-control studies did not find differences in body image satisfaction and self-esteem when comparing women with and without PCOS, and all women seem to idealize a slender body shape (11-13). However all studies are hampered by small sample size.

Given that negative body image in PCOS may result in increased depression and poorer health-related QoL, body image of women with PCOS should be considered as part of a comprehensive assessment and management plan. Recommendations for screening and assessment that are easy to use and widely applicable are needed in PCOS. If identified, addressing negative body and associated mood disorders may assist to improve emotional wellbeing and QoL in PCOS, although more research in this area is needed.

Desirable effects

How substantial are the desirable anticipated effects?

Research evidence

No evidence was identified about the effects of assessing body image distress or which tool/method is most effective in women with PCOS.

Additional considerations

Negative body image appears in women with PCOS and is related to depression and reduced QoL, hence it is important that, in women with PCOS, negative body image is considered. It is not usual practice to screen and assess women with PCOS for negative body image. Detection of negative body image provides the opportunity to address both psychological aspects such as self-esteem and self-acceptance as well as working on the physical aspects of the condition such as hirsutism, overweight and acne if appropriate.

Undesirable effects

How substantial are the undesirable anticipated effects?

Screening may be problematic if effective options for treatment/support are not available.

Resources required

How large are the resource requirements (costs)?

Costs of self-administration of body image assessment tools in clinical research studies are nominal. These relate to staff time to distribute the tools and consider or enter and analyse the data only.

In practice tools can be completed outside contact time, costs are minimal and relate to health professional time to score and explain the tools. The resource requirements here on a larger scale are significant.
Cost-effectiveness

Does the cost-effectiveness of the intervention favour the intervention or the comparison?

There was no evidence to inform this consideration. Screening may have resource implications in terms of impact on length of consultation, however this can be reduced by the use of the Emotional Wellbeing General Screening Tool and other tools recommended in this guideline.

Intervention may require referral to other health practitioners. Where needed, access to appropriately trained and experienced health professionals is required.

Acceptability

It is not usual practice to screen for negative body image in PCOS. Screening for negative body image may pick up patients who would otherwise be missed. Stronger focus on what is most relevant to the patient, as identified in question 3 to 5 in the recommendation.

A shift in cultural mind set may be required.

Feasibility

Is the intervention feasible to implement?

Fully feasible in clinical research but of limited feasibility in standard care.

CONCLUSIONS

Practice point

Health professionals should be aware that features of PCOS can impact body image.

Practice point

To screen for negative body image, the following questions could be asked:

1. Do you worry a lot about the way you look and wish you could think about it less?
2. On a typical day, do you spend more than 1 hour per day worrying about your appearance? (More than 1 hour a day is considered excessive)
3. What specific concerns do you have about your appearance?
4. What effect does it have on your life?
5. Does it make it hard to do your work or be with your friends and family?

If an issue is identified, the practitioner could further assess negative body image by:

1. Identifying any focus of concern of the patient and respond appropriately
2. Assessing the level of depression and/or anxiety (if they have not done so already) (see 4.1a)
3. Identifying if there is any distortion of body image (e.g. presence of anorexia nervosa (see 4.3) or body dysmorphic disorder)

Justification

Addressed above in resources, cost, acceptability and feasibility

Subgroup considerations

NA
**Implementation considerations**

It is not usual practice to screen PCOS women for negative body image. Screening for negative body image may pick up patients who would otherwise be missed. Stronger focus on what is most relevant to the patient, as identified in question 3 to 5 in the recommendation.

Screening may have resource implications in terms of impact on length of consultation, however this can be reduced by the use of the emotional wellbeing general screening tool and other tools recommended in this guideline. Access to appropriately trained and experienced health professionals and a shift in cultural mind set may be required.

Intervention may require referral to other health practitioners. However, implementation of the recommendation is not expected to require changes in the way care is organised.

**Monitoring and evaluation**

Body image assessment with any available body image scale should be included in all clinical, health services and population health research in PCOS

**Research priorities**

Determination of the clinical meaningful differences in body image distress scores should be undertaken with urgency and validation of the use of the body image assessment tools over time should be completed, acknowledging that PCOS is a dynamic condition that changes over time.
References


NARRATIVE REVIEW: 1) In women with PCOS what is the prevalence and severity of disordered eating, and should they be screened?

NARRATIVE REVIEW: 2) In women with PCOS, what is the most effective tool/method to assess disordered eating?

Prevalence and Severity of Eating Disorders/Disordered Eating

Diagnosable eating disorders include Anorexia Nervosa (AN); Bulimia Nervosa (BN), Binge-Eating Disorder (BED), Other Specified Feeding or Eating Disorder (OSFED; atypical AN, BN of low frequency and/or duration, BED of low frequency and limited duration, purging disorder, and night eating syndrome), and Unspecified Feeding or Eating Disorders (USFED; symptoms consistent with eating disorders, including the severity of symptoms and distress and impairment, but do not meet the full criteria for any of the eating disorder diagnoses). The prevalence of AN in women is 0.9%, BN is 1.5% and BED is 3.5% [1]. There is a lack of data regarding the prevalence of USFED and OSFED however, given the range of disorders covered by these categories, rates are likely higher than that of the other eating disorders. The associated disturbed eating and eating-related behaviours impair physical and psychosocial health and wellbeing. Obesity is not considered an eating disorder but it is associated with increased risk of binge eating disorder and disordered eating [2].

Disordered eating refers to eating and weight related symptoms commonly associated with an eating disorder, this can include behavioural (e.g., bingeing, restriction), cognitive (e.g., dietary restraint, negative body image), and emotional (e.g., emotional eating) factors. The prevalence of disordered eating is far higher than the prevalence of eating disorders; many women who do not meet full criteria for an eating disorder experience disordered eating and associated distress. For example, Australian research [3] reports that 7.5% of women surveyed experienced binge eating, 2.1% purging, and 5.2% strict dieting or fasting.

There is a lack of good evidence regarding the prevalence of eating disorders and disordered eating in women with PCOS. Available data suggests that the prevalence of eating disorders and disordered eating is higher in women with PCOS that in the general community. In the only study to use a clinical interview (MINI for DSM-IV) to assess eating disorder prevalence in women with PCOS (n=49), Mansson and colleagues [4] reported increased prevalence of any eating disorder (21% vs 4%) but not bulimia nervosa (12% vs 4%) compared to controls. Of note, the MINI only assesses AN and BN, and this study uses the older DSM-IV diagnostic criteria.

A recent Swedish registry study of women with PCOS (n=24 385) and age- and county of residence-matched controls reported an increased risk of BN (OR 1.35; 95% CI 1.15-1.58: AOR 1.21; 95% CI 1.03, 1.41), but not AN, among women with PCOS before and after controlling for psychiatric comorbidity [5]. A Swedish survey of women with PCOS recruited from the community (n=72) reported mixed results. Women with PCOS reported higher symptoms of AN and BN (EAT-40 Total) but no difference in cognitive restraint, uncontrolled eating, or emotional eating (TFEQ-21) or current symptoms of BN [6].

A recent US survey study of treatment-seeking women with PCOS (n=148) reported increased disordered eating behaviours and cognitions (EDE-Q Total score; 12.16% vs. 2.83%), binge episodes (3.49 vs. 1.71), and compulsive exercise episodes (2.23 vs. 0.51) than controls in the previous 28 days [7]. Questionnaire data was also used to estimate eating disorder prevalence based on DSM5 criteria. Overall 28% of women with PCOS reported symptoms consistent with an eating disorder. Six percent reported symptoms consistent with BN, 18% BED, and 13% night eating syndrome. There were no cases of AN [7]. An earlier US survey study of women with PCOS (n=103) also reported an increased prevalence of BED in women with PCOS compared to controls (2.6% vs 1.9%)[8].

Women with PCOS are at increased risk of experiencing many of the identified risk factors for eating disorders [9]. They are at increased risk of overweight/obesity, depression, anxiety, self-esteem and poor body image. They are also more likely to be highly motivation for weight loss and to be prescribed dietary restriction. Potential endocrine mechanisms have also been proposed[10]. Available data suggests that, in women with PCOS, disordered eating is associated with a higher body weight [7, 11], anxiety [7], depression [8] and poorer quality of life [7].
Eating disorders and disordered eating

In women with PCOS it is not known whether: phenotypic differences are associated with different rates of eating disorders or disordered eating; the prevalence of eating disorders or disordered eating changes over time; or PCCS treatments impact on the prevalence of eating disorders or disordered eating.

Should Eating Disorders/Disordered Eating be Screened?

The high prevalence of eating disorders and disordered eating in women with PCOS, and the negative biopsychosocial consequences of eating disorders and disordered eating highlight the need for screening for eating disorders and disordered eating in women with PCOS.

The importance of screening for eating disorders and disordered eating is noted in the Australian Evidence-based Guideline for the assessment and management of polycystic ovary syndrome (PCOS). Screening is also recommended for women with PCOS and/or PCOS symptoms in a number of eating disorder guidelines. For example, the Australian National Eating Disorders Collaboration list women with PCOS as one of the high risk groups who may benefit from screening (www.nedc.com.au/identifying-people-at-risk). Likewise the draft National Institute for Health and Care Excellence Guidelines for Eating Disorders: Recognition and Treatment (www.nice.org.uk/guidance/indevelopment/gid-cgwave0703/documents) suggest that clinicians think about the possibility of an eating disorder in individuals with a range of symptoms relevant to PCOS (see below).

Assessment of Eating Disorders/Disordered Eating

Many women with eating disorders are undiagnosed and unaware that they have an eating disorder. Likewise, many women with disordered eating are unaware that their eating and weight related thoughts and behaviours are unusual and/or causing distress. Therefore, screening, assessment and diagnosis are essential.

Unfortunately there are not standardised, widely implemented processes for screening and assessment. The variety of eating disorder diagnosis, and associated symptoms makes it difficult to identify simple screening and assessment methods that cover all eating disorder diagnosis and symptoms. The draft National Institute for Health and Care Excellence Guidelines for Eating Disorders: Recognition and Treatment ([12]; www.nedc.com.au/identifying-people-at-risk) consider questions relating to the utility, reliability and validity of instruments, tools and methods for screening and assessing eating disorders.

This review highlighted the limited, and low quality evidence regarding eating disorder screening tools. It was concluded that none of the tools are effective for identifying eating disorders when used in isolation (given the high variability of false positives and negatives in across populations). Instead the clinician should use their judgement based on a full diagnostic interview. The SCOFF was the most commonly used screening tool in adults. Their review of the SCOFF indicated that a threshold of 2 or more was optimal for identifying the presence of an eating disorder (both generally and for the specific disorders of anorexia, bulimia and EDNOS). Its sensitivity (pooled estimate) was 0.9 (i.e., 10% of people with an eating disorder would not be detected with the test. The SCOFF takes only a few minutes to administer [12]. Of note, the final two questions have been shown to be useful screening questions (Cotton, 2003 #28)

- Does your weight affect the way you feel about yourself?
- Are you satisfied with your eating patterns?

<table>
<thead>
<tr>
<th>SCOFF</th>
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<tbody>
<tr>
<td>S – Do you make yourself Sick because you feel uncomfortably full?</td>
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<tr>
<td>C – Do you worry you have lost Control over how much you eat?</td>
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<tr>
<td>O – Have you recently lost more than 6.35 kg in a three-month period?</td>
</tr>
<tr>
<td>F – Do you believe yourself to be Fat when others say you are too thin?</td>
</tr>
</tbody>
</table>
F – Would you say Food dominates your life?

An answer of ‘yes’ to two or more questions indicates the need for a more comprehensive assessment.

A further two questions have been shown to indicate a high sensitivity and specificity for bulimia nervosa.

1. Are you satisfied with your eating patterns?

2. Do you ever eat in secret?

The draft National Institute for Health and Care Excellence Guidelines for Eating Disorders: Recognition and Treatment [12] review of assessment tools identified evidence for: the Eating Disorder Examination-Questionnaire, Munich-ED, the 40-item Eating Attitudes Test, Structured Expert Interview for Anorexic and Bulimic Syndromes and Structured Inventory for Anorexic and Bulimic Syndromes self-report, EDE-Q, EDA-5 (interview and electronic application) and Bulimic Investigatory Test, Edinburgh. They concluded that the EDA-5 was the most versatile. The most sensitive tests for each diagnosis are listed in the table below. The EDE-Q was the most commonly used tool, but may miss important outcomes (e.g., bingeing).

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Better Tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexia Nervosa</td>
<td>EDA-5 App</td>
</tr>
<tr>
<td></td>
<td>EDE-Q (for both DSM-IV and DSM-5)</td>
</tr>
<tr>
<td></td>
<td>Munich-ED</td>
</tr>
<tr>
<td>Bulimia Nervosa</td>
<td>EDA-5 App</td>
</tr>
<tr>
<td></td>
<td>Munich ED-Quest</td>
</tr>
<tr>
<td></td>
<td>EDA-5</td>
</tr>
<tr>
<td>Binge Eating Disorder</td>
<td>EDA-5</td>
</tr>
<tr>
<td></td>
<td>EDE-Q for DSM-IV</td>
</tr>
<tr>
<td></td>
<td>EDA-5 App</td>
</tr>
<tr>
<td>OSFED</td>
<td>EDA-5</td>
</tr>
</tbody>
</table>

However, the committee highlighted the risk of false positives (and hence inappropriate treatment) with these tools due to the use of these assessment tools, particularly given a full diagnostic interview would be required.

The committee recommended (amongst other things) that [12])
(1) clinicians think about the possibility of an eating disorder in people with one or more of the following:
   o an unusually low or high BMI or body weight for their age
   o dieting or restrictive eating practices (such as dieting when they are underweight) that are worrying them, their family members or carers, or professionals
   o family members or carers report a change in eating behaviour
   o other mental health problems
   o a disproportionate concern about their weight (for example, concerns about weight gain as a side effect of contraceptive medication)
   o problems managing a chronic illness that affects diet, such as diabetes
   o menstrual or other endocrine disturbances, or unexplained gastrointestinal symptoms
   o physical signs of:
     ▪ starvation, such as poor circulation, dizziness, palpitations, fainting or pallor
     ▪ compensatory behaviours, such as laxative misuse, vomiting or excessive exercise
     ▪ dental erosion
   o taking part in activities associated with a high risk of eating disorders (for example, professional sport, fashion, dance, or modelling). And,
Professionals in primary and secondary mental health settings should assess the following in people with a suspected eating disorder:

- their physical health, including checking for any physical effects of starvation or of compensatory behaviours such as vomiting
- the presence of mental health problems commonly associated with eating disorders, including depression, anxiety, self-harm and obsessive compulsive disorder
- the possibility of alcohol or substance misuse.
- the need for emergency care in people whose physical health is compromised or who have a suicide risk.

Recommendations (Consistent with NICE)

- Eating disorders and disordered eating should be considered in all women with PCOS at diagnosis and regularly throughout treatment.
- If screening suggests the presence of an eating disorder or disordered eating, practitioners should further assess via a full diagnostic interview (e.g., EDE, EDAS)
- If a screening tool is to be used the SCOFF should be considered.
- The following two questions may be helpful in screening
  - Does your weight affect the way you feel about yourself?
  - Are you satisfied with your eating patterns?
- The EDE-Q may be a helpful assessment tool
Eating disorders and disordered eating

GRADE framework

Interactive Evidence to Decision Framework

1) In women with PCOS what is the prevalence and severity of disordered eating and should they be screened?

2) In women with PCOS, what is the most effective tool/method to assess disordered eating?

Background

Diagnosable eating disorders include Anorexia Nervosa (AN); Bulimia Nervosa (BN), Binge-Eating Disorder (BED), Other Specified Feeding or Eating Disorder (OSFED; atypical AN, BN of low frequency and/or duration, BED of low frequency and limited duration, purging disorder, and night eating syndrome), and Unspecified Feeding or Eating Disorders (USFED; symptoms consistent with eating disorders, including the severity of symptoms and distress and impairment, but do not meet the full criteria for any of the eating disorder diagnoses). Disordered eating refers to eating and weight related symptoms commonly associated with an eating disorder, this can include behavioural (e.g., bingeing, restriction), cognitive (e.g., dietary restraint, negative body image), and emotional (e.g., emotional eating) factors.

ASSESSMENT

Problem

Is the problem a priority?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>No</th>
<th>Probably No</th>
<th>Probably Yes</th>
<th>Yes</th>
</tr>
</thead>
</table>

Research evidence

The prevalence of AN in women is 0.9%, BN is 1.5% and BED is 3.5% [1]. There is a lack of data regarding the prevalence of USFED and OSFED however, given the range of disorders covered by these categories, rates are likely higher than that of the other eating disorders. The associated disturbed eating and eating-related behaviours impair physical and psychosocial health and wellbeing. Obesity is not considered an eating disorder but it is associated with increased risk of binge eating disorder and disordered eating [2].

Disordered eating refers to eating and weight related symptoms commonly associated with an eating disorder, this can include behavioural (e.g., bingeing, restriction), cognitive (e.g., dietary restraint, negative body image), and emotional (e.g., emotional eating) factors. The prevalence of disordered eating is far higher than the prevalence of eating disorders; many women who do not meet full criteria for an eating disorder experience disordered eating and associated distress. For example, Australian research [3] reports that 7.5% of women surveyed experienced binge eating, 2.1% purging, and 5.2% strict dieting or fasting.

There is a lack of good evidence regarding the prevalence of eating disorders and disordered eating in women with PCOS. Available data suggests that the prevalence of eating disorders and disordered eating is higher in women with PCOS that in the general community. In the only study to use a clinical interview (MINI for DSM-IV) to assess eating disorder prevalence in women with PCOS (n=49), Mansson and colleagues [4] reported increased prevalence of any eating disorder (21% vs 4%) but not bulimia nervosa (12% vs 4%) compared to controls. Of note, the MINI only assesses AN and BN, and this study uses the older DSM-IV diagnostic criteria.
A recent Swedish registry study of women with PCOS (n=24,385) and age- and county of residence-matched controls reported an increased risk of BN (OR 1.35; 95% CI 1.15-1.58; AOR 1.21; 95% CI 1.03, 1.41), but not AN, among women with PCOS before and after controlling for psychiatric comorbidity [5]. A Swedish survey of women with PCOS recruited from the community (n=72) reported mixed results. Women with PCOS reported higher symptoms of AN and BN (EAT-40 Total) but no difference in cognitive restraint, uncontrolled eating, or emotional eating (TFEQ-21) or current symptoms of BN [6].

A recent US survey study of treatment-seeking women with PCOS (n=148) reported increased disordered eating behaviours and cognitions (EDE-Q Total score; 12.16% vs. 2.83%), binge episodes (3.49 vs. 1.71), and compulsive exercise episodes (2.23 vs. 0.51) than controls in the previous 28 days [7]. Questionnaire data was also used to estimate eating disorder prevalence based on DSM5 criteria. Overall 28% of women with PCOS reported symptoms consistent with an eating disorder. Six percent reported symptoms consistent with BN, 18% BED, and 13% night eating syndrome. There were no cases of AN [7]. An earlier US survey study of women with PCOS (n=103) also reported an increased prevalence of BED in women with PCOS compared to controls (2.6% vs 1.9%) [8].

This research was recently collated in a systematic review and meta-analysis {Lee, under review #37}. Lee and colleagues identified eight studies reporting the prevalence of eating disorder diagnosis or symptoms assessed using validated measures in women with well-defined PCOS. Women with PCOS increased risk of having an eating disorder diagnosis (OR 3.87; 95% CI 1.43, 10.49; 4 studies) and of elevated eating disorder symptoms (OR3.05; 95% CI1.33, 6.99; 4 studies). The authors highlighted the need for routine eating disorder screening in women with PCOS.

Women with PCOS are at increased risk of experiencing many of the identified risk factors for eating disorders [9]. They are at increased risk of overweight/obesity, depression, anxiety, self-esteem and poor body image. They are also more likely to be highly motivated for weight loss and to be prescribed dietary restriction. Potential endocrine mechanisms have also been proposed [10]. Available data suggests that, in women with PCOS, disordered eating is associated with a higher body weight [7, 11], anxiety [7], depression [8] and poorer quality of life [7].

In women with PCOS it is not known whether: phenotypic differences are associated with different rates of eating disorders or disordered eating; the prevalence of eating disorders or disordered eating changes over time; or PCCS treatments impact on the prevalence of eating disorders or disordered eating.

Additional considerations

ED are associated with anxiety and depression which have a high prevalence in PCOS. ED are also associated with obesity, again this comorbidity is high in PCOS. Weight loss strategies may vary in obese women with and without ED.

Panel discussion

All in agreement for judgement.

Desirable effects

How substantial are the desirable anticipated effects?

Judgement

| ☐ Don't know | ☐ Varies | ☑ Trivial | ☐ 2 Small | ☐ 2 Moderate | ☑ 3 Large |

Research evidence

Should Eating Disorders/Disordered Eating be Screened?

The high prevalence of eating disorders and disordered eating in women with PCOS, and the negative biopsychosocial consequences of eating disorders and disordered eating highlight the need for screening for eating disorders and disordered eating in women with PCOS.
The importance of screening for eating disorders and disordered eating is noted in the Australian Evidence-based Guideline for the assessment and management of polycystic ovary syndrome (PCOS). Screening is also recommended for women with PCOS and/or PCOS symptoms in a number of eating disorder guidelines. For example, the Australian National Eating Disorders Collaboration list women with PCOS as one of the high risk groups who may benefit from screening (www.nedc.com.au/identifying-people-at-risk). Likewise the draft National Institute for Health and Care Excellence Guidelines for Eating Disorders: Recognition and Treatment (www.nice.org.uk/guidance/indevelopment/gid-cgwave0703/documents) suggest that clinicians think about the possibility of an eating disorder in individuals with a range of symptoms relevant to PCOS (see below).

Assessment of Eating Disorders/Disordered Eating

Many women with eating disorders are undiagnosed and unaware that they have an eating disorder. Likewise, many women with disordered eating are unaware that their eating and weight related thoughts and behaviours are unusual and/or causing distress. Therefore, screening, assessment and diagnosis are essential.

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- Does your weight affect the way you feel about yourself?
- Are you satisfied with your eating patterns?

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2. Do you ever eat in secret?
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- other mental health problems
- a disproportionate concern about their weight (for example, concerns about weight gain as a side effect of contraceptive medication)
- problems managing a chronic illness that affects diet, such as diabetes
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- physical signs of:
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  - compensatory behaviours, such as laxative misuse, vomiting or excessive exercise
  - dental erosion
- taking part in activities associated with a high risk of eating disorders (for example, professional sport, fashion, dance, or modelling). And,

(2) Professionals in primary and secondary mental health settings should assess the following in people with a suspected eating disorder:

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- the presence of mental health problems commonly associated with eating disorders, including depression, anxiety, self-harm and obsessive compulsive disorder
- the possibility of alcohol or substance misuse.
- the need for emergency care in people whose physical health is compromised or who have a suicide risk.

Additional considerations
None.

Panel discussion
All in agreement for judgement.

Undesirable effects
How substantial are the undesirable anticipated effects?

Judgement

<table>
<thead>
<tr>
<th></th>
<th>Don't know</th>
<th>Varies</th>
<th>Large</th>
<th>Moderate</th>
<th>Small</th>
<th>Trivial</th>
</tr>
</thead>
<tbody>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>

Research evidence
See above in ‘Desirable effects’.

Additional considerations
None
Eating disorders and disordered eating

Panel discussion
Screening/assessment may be problematic if those identified are not offered effective treatment.

Certainty of the evidence
What is the overall certainty of the evidence of effects?
Judgement

<table>
<thead>
<tr>
<th>No included studies</th>
<th>Very low</th>
<th>Low</th>
<th>Moderate</th>
<th>High</th>
</tr>
</thead>
</table>
Research evidence
See above in ‘Desirable effects’.
Additional considerations
None
Panel discussion
All in agreement for judgement.

Values
Is there important uncertainty about, or variability in, how much people value the main outcomes?
Judgement

<table>
<thead>
<tr>
<th>Important uncertainty or variability</th>
<th>Possibly important uncertainty or variability</th>
<th>Probably no important uncertainty or variability</th>
<th>No important uncertainty or variability</th>
</tr>
</thead>
</table>
Research evidence
Evidence not sought.
Additional considerations
None
Panel discussion
All in agreement for judgement.

Balance of effects
Does the balance between desirable and undesirable effects favour the intervention or the comparison?
Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Favours the comparison</th>
<th>Probably favours the comparison</th>
<th>Does not favour either the intervention or the comparison</th>
<th>Probably favours the intervention</th>
<th>Favours the intervention</th>
</tr>
</thead>
</table>
Research evidence
See above.
Additional considerations
See above.

Panel discussion
All in agreement for judgement.

**Resources required**

How large are the resource requirements (costs)?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Large costs</th>
<th>Moderate costs</th>
<th>Negligible costs or savings</th>
<th>Moderate savings</th>
<th>Large savings</th>
</tr>
</thead>
</table>

Research evidence
Evidence not sought for this criterion.

Additional considerations
Cost of screening will be relatively low.

Panel discussion
All in agreement for judgement.

**Cost-effectiveness**

Does the cost-effectiveness of the intervention favour the intervention or the comparison?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Favours the comparison</th>
<th>Probably favours the comparison</th>
<th>Does not favour either the intervention or the comparison</th>
<th>Probably favours the intervention</th>
<th>Favours the intervention</th>
</tr>
</thead>
</table>

Research evidence
Evidence not sought for this criterion.

Additional considerations
None.

Panel discussion
All in agreement for judgement.

**Equity**

What would be the impact on health equity?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
<th>Reduced</th>
<th>Probably reduced</th>
<th>Probably no impact</th>
<th>Probably increased</th>
<th>Increased</th>
</tr>
</thead>
</table>

Research evidence
Evidence not sought for this criterion.
Eating disorders and disordered eating

Additional considerations
None.

Panel discussion
Some settings may not have the resources/capability to treat the condition.

**Acceptability**

Is the intervention acceptable to key stakeholders?

<table>
<thead>
<tr>
<th>Judgement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know</td>
</tr>
<tr>
<td>Varies</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Probably No</td>
</tr>
<tr>
<td>Probably Yes</td>
</tr>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>

Research evidence
Evidence not sought for this criterion.

Additional considerations
Health professionals and women may have some sensitivities around screening.

Panel discussion
All in agreement for judgement.

**Feasibility**

Is the intervention feasible to implement?

<table>
<thead>
<tr>
<th>Judgement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know</td>
</tr>
<tr>
<td>Varies</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Probably No</td>
</tr>
<tr>
<td>Probably Yes</td>
</tr>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>

Research evidence
No research evidence in PCOS. However validated screening tools for ED have been used in the general population.

Additional considerations
None.

Panel discussion
Time, resources and expertise may present challenges.

CONCLUSIONS

**Consensus recommendation**

All health professionals should be aware of the increased prevalence of eating disorders and disordered eating associated with PCOS.

Consider screening for eating disorders and disordered eating associated with PCOS.

If treatment is warranted, psychological therapy should be offered, informed by regional clinical practice guidelines.

Judgement
Eating disorders and disordered eating can be screened using a stepped approach. Initial screening questions can include:

**Step 1:** The SCOFF may be a useful screening tool. The following questions (could also be asked:

- Does your weight affect the way you feel about yourself?
- Are you satisfied with your eating patterns?

**Step 2:** If any of the responses are positive, further screening should involve:

A) Assessment of risk factors and symptoms using age, culturally and regionally appropriate tools.

B) Referral to an appropriate professional to perform a further mental health assessment (which should include a diagnostic interview). If this is not the patient’s usual healthcare provider, inform the primary care physician.

**Justification**

A recent systematic review and meta-analysis {Lee, under review #7} demonstrated that women with PCOS increased risk of having an increased risk of eating disorder diagnosis (OR 3.87; 95% CI 1.43, 10.49; 4 studies) and eating disorder symptoms (OR 3.05; 95% CI 1.33, 6.99; 4 studies).

Limited evidence and controversy over optimal screening.

**Subgroup considerations**

Adolescents generally have a higher rate of disordered eating in general population.

Consider screening in adolescents who are recommended lifestyle recommendation.

Women with PCOS who are also obese are likely at higher risk of disordered eating and eating disorders.

**Implementation considerations**

Consider age, life stage, religion and sexual orientation when screening/assessing for eating disorders and disordered eating. The cultural identity and preferred language of a woman are also important considerations. Be aware of possible variations in presentation of eating disorders and disordered eating and conduct screening in a culturally sensitive manner. Consider using screening tools that have been translated and cross-culturally validated [13].

In many countries it is not usual practice to screen women with PCOS for eating disorders and disordered eating and doing so may identify affected patients who would otherwise be missed. Screening may have resource implications such as an impact on length of consultation, however this can be reduced by the use of stepped approach to screening recommended here. If eating disorders or disordered eating are detected, intervention may require referral to other health practitioners. Additional time with the patient may also be required to complete an appropriate care plan. Access to appropriately trained and experienced health professionals will be required. It is the responsibility of all health professionals to understand the impact of PCOS on psychological health and to screen for and manage these eating disorders and disordered eating.

**Monitoring and evaluation**

Ongoing monitoring of eating disorders and disordered eating should be considered particularly in response to significant changes in weight, and following initiation of PCOS related therapies. Surveys of consumers and health professionals on adherence to the guideline is recommended.


**Research priorities**

In adolescent subgroups and generally in PCOS using DSM5.
Whether the evidence is independent of obesity.
Prevalence, screening and treatment.
Validation of screening tools in diverse PCOS populations.
Relationships of mental health symptoms with PCOS features and the concept of PCOS-related distress.
Longitudinal follow up to determine frequency of screening for disordered eating and eating disorders.
Prevalence of disordered eating and eating disorders in different PCOS phenotypes.

**References**

NARRATIVE REVIEW: What are the information, resource and education needs of women and healthcare providers regarding PCOS?

Prevalence and problem
Delivering comprehensive, woman-centred care and providing accurate information are both key to delivering optimal care for PCOS. First-line management also relies on women’s engagement [1]; therefore, it is important to equip women to make informed decisions about their health, and to create opportunities for early engagement in preventive strategies for metabolic complications [2]. Women’s perceptions of receiving better quality information are also associated with better quality of life [3].

Clinical practice gap: need for guidance

Women’s experiences of PCOS care
Many women around the world report seeing multiple health professionals about their PCOS symptoms before a diagnosis is established [2, 4-6]. Women report having to flag their symptoms multiple times [7, 8], and experiencing long and confusing delays before receiving a diagnosis [2, 4, 5, 8]. Receiving a diagnosis is important to women [8]; however, a diagnosis can also lead to feelings of anxiety, frustration or lack of control if women feel uncertain about the nature of the condition or if they don’t have all the information they need [5-7]. Research often identifies weight, menstrual irregularity, infertility and hirsutism as key concerns for women with PCOS [2, 9]. However, women also feel that the psychological effects of PCOS are sometimes under-appreciated [7], or that their primary concern goes unrecognised [5].

Women’s information needs
At the time of PCOS diagnosis women want specific and practical information about lifestyle management, fertility consequences, medical therapy, cosmetic treatments, potential long-term consequences of PCOS and emotional support and counselling; yet this information is not often provided, or does not meet their needs [2, 4, 6-8, 10, 11]. Women’s initial source of information is their healthcare provider [7-9], however, women are frustrated if they feel this information is inadequate, particularly regarding the long-term health consequences, inaccurate or conflicting [2, 10]. Many women report seeking PCOS information from the internet [7, 8, 10], however find an unevenness in the quality of the information [8] and a lack of credibility in information provided by commercial entities [10] that may also contribute to feeling overwhelmed or anxious [5].

Healthcare providers’ knowledge and practices
Studies of healthcare providers’ practices regarding PCOS suggest that diagnosis and management varies depending on specialty. Rates of undiagnosed PCOS are reported to vary between endocrinology, infertility, gynaecology and dermatology clinics (lowest in infertility and highest in dermatology) [12]. Importantly, while the predominant presenting symptom often differs between clinical settings, menstrual disturbance is present in most women [12]. Differences between gynaecologists and endocrinologists have been reported regarding the tests ordered to establish a PCOS diagnosis, however most clinicians in both specialities recommend lifestyle management as the first-line therapy [13].

While a survey of dietitians reported that most provide advice consistent with evidence-based PCOS care [14], the same survey found that less than one-quarter of women with PCOS reported seeing a dietitian or receiving dietary advice from a doctor [14].

Regarding educational programs for healthcare providers, programs to develop a comprehensive understanding of women’s healthcare topics have been shown to result in better knowledge and confidence in managing PCOS among internal medicine residents [15]. Further research investigating the efficacy of PCOS-specific educational programs for healthcare providers is needed.

Summary of key information
A systematic search of peer-reviewed literature was conducted to identify articles investigating i) women’s experiences of PCOS care and obtaining PCOS information ii) women’s perceived needs for PCOS care and
Information resources, models of care, cultural and linguistic considerations, information and resources, iii) health care providers’ delivery of PCOS care and information, iv) health care providers’ perceived needs for PCOS information, education programs, or professional development.

Recommendations

Women with undiagnosed PCOS may see different healthcare providers depending on their primary concern. To facilitate timely diagnosis, general practitioners, endocrinologists, gynaecologists, dermatologists, nurses and allied health practitioners should all be aware of the features of PCOS and enquire about menstrual disturbance when obtaining patient histories.

It is recommended that PCOS information is comprehensive, evidence-based and inclusive of the bio-psycho-social dimensions of the condition [2, 4-6, 16]. Use a patient centred care model that helps women to prioritise their individual concerns to guide the co-development of appropriate medical and support interventions [16].

Women with PCOS are best supported by a range of resources: respectful and empathetic healthcare providers, websites, leaflets and support groups [8, 17, 18]. Women’s concerns, information and support needs differ across the life-time and with personal background [2, 8, 9]. Diagnosis is particularly a time of greater need [6]. Assist women to access accurate, high-quality resources and consider referring to dietitians, exercise physiologists and psychologists.

Finally, health professionals should address PCOS misconceptions [1], emphasise the long-term chronic nature of the condition and provide support to increase self-efficacy [11] and consumer engagement [1].
GRADE framework

Interactive Evidence to Decision Framework

What are the information, resource and education needs of women and healthcare providers regarding PCOS?

QUESTION

Question details

Population: Women with PCOS and healthcare providers who provide PCOS care

Option: Provision of information, resources and education for women and healthcare providers regarding PCOS diagnosis and care.

Main outcomes: Provision

Setting: Primary, specialist and allied health care

Perspective: Patients and healthcare providers

Background

Delivering comprehensive, woman-centred care and providing accurate information are both key to delivering optimal care for PCOS. First-line management also relies on women’s engagement [1]; therefore, it is important to equip women to make informed decisions about their health, and to create opportunities for early engagement in preventive strategies for metabolic complications [2]. Women’s perceptions of receiving better quality information are also associated with better quality of life [3].

A systematic search of peer-reviewed literature was conducted to identify articles investigating i) women’s experiences of PCOS care and obtaining PCOS information ii) women’s perceived needs for PCOS care and information, iii) health care providers’ delivery of PCOS care and information, iv) health care providers’ perceived needs for PCOS information, education programs, or professional development.

Subgroups

Subgroup name: Women

Subgroup name: Healthcare providers

ASSESSMENT

Problem

Is the problem a priority?

Judgement

Don't know  Varies  No  Probably No  Probably Yes  Yes
Information resources, models of care, cultural and linguistic considerations

Research evidence
Delivering comprehensive, woman-centred care and providing accurate information are both key to delivering optimal care for PCOS. First-line management also relies on women’s engagement [1]; therefore, it is important to equip women to make informed decisions about their health, and to create opportunities for early engagement in preventive strategies for metabolic complications [2]. Women’s perceptions of receiving better quality information are also associated with better quality of life [3].

Women with undiagnosed PCOS may see different healthcare providers depending on their primary concern. Use a patient centred care model that helps women to prioritise their individual concerns to guide the co-development of appropriate medical and support interventions [16]. It is recommended that PCOS information is comprehensive, evidence-based and inclusive of the bio-psycho-social dimensions of the condition [2, 4-6, 16]. Women’s concerns, information and support needs differ across the life-time and with personal background [2, 8, 9]. Diagnosis is particularly a time of greater need [6].

Health professionals should address PCOS misconceptions [1], emphasise the long-term chronic nature of the condition and provide support to increase self-efficacy [11] and consumer engagement [1].

Additional considerations
Studies of PCOS healthcare for adolescents report similar findings to those of PCOS care for adults.


A retrospective cohort study suggests that PCOS is under-recognised in primary care.


Panel discussion
All in agreement for judgement. Many women report delays in diagnosis, dissatisfaction with diagnosis experience, current PCOS care and with the information and support they receive about the condition. This is a problem because first-line management (lifestyle modification) relies on women's engagement.

Desirable effects
How substantial are the desirable anticipated effects?

Judgement

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<tbody>
<tr>
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<td>Trivial</td>
<td>Small</td>
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</table>

Research evidence - WOMEN
Women report having to flag their symptoms multiple times [7, 8], experiencing long and confusing delays before receiving a diagnosis [2, 4, 5, 8], or that their primary concern goes unrecognised [5]. However, receiving a diagnosis can lead to feelings of anxiety, frustration or lack of control if women feel uncertain about the nature of the condition or if they don’t have all the information they need [5-7].
Women’s perceptions of receiving better quality information are also associated with better quality of life [3]. At the time of PCOS diagnosis, women may want information about lifestyle management, fertility consequences, medical therapy, cosmetic treatments, potential long-term consequences of PCOS and emotional support and counselling; yet all this information is not often provided, or does not meet their needs [2, 4, 6-8, 10, 11]. Women are frustrated if they feel the information they receive from healthcare providers is inadequate, inaccurate or conflicting [2, 10]. Many women report finding discrepancies in the quality of PCOS information available from the internet [8] and a lack of credibility in information provided by commercial entities [10] and these issues may contribute to feeling overwhelmed or anxious [5].

Research evidence – HEALTHCARE PROVIDERS
Rates of undiagnosed PCOS are reported to vary between endocrinology, infertility, gynaecology and dermatology clinics [12]. Importantly, while the predominant presenting symptom often differs between clinical settings, menstrual disturbance is present in most women [12].

Universal application of the widely recommended Rotterdam diagnostic criteria and the appropriate diagnostic tests appears to remain a challenge, with considerable variation reported across regions and specialties (Doll 2012, Ning 2013, Conway 2014, Dokras 2017). This is likely to contribute to delays in diagnosis, delays in optimal management, confusion and frustration for both women and healthcare providers.

Management strategies for PCOS vary across specialties, which is expected given that women are likely to see different clinicians depending on their primary concern. However, there is wide variation across studies regarding how commonly lifestyle management is recommended for either fertility or non-fertility concerns (Doll 2012, Conway 2014, Dokras 2017 [13]).

While a survey of dietitians reported that most provide advice consistent with evidence-based PCOS care [14], the same survey found that less than one-quarter of women with PCOS reported seeing a dietitian or receiving dietary advice from a doctor [14].

Awareness of potential metabolic comorbidities appears to be high among healthcare providers (Dokras 2017, Doll 2012, Dhesi 2016, Conway 2014) but a comprehensive understanding of current metabolic screening practices across different settings and specialties is lacking.

Regarding educational programs for healthcare providers, programs to develop a comprehensive understanding of women’s healthcare topics have been shown to result in better knowledge and confidence in managing PCOS among internal medicine residents [15]. Further research investigating the efficacy of PCOS-specific educational programs for healthcare providers is needed.

Additional considerations
A retrospective cohort study suggests that PCOS is under-recognised in primary care (Ding 2016).
Studies of PCOS healthcare for adolescents report similar findings to those of PCOS care for adults (Auble et al 2013, Bonny et al 2012).

Panel discussion
All in agreement for judgement. Timely diagnosis and equipping women to make informed decisions about their health creates opportunities to improve current symptom experience and for early engagement in preventive strategies for comorbidities.

Undesirable effects
How substantial are the undesirable anticipated effects?

Judgement

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<tr>
<th></th>
<th>Don't know</th>
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<tbody>
<tr>
<td>Undesirable</td>
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</table>
Information resources, models of care, cultural and linguistic considerations_ information and resources

Research evidence
See above in ‘Desirable effects’.

Additional considerations
See above in ‘Desirable effects’.

Panel discussion
All in agreement for judgement. Studies of healthcare providers’ practices regarding PCOS suggest that diagnosis and management varies depending on specialty.

Certainty of the evidence

What is the overall certainty of the evidence of effects?

Judgement

<table>
<thead>
<tr>
<th>No included studies</th>
<th>Very low</th>
<th>Low</th>
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<th>High</th>
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</thead>
</table>

Research evidence
See above in ‘Desirable effects’.

Additional considerations
See above in ‘Desirable effects’.

Panel discussion
All in agreement for judgement.

Values

Is there important uncertainty about, or variability in, how much people value the main outcomes?

Judgement

<table>
<thead>
<tr>
<th>Important uncertainty or variability</th>
<th>Possibly important uncertainty or variability</th>
<th>Probably no important uncertainty or variability</th>
<th>No important uncertainty or variability</th>
</tr>
</thead>
</table>

Research evidence
Refer to 'research evidence' in 'problem' and 'desirable effects'.

Additional considerations
None

Panel discussion
All in agreement for judgement. Weight, menstrual irregularity, infertility and hirsutism are key concerns for women with PCOS. However, women also feel that the psychological effects of PCOS are sometimes under-appreciated, or that their primary concern goes unrecognised. Women’s initial source of information is their healthcare provider.

Balance of effects

Does the balance between desirable and undesirable effects favour the intervention or the comparison?

Judgement
### Information resources, models of care, cultural and linguistic considerations

<table>
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<tr>
<th>Information and resources</th>
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<td>Favours the comparison</td>
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<td>Probably favours the comparison</td>
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<tr>
<td>Does not favour either the intervention or the comparison</td>
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<tr>
<td>Probably favours the intervention</td>
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<tr>
<td>Favours the intervention</td>
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</table>

**Research evidence**

Refer to ‘research evidence’ in ‘problem' and 'desirable effects'.

**Additional considerations**

None

**Panel discussion**

All in agreement for judgement.

---

## Resources required

### How large are the resource requirements (costs)?

**Judgement**

<table>
<thead>
<tr>
<th>Don’t know</th>
<th>Varies</th>
<th>Large costs</th>
<th>Moderate costs</th>
<th>Negligible costs or savings</th>
<th>Moderate savings</th>
<th>Large savings</th>
</tr>
</thead>
</table>

**Research evidence**

Evidence not sought

**Additional considerations**

Potential to increase use of existing resources prepared for women and health professionals.

However, while resources from professional societies exist, the level of involvement of patients, physicians and other PCOS healthcare providers in their development varies. Co-development of resources with women with PCOS and a range of different healthcare providers is crucial to ensure the resources will actually meet the needs of the end users. This may mean that existing resources require revision or replacement.

Resources should also be based on evidence-based guidelines and the research literature regarding evidence-practice gaps relevant to the target audience.

**Panel discussion**

There is limited point to the guideline investment without implementation resources. This responsibility could be shared across stakeholder groups.

---

## Certainty of evidence of required resources

### What is the certainty of the evidence of resource requirements (costs)?

**Judgement**

<table>
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<th>No included studies</th>
<th>Very low</th>
<th>Low</th>
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<th>High</th>
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</thead>
</table>

**Research evidence**

Evidence not sought

**Additional considerations**
Information resources, models of care, cultural and linguistic considerations

See above in ‘Resources required’.

Panel discussion
All in agreement for judgement.

**Cost-effectiveness**

Does the cost-effectiveness of the intervention favour the intervention or the comparison?

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<td>Varies</td>
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<td>Favours the comparison</td>
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<tr>
<td>Probably favours the comparison</td>
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<tr>
<td>Does not favour either the intervention or the comparison</td>
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<tr>
<td>Probably favours the intervention</td>
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<tr>
<td>Favours the intervention</td>
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</table>

Research evidence
Evidence not sought.

Additional considerations
None.

Panel discussion
All in agreement for judgement. Education likely to improve care and health outcomes and may reduce costs.

**Equity**

What would be the impact on health equity?

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<th>Judgement</th>
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<td>Reduced</td>
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<td>Probably reduced</td>
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<td>Probably no impact</td>
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<td>Probably increased</td>
<td></td>
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<tr>
<td>Increased</td>
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</table>

Research evidence
Evidence not sought.

Additional considerations
It is important to ensure that resources for women are designed with a low reading level and a low health literacy level. It is also important that resources both women and healthcare providers are culturally appropriate and available in languages other than English.

Panel discussion
All in agreement for judgement.

**Acceptability**

Is the intervention acceptable to key stakeholders?

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<tr>
<td>Varies</td>
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<tr>
<td>No</td>
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<tr>
<td>Probably No</td>
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<tr>
<td>Probably Yes</td>
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<tr>
<td>Yes</td>
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</tbody>
</table>

Research evidence
Information resources, models of care, cultural and linguistic considerations _ information and resources

At the time of PCOS diagnosis women want specific and practical information about lifestyle management, fertility consequences, medical therapy, cosmetic treatments, potential long-term consequences of PCOS and emotional support and counselling [2, 4, 6-8, 10, 11]. Women’s initial source of information is their healthcare provider [7-9].

Additional considerations
None

Panel discussion
All in agreement for judgement.

Feasibility
Is the intervention feasible to implement?

Judgement

<table>
<thead>
<tr>
<th>Don't know</th>
<th>Varies</th>
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<th>Probably No</th>
<th>Probably Yes</th>
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</table>

Research evidence
Evidence not sought

Additional considerations
Patient surveys indicate dissatisfaction with PCOS related information received. Therefore providing information should be feasible during visit when diagnosis is established and ongoing follow up visits.

Panel discussion
All in agreement for judgement.

CONCLUSIONS

Consensus recommendations

1) Information and education resources for women with PCOS should be culturally appropriate, tailored and high-quality, should use a respectful and empathetic approach, and should promote self-care initiatives such as peer support groups.
2) Information and education for healthcare providers should promote the recommended diagnostic criteria, appropriate screening for comorbidities and effective lifestyle management.
3) PCOS information should be comprehensive, evidence-based and inclusive of the bio-psycho-social dimensions of PCOS across the life-span.

Judgement

<table>
<thead>
<tr>
<th>Strong recommendation against the intervention</th>
<th>Conditional recommendation against the intervention</th>
<th>Conditional recommendation for either the intervention or the comparison</th>
<th>Conditional recommendation for the intervention</th>
<th>Strong recommendation for the intervention</th>
</tr>
</thead>
</table>

Justification
Evidence demonstrates key gap areas such as diagnosis, biopsychosocial approach, lifestyle and screening.

Subgroup considerations
It is important to ensure that resources for women are designed with a low reading level and a low health literacy level. It is also important that resources both women and healthcare providers are culturally appropriate and available in languages other than English.
Information resources, models of care, cultural and linguistic considerations

Implementation considerations
Resources should be based on evidence-based guidelines, research literature and co-developed with end users.

Monitoring and evaluation
Feedback from both women and healthcare providers should be sought regarding their experiences of using new resources.

Research priorities
Effect of information, education and resources on improving uptake of evidence-based healthcare recommendations, quality of life and health outcomes.
Information resources, models of care, cultural and linguistic considerations

References


EVIDENCE AND NARRATIVE REVIEW: What is the effectiveness of different models of care compared to usual care in PCOS?
(No studies identified by the search so key contacts prepared a narrative review)

Summary

None of the studies identified in the systematic search met the selection criteria (PICO). Four studies described models of care in terms of barriers and enablers as well as satisfaction of patients and care providers and inform a narrative synthesis by the key contacts that demonstrates the value of self-management and social support in care delivery; and multidisciplinary clinics in remote, Indigenous areas, despite limited resources. Methodologically rigorous and practical studies addressing important outcomes to demonstrate effectiveness of models of care are needed. In particular, the transition from paediatric to adult care needs further investigation.

Narrative synthesis

Prevalence and problem

A woman with PCOS may face multiple health problems as well as psychological and social distress. She may need to see multiple health care providers such as a general practitioner, dietitian, psychologist, exercise physiologist, endocrinologist, gynaecologist and infertility specialist. This multidisciplinary team approach has been used in the management of a number of chronic diseases and has been credited with improvements in health related outcomes including general wellbeing. However there have been a number of criticisms with the multidisciplinary care model, namely the compartmentalization of patient care and the limited communication between health professionals. Here we suggest a clinical consensus recommendation to offer Interdisciplinary care to women with PCOS. An interdisciplinary care model is “the collaboration between a woman with PCOS and a care team who have shared goals for her total wellbeing”.

Clinical practice gap: need for guidance

The original Australian PCOS guideline recommendation for interdisciplinary care in PCOS was based on consensus because no evidence was identified addressing the effectiveness of interdisciplinary care in women with PCOS. Therefore, more research is needed to document that this model of care is more effective than a single specialist care model. Furthermore, little is known about other models of care, especially those that focus on self-management or provide psychological and social support to women with PCOS and their benefits to disease management.
Summary of key information

The systematic search did not identify any studies addressing the effectiveness of any type of model of care. Four studies were identified as relevant that described models of care in terms of barriers and enablers as well as satisfaction of patients and care providers. One study provides pilot data on the function of a pilot multidisciplinary PCO clinic in an Indigenous remote population (1); the remaining three studies examine the benefits of informational and socio-emotional support as models of care on PCOS outcomes (2-4).

Evaluation data on a PCOS clinic that offered comprehensive evidence-based service to Indigenous women with PCOS in the Torres Strait area of Australia after 12 months of implementation showed that the clinic was largely successful in providing evidence-based care, emotional screening and lifestyle management despite limited resources (1). The services were greatly valued by both patients and health care workers. Barriers to clinic sustainability included staffing limitations, lack of administrative support, funding, high staff turnover and system issues (1).

The role of support groups, as models of care, on PCOS outcomes was examined in two studies (2,3). The first study involved an online peer-support group based in the UK (2). Fifty participants with PCOS responded to a series of open-ended questions via an online survey. Qualitative analysis of the data revealed a range of positive benefits, such as “connecting with people who understand”, access to information and advice, building confidence in interaction with health care professionals, help with treatment related decision-making and improvement in adjustment and management. However, there were also a couple of disempowering experiences such as “reading about the negative experiences of others” and “feeling like an outsider”. The second study reports on the experiences of a nurse–led peer support group from UK (3). Qualitative interviews were conducted in 13 patients. Results revealed that participation in the support group provided opportunities for social comparison and feeling less isolated/more empowered, offered access to relevant information and resulted in direct positive effects on self-management behaviors.

A study from Canada involved 43 women with PCOS who received an educational curriculum on PCOS as part of a research study and then were invited to complete an online questionnaire (4). Participants felt that education about PCOS increased their motivation to implement preventive health management strategies, enhanced their satisfaction with their health care provider and empowered them to participate in the management of their condition.

Conclusions

There are still sparse data on the outcomes of multidisciplinary and interdisciplinary models of care in PCOS, although pilot data suggest that multidisciplinary clinics in remote Indigenous areas can be highly successful albeit limited resources (1). Clearly more research is needed in this area. Specifically to adolescents with PCOS, there was no study addressing outcomes transitioning from paediatric to adult care.

There is a small but growing body of evidence about the value of self-management and social support in care delivery. Specifically, two studies on support groups suggest that peer support groups in PCOS can alleviate patients’ psychosocial distress, provide relevant information and promote self-management activities (2,3). These groups can be led by a heath professional, i.e. a nurse. Online support groups can provide a relative inexpensive and convenient alternative to face-to-face groups.

Structured educational series can increase disease understanding and improve compliance with lifestyle changes (4), and such educational models can be not only clinically relevant but also cost-effective.
What is the effectiveness of different models of care compared to usual care?

**Question details**

**Problem:** Women with PCOS access care from different health care disciplines but not necessarily in a co-ordinated approach.

**Option:** NA

**Comparison:** NA

**Main outcomes:**
- Delivery of a Care Model, Cost Effectiveness (long-term), Patient-defined outcomes (e.g. satisfaction with care), Improved communication (between staff and between staff and patients), Patient Health Outcomes (e.g. improved physical functioning, improved mental functioning), Timely access to care and treatment (efficiency of care), Quality of Life, Self-rated Emotional Wellbeing. Optimal self-management indicators.

**Setting:** Primary care

**Perspective:** Health care provider and patient

**Background**

Women with PCOS frequently face multiple health problems and may see numerous health care providers. This multidisciplinary team approach may lack coordination and communication among providers. Instead, an interdisciplinary care model that calls for “the collaboration between a woman with PCOS and a care team who have shared goals for her total wellbeing” has been recommended. There is little evidence at the moment that the interdisciplinary care model results in better disease outcomes or improvement in quality of life. Furthermore, women with PCOS may suffer psychological and social distress, and thus, benefit from care models that promote informational, psychological and social support. Again, there is lack of evidence about the effectiveness of these models of care compared to standard care.
ASSSESSMENT

**Problem**

**Is the problem a priority?**

Judgement

| Don't know | Varies | No | Probably No | Probably Yes | Yes |

Research evidence

Evidence not sought.

Additional considerations

In chronic illness, models of care are known to influence patient survival, outcomes and quality of life. Identifying models of care that deliver evidence-based care in a cost effective fashion in PCOS are expected to be beneficial for both affected individuals and health care systems.

Panel discussion

All in agreement for judgement.

**Desirable effects**

**How substantial are the desirable anticipated effects?**

Judgement

| Don't know | Varies | Trivial | Small | Moderate | Large |

Research evidence

When a systematic evidence review was conducted, no evidence was identified about the effectiveness of models of care in women with PCOS.

Here we present a narrative review. Literature search resulted in four relevant studies: one study provides pilot data on the function of a pilot multidisciplinary PCOS clinic in an Indigenous remote population (1); the remaining three studies examine the benefits of informational and socio-emotional support as models of care on PCOS outcomes (2-4).

One study involved an online peer-support group based in UK (2) and included fifty participants with PCOS who responded to a series of open ended questions via an on line survey. Qualitative analysis of the data revealed a range of positive benefits, such as “connecting with people who understand”, access to information and advice, building confidence in interaction with health care professionals, help with treatment related decision-making and improvement in adjustment and management.
A study from the UK reports on the experiences of a nurse-led peer support group (3). Qualitative interviews were conducted in 13 patients. Results revealed that participation in the support group provided opportunities for social comparison and feeling less isolated/more empowered, offered access to relevant information and resulted in direct positive effects on self-management behaviors.

A study from Canada involved 43 women with PCOS who received an educational curriculum on PCOS as part of a research study and then were invited to complete an online questionnaire (4). Participants felt that education about PCOS increased their motivation to implement preventive health management strategies, enhanced their satisfaction with their health care provider and empowered to participate in the management of their condition.

Additional considerations
Participants in self-management and psychosocial support programs expressed greater adherence to disease management and a positive impact on overall well-being.

A narrative synthesis of studies describing support groups suggest a range of positive benefits, such as:
- connecting with people who understand
- access to information and advice
- building confidence in interaction with health care professionals
- help with treatment related decision-making
- improvement in adjustment and management
- opportunities for social comparison and feeling less isolated/more empowered, offered
- access to relevant information and resulted in direct
- positive effects on self-management behaviors

An education based model increased motivation to implement preventive health management strategies, enhanced satisfaction with health care providers and empowered participation in the management of their condition.

Panel discussion
All in agreement for judgement.

Undesirable effects
How substantial are the undesirable anticipated effects?

Judgement

| Don't know | Varies | Large | Moderate | Small | Trivial |

Research evidence
See above in ‘Desirable effects’.
Additional considerations

Undesirable effects included “reading about the negative experiences of others” and “feeling like an outsider” (2).

Panel discussion
All in agreement for judgement.

**Certainty of the evidence**

**What is the overall certainty of the evidence of effects?**

**Judgement**

<table>
<thead>
<tr>
<th>No included studies</th>
<th>Very low</th>
<th>Low</th>
<th>Moderate</th>
<th>High</th>
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</thead>
</table>

**Research evidence**

See above in ‘Desirable effects’.

**Additional considerations**
None

**Panel discussion**
All in agreement for judgement.

**Values**

**Is there important uncertainty about, or variability in, how much people value the main outcomes?**

**Judgement**

<table>
<thead>
<tr>
<th>Important uncertainty or variability</th>
<th>Possibly important uncertainty or variability</th>
<th>Probably no important uncertainty or variability</th>
<th>No important uncertainty or variability</th>
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</table>

**Research evidence**

No evidence was identified about the effectiveness of different models of care in women with PCOS. Narrative review of the literature suggests that evaluation data on a PCOS clinic that offered comprehensive evidence based service to Indigenous women with PCOS in the Torres Strait area of Australia after 12 months of operation showed that the services were greatly valued by both patients and health care workers (1).

**Additional considerations**
Information resources, models of care, cultural and linguistic considerations

None.

Panel discussion
All in agreement for judgement.

**Balance of effects**

Does the balance between desirable and undesirable effects favour the option or the comparison?

<table>
<thead>
<tr>
<th>Judgement</th>
<th>Don't know</th>
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<th>Favours the comparison</th>
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<th>Does not favour either the option or the comparison</th>
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</table>

Research evidence
See above.

Additional considerations
See above.

Panel discussion
All in agreement for judgement.

**Resources required**

How large are the resource requirements (costs)?

<table>
<thead>
<tr>
<th>Judgement</th>
<th>Don't know</th>
<th>Varies</th>
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<th>Moderate costs</th>
<th>Negligible costs or savings</th>
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</table>

Research evidence
No evidence was identified about the effects or resource requirements of models of care in women with PCOS.

Additional considerations
Self-management can be facilitated with a structured educational program.
Psychosocial support can be achieved with peer support groups—health care professionals may lead or facilitate the group.

Panel discussion

Multi-disciplinary care with poor communication will increase costs. Interdisciplinary care with optimal integration and communication is likely to reduce costs and improve outcomes.

**Certainty of evidence of required resources**

What is the certainty of the evidence of resource requirements (costs)?

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<tr>
<td>No included studies</td>
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</table>

Research evidence

No evidence was identified about the effects or resource requirements of models of care in women with PCOS.

Additional considerations

None

Panel discussion

All in agreement for judgement.

**Cost-effectiveness**

Does the cost-effectiveness of the option favour the option or the comparison?

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</table>

Research evidence

No evidence was identified about the effects or cost effectiveness of models of care in women with PCOS.

Additional considerations
Information resources, models of care, cultural and linguistic considerations

Models of care that focus on development of educational series or support groups can provide informational and psychosocial support in a relative cost-effective way. The cost of an interdisciplinary care model is harder to assess. Panel discussion

All in agreement for judgement.

**Equity**

**What would be the impact on health equity?**

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<tr>
<th>Judgement</th>
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</table>

**Research evidence**

No evidence was identified about the impact on health equity associated with models of care in women with PCOS.

**Additional considerations**

An Australian study evaluating a clinic’s evidence based service for Aboriginal and Torres Strait Islander women with PCOS emphasized that adaptation of educational resources and longer consultation times are required in order to provide culturally appropriate care. Depending on the culture and family connections the need for group rather than individual consultations was also recommended. Among the cultural barriers were low health literacy, high level of tolerance to problems and unwillingness to see a male physician for comfort reasons.

Even though it does not seem possible at this point to generate evidence based recommendation, expert opinion and limited available data suggest that language is an important barrier for linguistically appropriate care. Sensitivity to patient’s needs, beliefs and cultural predispositions may help overcome communication gap due to linguistics. Panel discussion

Public vs. private funded models, differences in health care systems and settings, including rural and regional areas and developing countries.

**Acceptability**

**Is the option acceptable to key stakeholders?**

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<td>Probably No</td>
<td>Probably Yes</td>
<td>No</td>
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<td></td>
</tr>
</tbody>
</table>

**Research evidence**

No evidence to inform this criterion.

**Additional considerations**
The services of a comprehensive PCOS clinic for indigenous women with PCOS were greatly valued by both patients and health care workers.

Panel discussion
Might be different depending on acceptability of interdisciplinary care. Cost, healthcare systems and resources all effect acceptability. Women's expectations may also impact.

**Feasibility**

Is the option feasible to implement?

<table>
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<tr>
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<tbody>
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<td>Probably No</td>
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<tr>
<td>Probably Yes</td>
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<tr>
<td>Yes</td>
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</tbody>
</table>

Research evidence

No evidence was identified about feasibility of models of care in women with PCOS in a systematic evidence review. Narrative review of the literature suggests that evaluation data on a PCOS clinic that offered comprehensive evidence based service to indigenous women with PCOS in the Torres Strait area of Australia after 12 months of operation showed that the clinic was largely successful in providing evidence-based care, emotional screening and lifestyle management despite limited recourses (1). The services were greatly valued by both patients and health care workers. Barriers to clinic sustainability included staffing limitations, lack of administrative support, funding, high staff turnover and system issues (1).

Additional considerations

Models of care that incorporate on line support groups can be cost effective.
Interdisciplinary models of care have been used for care of patients with cancer and other chronic conditions.
Feasibility would vary based on the intervention and proposed model of care. Models of care that are focused on support groups, especially, on line support groups, can be easy to implement.

Panel discussion
Might be different depending on acceptability of interdisciplinary care. Cost, healthcare systems and resources all affect feasibility. Women's expectations may also impact.
CONCLUSIONS

Consensus recommendations
Interdisciplinary care should be offered to adolescents and adults with PCOS as needed.
Care should be provided in partnership with women.

Judgement

<table>
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<th>Strong recommendation against the option</th>
<th>Conditional recommendation against the option</th>
<th>Conditional recommendation for either the option or the comparison</th>
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</table>

Justification
There are still sparse data on the outcomes of multidisciplinary and interdisciplinary models of care in PCOS, although pilot data suggest that multidisciplinary clinics in remote indigent areas can be highly successful albeit limited resources (1). Clearly more research is needed in this area. Specifically to adolescents with PCOS, there was no study addressing outcomes transitioning from paediatric to adult to adult care.

There is a small but growing body of evidence about the value of self-management and social support in care delivery. Specifically, two studies on support groups suggest that peer support groups in PCOS can alleviate patients’ psychosocial distress, provide relevant information and promote self-management activities (2,3). These groups can be led be a health professional, i.e. a nurse. On line support groups can provide a relative inexpensive and convenient alternative to face-to-face groups. Structured educational series can increase disease understanding and improve compliance with lifestyle changes (4), and such educational models can be not only clinically relevant but also cost-effective.

The development of new models of care should involve stakeholder consultation (both women and healthcare providers) during the design and evaluation stages.

Subgroup considerations
There was no study focused on adolescents with PCOS.

Implementation considerations
Professional societies may consider providing educational webinars to patients and health care providers or develop PCOS educational curricula to be disseminated to various programs.

It is important to emphasise that women with PCOS and healthcare providers should be involved during the design of any model of care. This could mean inclusion of a stakeholder consultation phase or a more formal co-design/co-development role.

Monitoring and evaluation
Patient questionnaires before and after intervention.
Disease outcomes before and after intervention among various clinics/programs.
Healthcare provider questionnaires before and after intervention.

Referral patterns on health administrative datasets.

**Research priorities**

There is still need in PCOS for studies comparing various models of care with end-points various disease outcomes, quality of life and cost effectiveness.

The studies need to include both adolescent and women with PCOS in diverse populations and settings.
List of included studies

### Appendix I: Methods

#### PICO/selection criteria

<table>
<thead>
<tr>
<th>RANK: 5</th>
<th>Participants (P)</th>
<th>Intervention (I)</th>
<th>Comparison (C)</th>
<th>Outcomes (O)</th>
<th>Study type</th>
<th>Limits</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Females of any age, ethnicity or weight diagnosed with PCOS (by Rotterdam, NIH or AES). Subgroups: • Adolescents • Phenotypes • Ethnicity • Geographical</td>
<td>Models of care (collaboration between disciplines – biopsychosocial approach to wellbeing) Note where defined. Include: interdisciplinary, integrated primary or specialist care; transition of care; individually tailored care plans; self management.</td>
<td>Usual care or others</td>
<td>Delivery of a Care Model, Cost Effectiveness (long-term), Patient-defined outcomes (e.g. satisfaction with care), Improved communication (between staff and between staff and patients), Patient Health Outcomes (e.g. improved physical functioning, improved mental functioning), Timely access to care and treatment (efficiency of care), Quality of Life, Self-rated Emotional Wellbeing. Optimal self-management indicators.</td>
<td>Evidence based guidelines, systematic reviews, any primary study.</td>
<td>English language. Update original search (not addressed in WHO GL).</td>
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#### Inclusion criteria

- Females without diagnosed PCOS.

#### Exclusion criteria

- Females without diagnosed PCOS.

Outcomes (O) include delivery of a care model, cost effectiveness (long-term), patient-defined outcomes (e.g. satisfaction with care), improved communication (between staff and between staff and patients), patient health outcomes (e.g. improved physical functioning, improved mental functioning), timely access to care and treatment (efficiency of care), quality of life, self-rated emotional wellbeing, optimal self-management indicators.
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NARRATIVE REVIEW: Access to culturally and linguistically diverse appropriate care

Prevalence of the problem
PCOS is a common disorder and worldwide population of PCOS includes patients with a diverse social and linguistic background. There are cultural variations in how patients perceive their disease, although this contact’s experience and personal communication with other experts suggest there are more similarities across ethnic/racial/geographic groups than dissimilarities for women with PCOS.

Clinical practice gap: need for guidance
It is important to determine and address cultural and linguistic factors that could influence access of patients to appropriate care. We should note that language is an obvious barrier to appropriate care.

Summary of key information
Although data are scarce in the literature on provision and need for culturally and linguistically competent medical care in PCOS there are a few studies that could guide the development of recommendations.

An Australian study evaluating a clinic’s evidence based service for Aboriginal and Torres Strait Islander women with PCOS emphasized that adaptation of educational resources and longer consultation times are required in order to provide culturally appropriate care. Depending on the culture and family connections the need for group rather than individual consultations was also recommended. Among the cultural barriers were low health literacy, high level of tolerance to problems and unwillingness to see a male physician for comfort reasons (1).

A study looking at implications of participation in a clinical trial of PCOS reported that women with PCOS felt they had more knowledge and motivation in the management of their condition (2). Similarly, peer to peer online support and participation in a nurse-led peer support group appears to help access to information, advice and appropriate care (3,4).

A recent online survey of women with PCOS from 32 countries reported that there is a delayed diagnosis and lack of information associated with dissatisfaction in women with PCOS (5).

We should note that all studies above are limited to English-speaking women. It would be of interest to look at potential contribution of diverse cultural backgrounds to dissatisfaction of women in the last study as well as whether these results could be extrapolated to women with PCOS speaking other languages.

Recommendations

CLINICAL CONSENSUS RECOMMENDATION
At this point the GDG was unable to generate evidence based recommendation. Limited available data suggest that language is an important barrier for linguistically appropriate care. Sensitivity to patient’s needs, beliefs and cultural predispositions may help overcome communication gap due to linguistics.

RESEARCH RECOMMENDATION
Studies looking at potential interaction of cultural differences and appropriate care for PCOS in various populations including women speaking languages other than English are needed.
Information resources, models of care, cultural and linguistic considerations

GRADe framework

Interactive Evidence to Decision Framework

Access to culturally and linguistically diverse appropriate care

Background

PCOS is a common disorder and worldwide population of PCOS includes patients with a diverse social and linguistic background. There are cultural variations in how patients perceive their disease, although this contact’s experience and personal communication with other experts suggest there are more similarities across ethnic/racial/geographic groups than dissimilarities for women with PCOS.

ASSESSMENT

Problem

Is the problem a priority?

Judgement

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Research evidence

PCOS is a common disorder and the worldwide population of PCOS includes patients with a diverse social and linguistic background. There are cultural variations in how patients perceive their disease, although experience among clinical experts suggest there are more similarities across ethnic/racial/geographic groups than dissimilarities for women with PCOS.

Additional considerations

None.

Panel discussion

All in agreement for judgement.

Desirable effects

How substantial are the desirable anticipated effects?

Judgement

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</table>

Research evidence

There is very limited literature on provision and need for culturally and linguistically competent medical care in PCOS.

An Australian study evaluating a clinic’s evidence-based service for Aboriginal and Torres Strait Islander women with PCOS emphasized that adaptation of educational resources and longer consultation times are required in order to provide culturally appropriate care. Depending on the culture and family connections the need for group rather than individual consultations was also recommended. Among the cultural barriers were low health literacy, high level of tolerance to problems and unwillingness to see a male physician for comfort reasons (1).

A study looking at implications of participation in a clinical trial of PCOS reported that women with PCOS felt they had more knowledge and motivation in the management of their condition (2). Similarly, peer to peer online support and participation in a nurse-led peer support group appears to help access to information, advice and appropriate care (3,4).
A recent online survey of women with PCOS from 32 countries reported that there is a delayed diagnosis and lack of information associated with dissatisfaction in women with PCOS (5).

Additional considerations
None.

Panel discussion
All in agreement for judgement.

Undesirable effects
How substantial are the undesirable anticipated effects?

Judgement

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</table>

Research evidence
See above in ‘Desirable effects’.

Additional considerations
None

Panel discussion
All in agreement for judgement.

Certainty of the evidence
What is the overall certainty of the evidence of effects?

Judgement

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Research evidence
See above in ‘Desirable effects’.

Additional considerations
None

Panel discussion
All in agreement for judgement.

Values
Is there important uncertainty about, or variability in, how much people value the main outcomes?

Judgement

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Research evidence
The literature is not available to address this criterion.
**Balance of effects**

Does the balance between desirable and undesirable effects favour the intervention or the comparison?

**Judgement**

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**Research evidence**

See above.

**Additional considerations**

None

**Panel discussion**

All in agreement for judgement.

**Resources required**

How large are the resource requirements (costs)?

**Judgement**

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</table>

**Research evidence**

The literature is not available to address this criterion.

**Additional considerations**

None

**Panel discussion**

All in agreement for judgement. Local resources should be engaged to support this recommendation. Whilst some costs are anticipated, principles are consistent with optimal patient care.

**Certainty of evidence of required resources**

What is the certainty of the evidence of resource requirements (costs)?

**Judgement**

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</table>

**Research evidence**
Information resources, models of care, cultural and linguistic considerations

The literature is not available to address this criterion.

Additional considerations
None

Panel discussion
All in agreement for judgement.

Cost-effectiveness

Does the cost-effectiveness of the intervention favour the intervention or the comparison?

Judgement

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</table>

Research evidence

The literature is not available to address this criterion.

Additional considerations
None

Panel discussion
All in agreement for judgement.

Equity

What would be the impact on health equity?

Judgement

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</table>

Research evidence

None

Additional considerations
It is important to determine and address cultural and linguistic factors that could influence access of patients to appropriate care. We should note that language is an obvious barrier to appropriate care.

Panel discussion
All in agreement for judgement. Women with PCOS internationally have a right to culturally and linguistically appropriate evidence-based care.

Acceptability

Is the intervention acceptable to key stakeholders?

Judgement

<table>
<thead>
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120
Information resources, models of care, cultural and linguistic considerations

Research evidence
The literature is not available to address this criterion.

Additional considerations
Women with PCOS internationally have a right to culturally and linguistically appropriate evidence-based care.

Panel discussion
All in agreement for judgement.

Feasibility

Is the intervention feasible to implement?

Judgement

| | Don't know | Varies | No | Probably No | Probably Yes | Yes |

Research evidence
The literature is not available to address this criterion.

Additional considerations
None

Panel discussion
All in agreement for judgement. Varies according to local context.
Information resources, models of care, cultural and linguistic considerations_ cultural and linguistic considerations

CONCLUSIONS

Consensus recommendation

Sensitivity to patient’s needs, communication, beliefs and cultural predispositions should be considered and addressed through provision of culturally and linguistically appropriate care.

Judgement

<table>
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<tr>
<th>Strong recommendation against the intervention</th>
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Practice point

Active involvement of international societies to increase engagement.

Justification

Clinical similarities in the condition are acknowledged irrespective of culture and racial influences.

Culturally appropriate care involves more than linguistic considerations and is just as important for women who speak English but are not of the cultural majority.

Subgroup considerations

Implementation considerations

Everyone involved in the dissemination and implementation of this guideline must consider culturally and linguistically appropriate delivery to suit individual patients' needs and beliefs.

Broad international consultation with women with PCOS, professional societies and stakeholders must inform the dissemination and implementation of this guideline.

Monitoring and evaluation

International evaluation of the guideline should include aspects of cultural and linguistic appropriateness.

Research priorities

We should note that all studies above are limited to English-speaking women. It would be of interest to look at potential contribution of diverse cultural backgrounds to dissatisfaction of women in the last study as well as whether these results could be extrapolated to women with PCOS speaking other languages.

Studies looking at potential interaction of cultural differences and appropriate care for PCOS in various populations including women speaking languages other than English are needed.

References


3. Holbrey S, Coulson NS. A qualitative investigation of the impact of peer to peer online support for women living with polycystic ovary syndrome. BMC women’s health 2013; 13:51
EVIDENCE AND NARRATIVE REVIEW: Is acupuncture effective for management and support of depression and/or anxiety, disordered eating, body image distress, self-esteem, feminine identity or psychosexual dysfunction in women with PCOS?

(No studies identified by the search so key contacts prepared a narrative review. No recommendations have been made from this evidence review.)

Narrative synthesis

Clinical need for the question

With a high prevalence of depression and/or anxiety, disordered eating, body image distress, self-esteem, feminine identity or psychosexual dysfunction (Lee, Cooney et al. 2017, Cooney 2017), it is of importance to alleviate psychiatric symptoms and to prevent long-term physical and psychiatric complications. First line treatment of women with PCOS is lifestyle intervention focusing on diet and exercise. One alternative treatment to alleviate these symptoms could be acupuncture.

Clinical practice gap: need for guidance

Acupuncture and counselling for patients presenting with depression in primary care has been shown to reduced depression at 3 months when compared to usual care alone with no difference between acupuncture and counselling (MacPherson, Richmond et al. 2013). Acupuncture has also been shown to improve of major depression disorder in women (Luo, Jia et al. 1985, Luo, Meng et al. 1998, Yeung, Chung et al. 2011, Gronier, Letombe et al. 2012), and in women with depression during pregnancy (Manber, Schnyer et al. 2004, Manber, Schnyer et al. 2010). In women with breast cancer, 12 weeks of acupuncture improved HRQoL and sleep assessed with the Women’s Health Questionnaire (Frisk, Kallstrom et al. 2011), general well-being assessed with the Symptom Checklist and mood assessed with the Mood Scale (Nedstrand, Wyon et al. 2006).

Acupuncture has been found to improve some PCOS related symptoms (Jedel, Labrie et al. 2011, Johansson, Redman et al. 2013), an effect that is partly mediated via modulation of sympathetic nerve activity (Stener-Victorin, Jedel et al. 2009). Although there are a few studies indicating that acupuncture may improve symptoms of anxiety and depression in non-PCOS patients, only two randomized controlled trials studies has investigated the effects of acupuncture in women with PCOS (Stener-Victorin, Holm et al. 2013, Jin, Pang et al. 2016).

Sixteen weeks of acupuncture treatment, twice a week for 2 weeks and thereafter once per week, in women with PCOS resulted in a modest improvement in symptoms of anxiety measured with Brief Scale for Anxiety (BAS) at follow up 4 months after last acupuncture treatment, with no effect in the exercise and no intervention groups (Stener-Victorin, Holm et al. 2013). Symptoms of depression measured by Montgomery Åsberg Depression Rating Scale (MADRS-S) was unaffected. In the second study, acupuncture treatment 3 times per week during 3 months significantly reduced the scores of somatization, interpersonal sensitivity, depression, anxiety and hostility in the symptom checklist-90 (SCL-90) and improved more than Diane 35 for 3 months (Jin, Pang et al. 2016). These data suggest continued investigation of the effect of acupuncture on symptoms of anxiety and depression in women with PCOS. None of the studies reported any negative side-effects.

No studies on acupuncture and disordered eating, body image distress, self-esteem, feminine identity or psychosexual dysfunction in women with PCOS has been found.

Summary of key information

There are currently no evidence for the use of acupuncture in for management and support of depression and/or anxiety, disordered eating, body image distress, self-esteem, feminine identity or psychosexual dysfunction.
Recommendation

RESEARCH RECOMMENDATION
Methodological rigorous trials in women with PCOS with especially symptoms of depression and/or anxiety are important to elucidate whether acupuncture relieve these symptoms as primary outcomes.

References


### Appendix I: Methods

#### PICO/selection criteria

<table>
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<tr>
<th>Ranked</th>
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<th>Participants (P)</th>
<th>Intervention (I)</th>
<th>Comparison (C)</th>
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<td>Females of any age, ethnicity or weight diagnosed with PCOS (by Rotterdam, NIH or AES). Subgrouped by: diagnosed depression and/or anxiety, disordered eating, body image distress and/or psychosexual dysfunction using a different screening tool than that used for outcomes. Subgroups:  - Adolescents  - Ethnicity  - Phenotype If no evidence in PCOS, relevant evidence will be sought narratively by key contact (not searched by evidence team).</td>
<td>Acupuncture including manual and electrical stimulation, any needle placement and depth of needle insertion</td>
<td>Placebo or psychological or pharmacological i.e. OCP, metformin, flutamide; lifestyle interventions including diet and exercise.</td>
<td>Changes in depression and/or anxiety, disordered eating, body image distress, self-esteem, feminine identity and/or psychosexual dysfunction. Self-management indicators.</td>
<td>Evidence based guidelines, systematic reviews, health technology assessment s, randomised controlled trials.</td>
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#### Inclusion criteria

- Females of any age, ethnicity or weight diagnosed with PCOS (by Rotterdam, NIH or AES).
- Subgrouped by: diagnosed depression and/or anxiety, disordered eating, body image distress and/or psychosexual dysfunction using a different screening tool than that used for outcomes.
- Subgroups:
  - Adolescents
  - Ethnicity
  - Phenotype
- If no evidence in PCOS, relevant evidence will be sought narratively by key contact (not searched by evidence team).

#### Exclusion criteria

- Females without diagnosed PCOS.
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11 or/1-10
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13 exp Acupuncture/
14 exp Trigger Points/
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Screened 155
Excluded based on T & A 125
Excluded based on full text 30
Unable to retrieve full text 0
Included 0
EVIDENCE AND NARRATIVE REVIEW: Is psychological therapy effective for management and support of depression and/or anxiety, disordered eating, body image distress, self-esteem, feminine identity or psychosexual dysfunction in women with PCOS?
(Insufficient evidence identified by the search so key contacts prepared a narrative review. No recommendations have been made from this evidence review.)

Summary

One RCT was identified by the systematic search. It compared a mindfulness stress management program to no intervention and measured stress, anxiety, depression and quality of life in 46 women with PCOS (23 in mindfulness group and 15 in control group). Statistically significant difference between groups for DASS21 depression and stress subscales; and total life and general satisfaction. Authors conclude that their pilot results are promising for “ameliorating stress, anxiety, depression and the quality of life in women with PCOS and could be used as an adjunct method to the conventional management of these women”.

Narrative synthesis

Mental Health Disorders

Women with PCOS have a higher prevalence of clinically significant self-reported symptoms of depression, anxiety and eating disorders. Available research also suggests that women with PCOS have higher prevalence of depressive disorders, anxiety disorders and eating disorders as diagnosed by a psychiatrist using structured clinical interview.

In a recent systematic review and meta-analyses (N=30) women with PCOS had increased odds of any depressive symptoms (OR: 3.78; 95% CI: 3.03–4.72; 18 studies) and of moderate/severe depressive symptoms (OR: 4.18; 95% CI: 2.68–6.52; 11 studies). Women with PCOS had increased odds of any anxiety symptoms (OR: 5.62; 95% CI: 3.22–9.80, nine studies) and of moderate/severe anxiety symptoms (OR: 6.55; 95% CI: 2.87, 14.93; five studies). When subjects were matched on BMI, women with PCOS still had higher odds of both depressive (OR: 3.25; 95% CI 1.73–6.09; four studies) and anxiety symptoms (OR: 6.30, 95% CI: 1.88–21.09; three studies). There was no substantial heterogeneity among studies in the overall MA on depressive symptoms ($I^2 = 22.4\%, P = 0.19$), but there was significant heterogeneity among studies in the analysis on anxiety symptoms ($I^2 = 59.6\%, P = 0.01$). (Cooney et.al. 2017). Most studies used self-report tools. The two studies which in which mental illness was diagnosed by a psychiatrist also reported elevated levels of depressive disorders and anxiety disorders (Mansson et al., 2008; Sayyah-Melli et al., 2015).

In a recent systematic review and meta-analyses (n=8) women with PCOS had higher odds of having abnormally elevated ED scores when compared to controls (OR 3.05; 95% CI 1.33, 6.99; 4 studies) (Figure 2A). In three of the four studies, the women with PCOS had a higher mean BMI than the controls. Women with PCOS also had higher odds of having any ED diagnosis compared to controls (OR 3.87; 95% CI 1.43, 10.49; 4 studies) (Figure 2B). Of the studies reporting the prevalence of specific ED diagnoses, only one used a diagnostic tool, the MINI (Månsson et al., 2008). The remaining studies used screening tools and assessed for fulfillment of diagnostic criteria based on the survey answers provided (Bernadett & Szymán-N, 2016; Karacan et al., 2014; Larsson et al., 2016; Lee et al., 2017). In all studies, the women with PCOS had a higher mean BMI than the controls. No studies identified any cases of AN, and none reported data on EDNOS. The odds of BN (OR 2.23; 95% CI 0.66, 7.55; 3 studies, Figure 2C) and BED
A range of psychological options are effective for the treatment of depressive disorders, anxiety disorders, and eating disorders. The choice of treatment is dependent on participant characteristics (e.g., age), diagnosis and symptoms severity, and available resources.

Local clinical practice guidelines typically provide guidance regarding identification, assessment and treatment for these disorders. They typically include information about treatment sequencing when multiple mental health disorders (or comorbid symptoms) are present, matching treatment intensity to symptoms severity including using stepped care treatment models, and consideration of physical health conditions when treating mental health disorders.

Links to some relevant guidelines are provided below.

- National Health and Medical Research Centre: [https://www.clinicalguidelines.gov.au/](https://www.clinicalguidelines.gov.au/)

### Mental Health Symptoms

There is no study investigating prevalence of body image distress in women with PCOS. One study demonstrated that women with PCOS, compared with control women, had a negative body image in 7 out of 10 subscales of the validated Multidimensional Body-Self Relations Questionnaire (3). Women with PCOS appear to feel less physically attractive, healthy or physically fit and are less satisfied with their body size and appearance than women without PCOS (4). Infertile women with PCOS have lower self-esteem and body satisfaction as measured with the Body Image Concern Inventory (BICI) than non-infertile women with PCOS (5). Further, hirsute women experienced lower self-esteem than non-hirsute women, and women with menstrual irregularities and higher BMI had more body dissatisfaction (5).

The prevalence of psychosexual dysfunction varies from 13.3% to 62.5% in PCOS patients [2-5]. It appears that women with PCOS suffer from greater psychosexual dysfunction than women in the general population in most studies [6]. Whilst there is limited quality research in this area, studies [6-8] do show a correlation between PCOS and reduced QoL, sexual satisfaction and feminine identity. Physical PCOS symptoms such as hirsutism, obesity, menstrual irregularity and infertility may cause loss of feminine identity and a feeling of being unattractive which may impact on sexuality [6,7,9]. Women with PCOS also report less sexual satisfaction and lower sexual self-worth than women without PCOS and sexual dysfunction impacts more on relationships in women with PCOS [10]. Overall, psychosexual dysfunction appears to be more
common in women with PCOS, may be an important issue for the individual woman and is likely to impact on QoL and relationships. Till now, there was only one study [3] published in 2013 showed that the prevalence of sexual dysfunction in the PCOS group was similar to general population (25% vs 19%; P=0.54), and no significant difference was found according to each domain score of female sexual function index (FSFI).

Of note, negative body image, low self-esteem and psychosexual dysfunction are core features and/or common comorbidities of depressive, anxiety and eating disorders. Therefore these symptoms are likely to improve if depressive, anxiety or eating disorders are successfully treated.

There are no broadly accepted guidelines for the treatment of body image distress, self-esteem, feminine identity or psychosexual dysfunction. Therefore psychological treatment of these mental health symptoms should be guided by the results of systematic reviews and meta-analyses where available, or where they are not available high quality randomised controlled trials.

**Body Image:** Empirical support has been established for the effectiveness of body image cognitive-behavioural (BI-CBT) interventions in treating negative body image. For example, a meta-analysis of 19 stand-alone body image cognitive behaviour therapies (CBT) found that CBT was effective in improving attitudinal and behavioural aspects of body image, as well as associated depression, anxiety, self-esteem and eating attitudes and behaviour in both clinical (e.g., individuals with eating disorders) and non-clinical samples (Jarry & Ip, 2015). A more recent meta-analysis of 63 stand-alone BI interventions (predominantly cognitive-behavioural based) also concluded that interventions resulted in small to medium improvements in body image and beauty ideal, and a large impact on body ideal internalisation. Effect sizes were larger when studies: (1) used a group intervention format rather than individual interventions, (2) were facilitated (rather than self-help), and (3) were conducted across multiple sessions. Thirty-one treatment strategies used in these studies; twelve of these strategies (e.g., monitoring and restructuring of cognitions, exposure exercises) were associated with larger body image improvements, and three were associated with poorer body image (e.g., self-esteem exercises, discussing physical activity; Alleva, Sheeran, Webb, Martijn, & Miles, 2015).

**Self-esteem:** There is surprising little research examining stand-alone interventions for low self-esteem. The few published studies evaluate a cognitive behavioural treatment program (M. Fennell, 2006) based on a cognitive conceptualisation of low self-esteem (M. J. V. Fennell, 1997). In one of the only randomised controlled trials of this intervention, a 10-session individual program resulted in greater improvements in self-esteem, overall functioning, depressive symptoms and number of psychiatric illnesses at the end of treatment. Improvements were maintained at 11 week follow-up. A second study evaluated this program delivered in a 10-session group format. Following treatment participants reported improvements in self-esteem and symptoms of depression and anxiety. Improvements were maintained at 3-month follow-up. This program is available for use in a self-help format (M. Fennell, 2006).

**Recommendations**

Women with PCOS with depressive, anxiety, and/or eating disorders should be offered treatment guided by regional clinical practice guidelines.

Women with PCOS with disordered eating, body image distress, self-esteem, problems with feminine identity or psychosexual dysfunction may be offered cognitive behavioural treatment where appropriate.
If multiple mental health disorders are present (i.e., depression, anxiety, eating disorders), rather than psychosocial symptoms (i.e., disordered eating, body image distress, self-esteem, feminine identity or psychosexual dysfunction) psychiatric treatment should be prioritised.
Is psychological therapy effective for management and support of depression and/or anxiety, disordered eating, body image distress, self-esteem, feminine identity or psychosexual dysfunction in women with PCOS?

QUESTION

Question details

Population: Women with PCOS
Option: Psychological therapy

Main outcomes:
- Depression
- Anxiety
- Eating Disorders/Disordered Eating
- Body Image Distress
- Low Self-Esteem
- Feminine Identity
- Psychosocial Dysfunction

Setting: Primary and specialist care
Perspective: Patients and health professionals

Background

Women with PCOS are at increased risk of experiencing depression, anxiety, eating disorders/disordered eating, body image distress, low self-esteem, difficulties with feminine identity and psychosexual dysfunction. Each of these conditions are associated with significant distress and impairment and thus warrant treatment. These conditions are also likely to impact on the outcomes of treatments for women with PCOS which makes provision of effective treatment for these conditions even more important.

An evidence review was conducted and one study with a small sample size was identified. There is insufficient evidence about effectiveness of psychological therapy in women with PCOS, therefore the literature about psychological therapy in the general population has been used to inform this consensus recommendation.
ASSESSMENT

Problem

Is the problem a priority?

Judgement

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</table>

Research evidence

Women with PCOS are at increased risk of experiencing depression, anxiety, eating disorders/disordered eating, body image distress, low self-esteem, difficulties with feminine identity and psychosexual dysfunction. Each of these conditions are associated with significant distress and impairment and thus warrant treatment. These conditions are also likely to impact on the outcomes of treatments for women with PCOS which makes provision of effective treatment for these conditions even more important.

There is insufficient evidence about effectiveness of psychological therapy in women with PCOS.

Numerous empirically supported treatments (e.g., cognitive behaviour therapy, behaviour therapy, interpersonal therapy) are available for the treatment of depression, anxiety, eating disorders/disordered eating in the general population. These treatments result in clinically significant improvements in the condition and associated distress and impairment, as well as broader improvements including quality of life and social functioning. These interventions have also been shown to be cost-effective.

Available research suggests that psychological treatment, particularly cognitive behaviour therapy, is effective in improving body image distress and low self-esteem. These treatments have been shown to improve the condition and associated distress and impairment. Cost-effectiveness of these interventions has not been assessed.

There is little evidence of negative effects of empirically supported psychosocial treatments for these conditions. Most empirically supported treatments are delivered over multiple sessions (typically 10 - 20), this intensity of treatment is often not available in public health care systems and/or funded by private health insurance. Additionally, attrition from treatment can be high (up to 30%). Therefore there is a risk that women will not receive a full dose of treatment. Empirically supported interventions may not be available in some areas. Other undesirably effects might include women with PCOS receiving non-empirically supported treatments which may be ineffective or even harmful.

Additional considerations

None.

Panel discussion

All in agreement for judgement.

Desirable effects

How substantial are the desirable anticipated effects?

Judgement
Research evidence

There is insufficient evidence about effectiveness of psychological therapy in women with PCOS. One RCT was identified by the systematic search. It compared a mindfulness stress management program to no intervention and measured stress, anxiety, depression and quality of life in 46 women with PCOS (23 in mindfulness group and 15 in control group). Statistically significant difference between groups for DASS21 depression and stress subscales; and total life and general satisfaction. Authors conclude that their pilot results are promising for “ameliorating stress, anxiety, depression and the quality of life in women with PCOS and could be used as an adjunct method to the conventional management of these women.

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Additional considerations

None.

Panel discussion

All in agreement for judgement.

Undesirable effects

How substantial are the undesirable anticipated effects?

Judgement
See above in ‘Desirable effects’.

Additional considerations
None.

Panel discussion
All in agreement for judgement.

_Certainty of the evidence_

What is the overall certainty of the evidence of effects?

Judgement

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Research evidence
See above in ‘Desirable effects’.

Additional considerations
None.

Panel discussion
All in agreement for judgement.

_Values_

Is there important uncertainty about, or variability in, how much people value the main outcomes?

Judgement

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Research evidence
Insufficient evidence to address this criterion.

Additional considerations
Psychological therapy

Panel discussion
All in agreement for judgement.

**Balance of effects**

Does the balance between desirable and undesirable effects favour the intervention or the comparison?

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Research evidence
See above in ‘Desirable effects’.

Additional considerations
None.

Panel discussion
All in agreement for judgement.

**Resources required**

How large are the resource requirements (costs)?

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Research evidence
Insufficient evidence to address this criterion.

Additional considerations
None
Panel discussion
All in agreement for judgement.

Certainty of evidence of required resources
What is the certainty of the evidence of resource requirements (costs)?
Judgement

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Research evidence
Insufficient evidence to address this criterion.

Additional considerations
None

Panel discussion
All in agreement for judgement.

Cost-effectiveness
Does the cost-effectiveness of the intervention favour the intervention or the comparison?
Judgement

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Research evidence
Insufficient evidence to address this criterion.

Additional considerations
None

Panel discussion
Equity
What would be the impact on health equity?

Judgement

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Research evidence
Insufficient evidence to fully assess this criterion.

Additional considerations
None

Panel discussion
All in agreement for judgement.

Acceptability
Is the intervention acceptable to key stakeholders?

Judgement

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Research evidence
Insufficient evidence to address this criterion.

Additional considerations
None

Panel discussion
All in agreement for judgement.

Feasibility
### Is the intervention feasible to implement?

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</table>

**Research evidence**
Insufficient evidence to address this criterion.

**Additional considerations**
None

**Panel discussion**
All in agreement for judgement.
CONCLUSIONS

Consensus recommendation
If treatment is warranted, psychological therapy and/or pharmacological treatment should be offered, informed by regional clinical practice guidelines. *(Will be grouped in guideline with recommendations listed in prevalence framework)*

Judgement

| Strong recommendation against the intervention | Conditional recommendation against the intervention | Conditional recommendation for either the intervention or the comparison | Conditional recommendation for the intervention | Strong recommendation for the intervention |

Practice point
Women with PCOS diagnosed with depressive, anxiety, and/or eating disorders should be offered psychological therapy and/or pharmacological treatment guided by the woman's preference and local clinical practice guidelines.

Justification
Treatment of depression, anxiety, eating disorders/disordered eating should be guided by local clinical practice guidelines. These guidelines typically provide guidance regarding identification, assessment and treatment (including treatment sequencing) for these disorders.

Links to some relevant guidelines are provided below.
- National Institute of Mental Health: https://www.nimh.nih.gov/health/index.shtml
- American Psychiatric Association
- National Health and Medical Research Centre: https://www.clinicalguidelines.gov.au/
Of note, negative body image, low self-esteem and psychosexual dysfunction are core features and/or common comorbidities of these disorders. Therefore, these symptoms are likely to improve if depression, anxiety or eating disorders are successfully treated.

If mental health disorders are present, psychiatric disorders (i.e., depression, anxiety, eating disorders/disordered eating), rather than psychosocial symptoms (i.e., body image distress, self-esteem, feminine identity or psychosexual dysfunction) medical assessment and therapy should be prioritised for treatment over.

There are no broadly accepted guidelines for the treatment of body image distress, self-esteem, feminine identity or psychosexual dysfunction. Treatment of body image distress, self-esteem, feminine identity or psychosexual dysfunction should be guided by the results of systematic reviews and meta-analyses where available, or where they are not available high quality randomised controlled trials.

Negative body image should be treated with a cognitive-behavioural body image intervention.

Low self-esteem should be treated with a cognitive-behavioural body image intervention.

**Subgroup considerations**

**Implementation considerations**

Time consuming

Cost effectiveness

**Monitoring and evaluation**

Time consuming

**Research priorities**

Need studies examining the impact of CBT on depression, anxiety and ED specifically in women with PCOS.
### Psychological therapy

#### Appendix I: Methods and evidence review

### PICO/selection criteria

<table>
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<tr>
<th>Ranked</th>
<th>Participants (P)</th>
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<td>Females of any age, ethnicity or weight diagnosed with PCOS (by Rotterdam, NIH or AES). Diagnosed depression and/or anxiety, disordered eating, body image distress and/or psychosexual dysfunction using any standardised assessment. Subgroups: • Adolescents • Ethnicity • Phenotype If no evidence in PCOS, relevant evidence will be sought narratively by key contact (not searched by evidence team).</td>
<td>Psychological therapy including: • Acceptance and commitment therapy • Compassionate mind training • Functional analytic psychotherapy • Behavioural activation • Metacognitive therapy • Mindfulness-based cognitive therapy (MBCT) • Dialectical behaviour therapy (DBT) • Psychodynamic therapies • Behavioural therapies • Humanistic therapies • Interpersonal, cognitive analytic and other integrative therapies • Cognitive-behavioural therapies</td>
<td>Placebo • Wait list control • Usual care • Medication • Lifestyle intervention</td>
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<td>Evidence based guidelines, systematic reviews, health technology assessments, randomised controlled trials.</td>
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Duplicates removed over total 24

Screened 166

Excluded based on T & A 162

Excluded based on full text 3

Unable to retrieve full text 0

Included 1
Characteristics of included study

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<tr>
<th>Study ID</th>
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<th>Setting</th>
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<tr>
<td>Stefanaki 2015</td>
<td>Low</td>
<td>RCT</td>
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<td>C: 15</td>
<td>I: 23</td>
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<td>C: 23.7±4.4</td>
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Results of individual study

**DASS 21 (depression, anxiety, stress scales) questionnaire**

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**PSS-14 (perceived stress scale) questionnaire**

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**PCOSQ (polycystic ovary syndrome health-related quality of life) questionnaire**

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**Routine-daily life questionnaire**

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<td>I: 63.8±9.67</td>
<td>I: 26.95±5.34</td>
<td>I: 16.6±3.14</td>
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<td></td>
<td>C: 36.2±7.66</td>
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No adverse events in either group.
List of included studies

EVIDENCE AND NARRATIVE REVIEW: Are anti-depressants and anxiolytics effective for management and support of depression and/or anxiety or disordered eating in women with PCOS?

(No studies identified by the search so key contacts prepared a narrative review. No recommendations have been made from this evidence review.)

Narrative synthesis

There are a significant number of studies now demonstrating the prevalence of depression and anxiety disorders as well as eating disorders in women diagnosed with PCOS. Consideration of the available treatments is from a clinical practice perspective, as the evidence base from clinical trials of psychotropic medications in PCOS is lacking.

Antidepressants and the Management of Mood Disorder in Women with PCOS

Mood disorders is the broad term that encapsulates bipolar mood disorder, major depressive disorder, premenstrual dysphoric disorder, dysthymic disorder (which is a type of subclinical depression) and persistent depressive disorder. Each of these mood disorders has a range of multifactorial aetiologies. The Australian Clinical Practice Guidelines for Mood Disorders (1), advises that it is useful to construct a template to capture each patients’ problems using the biopsychosocial and lifestyle model (BPSL Model) and to consider the predisposing, precipitating and perpetuating factors. Considering the PCOS patient’s problems in this way is particularly useful, since the biological mechanisms related to mood disorder aetiology include altered reproductive and metabolic factors that are part of PCOS. In clinically managing depression in a woman with PCOs, any obvious precipitating environmental factors need to be addressed. Interpersonal violence, recent losses, physical ill health, financial and other social stresses are prominent factors that can trigger or perpetuate depression, in an acute or more persistent manner. It is important to take a careful history from the patient and her family and friends about any manic or hypomanic episodes to delineate bipolar from unipolar mood disorders. This delineation has very important implications for optimal management, prognosis, and avoiding iatrogenic worsening of affective instability. Following physical examination and laboratory investigations aiming to eliminate other comorbid conditions, moderate to severe Major Depressive Disorder in women with PCOS, will need antidepressant pharmacotherapy. From clinical experience, antidepressants are useful in managing depression in women with PCOS, who have moderate to severe depression. The first line of antidepressant treatment is usually with one of the following – an SSRI, ‘selective serotonin reuptake inhibitor’, NARI ‘noradrenergic reuptake inhibitor’, a NaSSA ‘noradrenergic and specific serotonergic antidepressants’, a NDRI ‘norepinephrine – dopamine reuptake inhibitor’ or a melatonin agonist. Second line treatment includes SNRIs ‘serotonin and noradrenaline reuptake inhibitors’, TCAs ‘tricyclic antidepressants’ or serotonin modulators. Third line treatment includes MAOIs ‘monoamine oxidase inhibitors’ and reversible MAOIs. (1)

Importantly, many women with PCOS describe premenstrual exacerbation of depressed mood and meet the criteria for a DSM 5 diagnosis of PMDD (premenstrual dysphoric disorder). In these women, the first line of treatment is usually with gonadal hormone modulation commonly with a combined oral contraceptive pill. If this is not successful, the next line of treatment is with an antidepressant and the medication of choice is the SSRI sertraline. This SSRI is
Anti-depressants and anxiolytics

often prescribed for use during the premenstrual week, ceasing use with menses. If this is inadequate, then sertraline can be prescribed in an ongoing manner.

Most SSRIs are used to treat women with combined depression and anxiety symptoms and in particular, sertraline has good anxiolytic benefit. Non-responsive depression in women with PCOS usually requires a change of antidepressant from an SSRI to one of the other first line drugs. Second line and third line antidepressants are occasionally needed and can be effective in women with PCOS who have severe depression.

Tolerability to side effects is an important determinant of adherence to medication and should be weighed against the efficacy profile of the antidepressant. The newer generation antidepressants are in general better tolerated than tricyclics or MAOIs and cause fewer problems with anticholinergic side effects such as sedation, dry mouth and constipation

Anxiolytics, Antidepressants and the Management of Anxiety Disorders in Women with PCOS

Anxiety disorders are common but often non-specific in women with PCOS. The “classical” symptoms of Generalised Anxiety Disorder, Social Anxiety Disorder, Panic Disorder and the phobias as described in the DSM 5, are often present in women with PCOS in a “subsyndromal” manner, making a full diagnosis of specific anxiety disorders difficult. In clinical practice, many women with PCOS present with a history of feeling constantly anxious, with intermittent exacerbation of anxiety symptoms and even panic. Another common clinical observation is the high prevalence of a history of early life trauma or poor attachment to parents, or early life loss/separations in women with PCOS. In these women, anxiety symptoms are constant and impair their quality of life. This type of anxiety is not very amenable to standard anxiolytic medication treatment. Psychotherapy using a trauma informed care model, is a more useful treatment for this type of anxiety disorder.

The most common treatment of anxiety in women with PCOS is usually with non-medication, psychotherapeutic interventions. Cognitive behavioural therapy, mindfulness, and combinations of psychotherapeutic approaches are considered to be the preferred treatment options for anxiety. Benzodiazepines are used in limited, short term fashion in women with PCOS and severe anxiety/panic, but are not recommended for longer term use because of the addiction issues. In particular, anxiolytics such as alprazolam are rapidly physiologically addictive as well as psychologically addictive, and can be impairing of cognition. It is more common practice to prescribe an SSRI (particularly sertraline) to treat anxiety if the preferred first line psychotherapeutic treatment options have not succeeded. Off-label use of very low dose antipsychotics are also used when anxiety symptoms are very severe – but both of these medications can cause weight gain and other metabolic issues – which is not ideal in PCOS. (2)

Anxiolytics, Antidepressants and the Management of Eating Disorders in Women with PCOS

Eating disorders of both extremes (over and under eating) have a wide range of aetiological factors. In PCOS, where the metabolic issues are critical, the psychological mechanisms involved in causing eating disorders include reactionary behaviours to the symptoms of PCOS, or as a separate comorbid issue. Poor self-esteem, poor self-image, a desire to control eating when all else seems out of control (seen in anorexic disorders), suppressed rage, a history of abusive relationships including sexual abuse, addictive behaviours and substituting food for other pleasures are some of the psychological drivers for the development of eating disorders. In general antidepressants are used to treat superimposed depression in women with PCOS who have eating disorders. Antidepressants are not usually indicated as specific treatment for eating disorders. Similarly, anxiolytics are not used as standard treatments for eating.
disorder, but may be used to treat comorbid anxiety. In general, in clinical practice, the actual eating disorder itself does not respond well to antidepressants or anxiolytic medications. (3)
GRADE framework

Interactive Evidence to Decision Framework

Are anti-depressants and anxiolytics effective for management and support of depression and/or anxiety or disordered eating in women with PCOS?

QUESTION

Question details

Population: Women with PCOS

Option: Anti-depressants and anxiolytics

Main outcomes:
- Depression
- Anxiety
- Eating disorders

Setting: Primary and specialist care

Perspective: Patients and health professionals

Background

We did not identify any evidence in women with PCOS for an evidence-based recommendation about the effectiveness of anti-depressants and anxiolytics and therefore a narrative review and a clinical consensus recommendation has been made based on key relevant sources of evidence-based information for the general population and the clinical expertise of the multidisciplinary guideline development group.

Subgroups

Subgroup name: Mood disorders

Subgroup name: Anxiety

Subgroup name: Eating disorders
ASSESSMENT

**Problem**

Is the problem a priority?

Judgement

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<th>Probably No</th>
<th>Probably Yes</th>
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Research evidence

Evidence not sought.

Additional considerations

In PCOS, there is a need to be really sure about a diagnosis of Major Depression Disorder and/or Generalised Anxiety Disorder before prescribing medications.

Seeking alternate options may be more appropriate, such as treating PCOS symptoms and reducing stigmatising diagnoses.

Panel discussion

The problem of mental illness in PCOS is a serious and prevalent one. Hence treatment for depression, anxiety, eating disorders and other mental health disorders in PCOS needs consideration despite the poor evidence base to date.

**Desirable effects**

How substantial are the desirable anticipated effects?

Judgement

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Research evidence

There are a significant number of studies now demonstrating the prevalence of depression and anxiety disorders as well as eating disorders in women diagnosed with PCOS.

Consideration of the available treatments is from a clinical practice perspective, since the evidence base from clinical trials of psychotropic medications in PCOS is lacking.

Additional considerations

Also, we need to consider the impact of PCOS related treatments such as COCPs, metformin, anti-androgens, laser therapy weight loss

In addition, treatment of anxiety and depressive symptoms may enable women to better adhere to weight loss interventions.
Caution is needed around understanding the prevalence of anxiety and depression in PCOS. Most evidence is based on studies using screening tools rather than clinical interviews establishing a diagnosis. Screening tools are likely to overestimate prevalence and high quality studies establishing the true prevalence are needed. To explain it another way, we know quite a lot about prevalence of symptoms but less about prevalence of clinical disorders. This is an important distinction in the context of management and medication recommendations.

Panel discussion
All in agreement for judgement.

Undesirable effects

How substantial are the undesirable anticipated effects?

Judgement

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Research evidence
See above in ‘Desirable effects’.

Additional considerations
Undesirable effects of anti-depressants and anxiolytics to be considered?

Panel discussion
All in agreement for judgement.

Certainty of the evidence

What is the overall certainty of the evidence of effects?

Judgement

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Research evidence
See above in ‘Desirable effects’.
Additional considerations
None.

Panel discussion
All in agreement for judgement.

Values
Is there important uncertainty about, or variability in, how much people value the main outcomes?

Judgement

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Research evidence
Considerations from the general literature regarding treatment with anti-depressants and anxiolytics should be considered? Some cause weight gain and may exacerbate PCOS features, which needs to be considered.

Additional considerations
The different conditions have different responses to antidepressant/ anxiolytic treatment - hence the overall judgement is that this varies. Patient surveys indicate that women desire psychological support and identified that they did not receive adequate information from their physicians. Moreover there were regional differences in concerns over depressive and anxiety symptoms between those residing in Europe and USA.

Balance of effects
Does the balance between desirable and undesirable effects favour the intervention or the comparison?

Judgement

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Research evidence
See above in ‘Desirable effects’.
Additional considerations
None.

Panel discussion
The balance between desired effects of antidepressants/anxiolytics and unwanted side effects needs to be considered for each patient.

**Resources required**

**How large are the resource requirements (costs)?**

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**Certainty of evidence of required resources**

**What is the certainty of the evidence of resource requirements (costs)?**

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Panel discussion
All in agreement for judgement.

**Cost-effectiveness**

**Does the cost-effectiveness of the intervention favour the intervention or the comparison?**

**Judgement**

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**Research evidence**

No evidence was noted in PCOS.

**Additional considerations**

**Equity**

**What would be the impact on health equity?**

**Judgement**

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**Research evidence**

No evidence sought.

**Additional considerations**

Access to assessment, health professional care and treatments will vary.

Panel discussion
All in agreement for judgement.
**Acceptability**

Is the intervention acceptable to key stakeholders?

Judgement

| Don't know | Varies | No | Probably No | Probably Yes | Yes |

Research evidence
No evidence sought.

Additional considerations
The GDG did not reach consensus on this issue, hence overall it was deemed that we did not know if this is acceptable.

Panel discussion

**Feasibility**

Is the intervention feasible to implement?

Judgement

| Don't know | Varies | No | Probably No | Probably Yes | Yes |

Research evidence
No evidence sought.

Additional considerations
Antidepressants and anxiolytics are widely available and hence feasible to prescribe. Therefore this area needs careful consideration in view of the potential use and misuse of these medications in the PCOS population.

Panel discussion
All in agreement for judgement.
CONCLUSIONS

Consensus recommendation

If treatment is warranted, psychological therapy and/or pharmacological treatment should be offered, informed by regional clinical practice guidelines. (Will be grouped in guideline with recommendations listed in prevalence framework)

Judgement

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Justification

The specific evidence base for antidepressant/ anxiolytic medication use in PCOS is lacking. The justification is based on clinical observation and general population Mood Disorder guidelines.

Overall, the evidence for the use of antidepressants and anxiolytics in PCOS is very limited.

Antidepressants are recommended for the treatment of true, sustained Major Depressive Disorder (persistent for more than 4 months), that is not fluctuating depressive symptoms. This should be managed by an experienced health professional. Other PCOS treatments could be considered initially and if the MDD persists and particularly if suicidal symptoms are present, then antidepressant treatment is recommended.

Anxiolytics, in particular benzodiazepines are **not** recommended for anxiety symptoms that are commonly seen in PCOS sufferers. This intermittent and fluctuating anxiety is thought to respond better to psychotherapy, in particular - cognitive behavioural therapy. If anxiety persists and is severe after 12 months of psychological therapies, then medical therapy could be used to treat the anxiety. This is useful if depression co-exists or develops as a result of the quality of life impact of ongoing anxiety.

Relevant medications have noted side effects including weight gain, agitation, cognitive changes and serotonin syndrome. Anxiolytics (commonly the benzodiazepines), are associated with physiological and psychological addiction.

Subgroup considerations

Patients of all age groups and sociodemographics were considered.

Implementation considerations
Anti-depressants and anxiolytics

Recommendations can be readily implemented in the primary and other health sectors - primarily the recommendation is for caution with prescribing these medications and to restrict use to true diagnosis of Major Depressive Disorder.

Monitoring and evaluation

Monitoring of drug side effects is in standard consultations and routine liver, kidney, full blood function tests conducted by primary health practitioners.

Research priorities

Do anti-depressants and anxiolytics improve mental health in PCOS?
Which agents are optimal?

References

1. Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for mood disorders
   Gin S Malhi et al

2. Canadian clinical practice guidelines for the management of anxiety, posttraumatic stress and obsessive-compulsive disorders
   Martin A Katzman et al
   BMC Psychiatry 2014, 14(Suppl 1):S1

3. Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of eating disorders
   Phillipa Hay et al
## Appendix I: Methods

### PICO/selection criteria

<table>
<thead>
<tr>
<th>Ranked 4</th>
<th>Participants (P)</th>
<th>Intervention (I)</th>
<th>Comparison (C)</th>
<th>Outcomes (O)</th>
<th>Study type</th>
<th>Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Females of any age, ethnicity or weight diagnosed with PCOS (by Rotterdam, NIH or AES). Diagnosed depression and/or anxiety, disordered eating, body image distress and/or psychosexual dysfunction using a different screening tool than that used for outcomes. Subgroups: • Adolescents • Ethnicity • Phenotype If no evidence in PCOS, relevant evidence will be sought narratively by key contact (not searched by evidence team).</td>
<td>Anti-depressants and anxiolytics.</td>
<td>Placebo or psychological or other pharmacological interventions; lifestyle interventions; acupuncture.</td>
<td>Changes in depression and/or anxiety and/or disordered eating. Self-management indicators.</td>
<td>Evidence based guidelines, systematic reviews, health technology assessments, randomised controlled trials.</td>
<td>English language. Any date. New search.</td>
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<tr>
<td></td>
<td>Females without diagnosed PCOS.</td>
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<td></td>
<td>Females without diagnosed PCOS.</td>
<td></td>
<td></td>
<td></td>
<td>Non-evidence based guidelines, non-systematic reviews, any study lower than a RCT.</td>
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Are anti-depressants and anxiolytics effective for management and support of depression and/or anxiety or disordered eating in women with PCOS?
<table>
<thead>
<tr>
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<tr>
<td>1 exp polycystic ovary syndrome/</td>
<td>(selective serotonin reuptake inhibit* or SSRI* or serotonin norepinephrine reuptake inhibit* or SNRI*).mp.</td>
</tr>
<tr>
<td>2 polycystic ovar*.mp.</td>
<td>20 (serotonin or norepinephrine or noradrenaline or neurotransmitter* or dopamin* ) adj (uptake or reuptake or re-uptake).mp.</td>
</tr>
<tr>
<td>3 poly-cystic ovar*.mp.</td>
<td>21 (tricyclic* or TCA* or tetracyclic* or TeCA* or heterocyclic*).mp.</td>
</tr>
<tr>
<td>4 PCO*.mp.</td>
<td>22 (monoamine oxidase inhibit* or MAOI* or rMAO*).mp.</td>
</tr>
<tr>
<td>5 (stein-leventhal or leventhal).mp.</td>
<td>23 ('Noradrenergic and specific serotonergic') or NaSSA*.mp.</td>
</tr>
<tr>
<td>6 anovulation/</td>
<td>24 (RIMA* or SARI* or NDRI* or NARI*).mp.</td>
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<tr>
<td>7 anovulat*.mp.</td>
<td>25 (St John* wort or hypericum).mp.</td>
</tr>
<tr>
<td>8 oligo-ovulat*.mp.</td>
<td>26 (Anxiolytic* or antianxiety or anti-anxiety or antipanic or anti-panic).mp.</td>
</tr>
<tr>
<td>9 oligoovulat*.mp.</td>
<td>27 or/12-26</td>
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<tr>
<td>10 (ovar* adj5 (sclerocystic or polycystic or poly-cystic or degenerat* or hyperandrogen* or hyper-androgen*)).mp.</td>
<td>28 search$.tw. or meta-analysis.mp. or meta-analysis.pt. or review.pt. or di.xs. or associated.tw.</td>
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<td>11 or/1-10</td>
<td>29 clinical trial.mp. or clinical trial.pt. or random.mp. or tu.xs.</td>
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<tr>
<td>12 exp Antidepressive Agents/</td>
<td>30 28 or 29</td>
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<td>13 exp Serotonin Uptake Inhibitors/</td>
<td>31 11 and 27 and 30</td>
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<tr>
<td>14 exp Monoamine Oxidase Inhibitors/</td>
<td>32 limit 31 to (English language and humans)</td>
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<td>15 exp Adrenergic Uptake Inhibitors/</td>
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<tr>
<td>16 exp Hypericum/</td>
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<tr>
<td>17 exp Anti-Anxiety Agents/</td>
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<td>18 (anti-depress* or antidepress*).mp.</td>
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Database search results

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<tr>
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</tbody>
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List of included studies