Impact of endometriosis on women's life decisions and goal attainment: a cross-sectional survey of members of an online patient community

Stacey A Missmer,¹,²,³ Frank Tu,⁴,⁵ Ahmed M Soliman,⁶ Stephanie E Chiuve,⁶ Sarah Cross,⁶ Samantha Eichner,⁶ Oscar Antunez Flores,⁶ Andrew Horne,⁷ Beth Schneider,⁸ Sawsan As-Sanie⁹

¹Department of Epidemiology, Harvard T. H. Chan School of Public Health, Boston, Massachusetts, USA
²Boston Center for Endometriosis, Boston, Massachusetts, USA
³Department of Obstetrics, Gynecology, and Reproductive Biology, Michigan State University, Grand Rapids, Michigan, USA
⁴Department of Obstetrics and Gynecology, NorthShore University Health System, Evanston, Illinois, USA
⁵Department of Obstetrics and Gynecology, Pritzker School of Medicine, University of Chicago, Evanston, Illinois, USA
⁶AbbVie Inc., North Chicago, Illinois, USA
⁷Medical Research Council Centre for Reproductive Health, University of Edinburgh, Edinburgh, UK
⁸MyHealthTeams, San Francisco, California, USA
⁹Department of Obstetrics and Gynecology, University of Michigan, Ann Arbor, Michigan, USA
**SUPPLEMENTAL FILE**

**Supplemental Table 1.** Women indicated how much they agreed or disagreed with the impact of endometriosis on the following: (A) pain, (B) work and education, (C) life experiences altered in a negative way, (D) impact on life, (E) feelings, and (F) management of impact.

**Supplemental Figure 1.** Impact of endometriosis on educational and professional achievements in the United States (A) and in the rest of the world (B).

**Survey.** MyEndometriosisTeam Survey – Life Course Impact Survey
Supplemental Table 1.

<table>
<thead>
<tr>
<th>S1A</th>
<th>Daily</th>
<th>A few times a week</th>
<th>A few times a month</th>
<th>Weekly</th>
<th>Monthly</th>
<th>Every few months</th>
<th>Never</th>
<th>Once or twice a year</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>(N = 743)</strong></td>
<td>415 (55.9)</td>
<td>160 (21.5)</td>
<td>78 (10.5)</td>
<td>43 (5.8)</td>
<td>31 (4.2)</td>
<td>9 (1.2)</td>
<td>4 (0.5)</td>
<td>3 (0.4)</td>
</tr>
<tr>
<td><strong>Less positive about future, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>(n = 589)</strong></td>
<td>362 (61.5)</td>
<td>120 (20.4)</td>
<td>50 (8.5)</td>
<td>31 (5.3)</td>
<td>16 (2.7)</td>
<td>6 (1.0)</td>
<td>2 (0.3)</td>
<td>2 (0.3)</td>
</tr>
<tr>
<td><strong>Remaining respondents</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>(n = 154)</strong></td>
<td>53 (34.4)</td>
<td>40 (26.0)</td>
<td>28 (182)</td>
<td>12 (7.8)</td>
<td>15 (9.7)</td>
<td>3 (1.9)</td>
<td>2 (1.3)</td>
<td>1 (0.6)</td>
</tr>
<tr>
<td><strong>Did not reach full potential, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>(n = 556)</strong></td>
<td>341 (61.3)</td>
<td>121 (21.8)</td>
<td>44 (7.9)</td>
<td>28 (5.0)</td>
<td>13 (2.3)</td>
<td>6 (1.1)</td>
<td>2 (0.4)</td>
<td>1 (0.2)</td>
</tr>
<tr>
<td><strong>Remaining respondents</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>(n = 187)</strong></td>
<td>74 (39.6)</td>
<td>39 (20.9)</td>
<td>15 (8.0)</td>
<td>34 (18.2)</td>
<td>18 (9.6)</td>
<td>3 (1.6)</td>
<td>2 (1.1)</td>
<td>2 (1.1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>S1B</th>
<th>Missed days of work</th>
<th>Missed school</th>
<th>Earned less money</th>
<th>Could not work at preferred job</th>
<th>Unable to work full time</th>
<th>Unable to achieve educational goals</th>
<th>Unable to work part time</th>
<th>Lost a job</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>(N = 743)</strong></td>
<td>550 (74.9)</td>
<td>413 (56.3)</td>
<td>404 (55.0)</td>
<td>355 (48.4)</td>
<td>338 (46.0)</td>
<td>290 (39.5)</td>
<td>226 (30.8)</td>
<td>212 (28.9)</td>
</tr>
<tr>
<td><strong>Less positive about future, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>(n = 589)</strong></td>
<td>463 (78.6)</td>
<td>343 (58.2)</td>
<td>359 (61.0)</td>
<td>316 (53.7)</td>
<td>300 (50.9)</td>
<td>257 (43.6)</td>
<td>202 (34.3)</td>
<td>190 (32.3)</td>
</tr>
<tr>
<td><strong>Remaining respondents</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>(n = 154)</strong></td>
<td>87 (56.5)</td>
<td>70 (45.5)</td>
<td>45 (29.2)</td>
<td>39 (25.3)</td>
<td>38 (24.7)</td>
<td>33 (21.4)</td>
<td>24 (15.6)</td>
<td>22 (14.3)</td>
</tr>
<tr>
<td><strong>Did not reach full potential, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>(n = 556)</strong></td>
<td>448 (80.6)</td>
<td>329 (59.2)</td>
<td>365 (65.6)</td>
<td>323 (58.1)</td>
<td>295 (53.1)</td>
<td>261 (46.9)</td>
<td>205 (36.9)</td>
<td>193 (34.7)</td>
</tr>
<tr>
<td><strong>Remaining respondents</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>(n = 187)</strong></td>
<td>102 (54.5)</td>
<td>84 (44.9)</td>
<td>39 (20.9)</td>
<td>32 (17.1)</td>
<td>43 (23.0)</td>
<td>29 (15.5)</td>
<td>21 (11.2)</td>
<td>19 (10.2)</td>
</tr>
</tbody>
</table>
### Table S1C

<table>
<thead>
<tr>
<th></th>
<th>Pelvic pain apart from period</th>
<th>Painful periods</th>
<th>Pelvic pain during period</th>
<th>Depression or anxiety</th>
<th>Painful sexual intercourse</th>
<th>Heavy period-related bleeding</th>
<th>Other endometriosis-related pain for symptoms</th>
<th>Taken prescription</th>
<th>Multiple surgeries</th>
<th>Infertility</th>
<th>Other symptoms or conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total, n (%)</strong> (N = 743)</td>
<td>651 (87.6)</td>
<td>650 (87.5)</td>
<td>633 (85.2)</td>
<td>598 (80.5)</td>
<td>576 (77.5)</td>
<td>524 (70.5)</td>
<td>452 (60.8)</td>
<td>427 (57.5)</td>
<td>363 (48.9)</td>
<td>342 (46.0)</td>
<td>317 (42.7)</td>
</tr>
<tr>
<td><strong>Less positive about future, n (%)</strong> (n = 589)</td>
<td>528 (89.6)</td>
<td>517 (87.8)</td>
<td>506 (85.9)</td>
<td>505 (85.7)</td>
<td>461 (78.3)</td>
<td>413 (70.1)</td>
<td>382 (64.9)</td>
<td>353 (59.9)</td>
<td>297 (50.4)</td>
<td>272 (46.2)</td>
<td>268 (45.5)</td>
</tr>
<tr>
<td><strong>Remaining respondents</strong> (n = 154)</td>
<td>123 (79.9)</td>
<td>133 (86.4)</td>
<td>127 (82.5)</td>
<td>93 (60.4)</td>
<td>115 (74.7)</td>
<td>111 (72.1)</td>
<td>70 (45.5)</td>
<td>74 (48.1)</td>
<td>66 (42.9)</td>
<td>70 (45.5)</td>
<td>49 (31.8)</td>
</tr>
<tr>
<td><strong>Did not reach full potential, n (%)</strong> (n = 556)</td>
<td>500 (89.9)</td>
<td>491 (88.3)</td>
<td>482 (86.7)</td>
<td>476 (85.6)</td>
<td>430 (77.3)</td>
<td>400 (71.9)</td>
<td>366 (65.8)</td>
<td>332 (59.7)</td>
<td>284 (51.1)</td>
<td>261 (46.9)</td>
<td>259 (46.6)</td>
</tr>
<tr>
<td><strong>Remaining respondents</strong> (n = 187)</td>
<td>151 (80.7)</td>
<td>159 (85.0)</td>
<td>151 (80.7)</td>
<td>122 (65.2)</td>
<td>146 (78.1)</td>
<td>124 (66.3)</td>
<td>86 (46.0)</td>
<td>95 (50.8)</td>
<td>79 (42.2)</td>
<td>81 (43.3)</td>
<td>58 (31.0)</td>
</tr>
</tbody>
</table>

### Table S1D

<table>
<thead>
<tr>
<th></th>
<th>Trouble performing daily tasks</th>
<th>Taken Rx medication</th>
<th>Gone to ER</th>
<th>Multiple surgeries</th>
<th>Depression/ anxiety medication</th>
<th>Unable to get pregnant</th>
<th>Saw mental health professional</th>
<th>Hospitalized overnight</th>
<th>Experienced miscarriage</th>
<th>Relationship ended because unable to have sex</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total, n (%)</strong> (N = 743)</td>
<td>594 (80.9)</td>
<td>529 (72.1)</td>
<td>485 (66.1)</td>
<td>406 (55.3)</td>
<td>380 (51.8)</td>
<td>317 (43.2)</td>
<td>316 (43.1)</td>
<td>313 (42.6)</td>
<td>213 (29.0)</td>
<td>147 (20.0)</td>
</tr>
<tr>
<td><strong>Less positive about future, n (%)</strong> (n = 589)</td>
<td>500 (84.9)</td>
<td>442 (75.0)</td>
<td>406 (68.9)</td>
<td>333 (56.5)</td>
<td>327 (55.5)</td>
<td>251 (42.6)</td>
<td>276 (46.9)</td>
<td>266 (45.2)</td>
<td>167 (28.4)</td>
<td>132 (22.4)</td>
</tr>
<tr>
<td><strong>Remaining respondents</strong> (n = 154)</td>
<td>94 (61.0)</td>
<td>87 (56.5)</td>
<td>79 (51.3)</td>
<td>73 (47.4)</td>
<td>53 (34.4)</td>
<td>66 (42.9)</td>
<td>40 (26.0)</td>
<td>47 (30.5)</td>
<td>46 (29.9)</td>
<td>15 (9.7)</td>
</tr>
<tr>
<td><strong>Did not reach full potential, n (%)</strong> (n = 556)</td>
<td>478 (86.0)</td>
<td>421 (75.7)</td>
<td>390 (70.1)</td>
<td>311 (55.9)</td>
<td>308 (55.4)</td>
<td>239 (43.0)</td>
<td>265 (47.7)</td>
<td>249 (44.8)</td>
<td>166 (29.9)</td>
<td>132 (23.7)</td>
</tr>
<tr>
<td><strong>Remaining respondents</strong> (n = 187)</td>
<td>116 (62.0)</td>
<td>108 (57.8)</td>
<td>95 (50.8)</td>
<td>95 (50.8)</td>
<td>72 (38.5)</td>
<td>78 (41.7)</td>
<td>51 (27.3)</td>
<td>64 (34.2)</td>
<td>47 (25.1)</td>
<td>15 (8.0)</td>
</tr>
<tr>
<td>S1E</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Depressed</td>
<td>Anxious</td>
<td>Unsexy</td>
<td>Low self-esteem</td>
<td>Insecure</td>
<td>Inadequate</td>
<td>Embarrassed</td>
<td>Unfulfilled</td>
<td>Judged by others</td>
<td>Guilty</td>
</tr>
<tr>
<td>Total, n (%) (N = 743)</td>
<td>607 (82.7)</td>
<td>592 (80.7)</td>
<td>572 (77.9)</td>
<td>554 (75.5)</td>
<td>538 (73.3)</td>
<td>487 (66.3)</td>
<td>479 (65.3)</td>
<td>437 (59.5)</td>
<td>428 (58.3)</td>
<td>402 (54.8)</td>
</tr>
<tr>
<td>Less positive about future, n (%) (n = 589)</td>
<td>517 (87.8)</td>
<td>491 (83.4)</td>
<td>468 (79.5)</td>
<td>478 (81.2)</td>
<td>469 (79.6)</td>
<td>421 (71.5)</td>
<td>415 (70.5)</td>
<td>387 (65.7)</td>
<td>380 (64.5)</td>
<td>350 (59.4)</td>
</tr>
<tr>
<td>Remaining respondents (n = 154)</td>
<td>90 (58.4)</td>
<td>101 (65.6)</td>
<td>104 (67.5)</td>
<td>76 (49.4)</td>
<td>69 (44.8)</td>
<td>66 (42.9)</td>
<td>64 (41.6)</td>
<td>50 (32.5)</td>
<td>48 (31.2)</td>
<td>52 (33.8)</td>
</tr>
<tr>
<td>Did not reach full potential, n (%) (n = 556)</td>
<td>487 (87.6)</td>
<td>462 (83.1)</td>
<td>441 (79.3)</td>
<td>443 (79.7)</td>
<td>434 (78.1)</td>
<td>401 (72.1)</td>
<td>393 (70.7)</td>
<td>375 (67.4)</td>
<td>352 (63.3)</td>
<td>330 (59.4)</td>
</tr>
<tr>
<td>Remaining respondents (n = 187)</td>
<td>120 (64.2)</td>
<td>130 (69.5)</td>
<td>131 (70.1)</td>
<td>111 (59.4)</td>
<td>104 (55.6)</td>
<td>86 (46.0)</td>
<td>86 (46.0)</td>
<td>62 (33.2)</td>
<td>76 (40.6)</td>
<td>72 (38.5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>S1F</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Talk to spouse or partner</td>
<td>Use non-medical methods for pain</td>
<td>Talk to friends and family</td>
<td>Educate self on treatments</td>
<td>Make doctor listen and respond to needs</td>
<td>Engage with other women with same experiences</td>
<td>Schedule social events around period</td>
<td>Pelvic floor or other exercises</td>
<td>Other</td>
<td>None of these</td>
<td></td>
</tr>
<tr>
<td>Total, n (%) (N = 743)</td>
<td>560 (76.3)</td>
<td>533 (72.6)</td>
<td>508 (69.2)</td>
<td>502 (68.4)</td>
<td>455 (62.0)</td>
<td>409 (55.7)</td>
<td>304 (41.4)</td>
<td>193 (26.3)</td>
<td>70 (9.5)</td>
<td>26 (3.5)</td>
<td></td>
</tr>
<tr>
<td>Less positive about future, n (%) (n = 589)</td>
<td>445 (75.6)</td>
<td>425 (72.2)</td>
<td>409 (69.4)</td>
<td>409 (69.4)</td>
<td>369 (62.6)</td>
<td>337 (57.2)</td>
<td>257 (43.6)</td>
<td>162 (27.5)</td>
<td>61 (10.4)</td>
<td>19 (3.2)</td>
<td></td>
</tr>
<tr>
<td>Remaining respondents (n = 154)</td>
<td>115 (74.7)</td>
<td>108 (70.1)</td>
<td>99 (64.3)</td>
<td>93 (60.4)</td>
<td>86 (55.8)</td>
<td>72 (46.8)</td>
<td>47 (30.5)</td>
<td>31 (20.1)</td>
<td>9 (5.8)</td>
<td>7 (4.5)</td>
<td></td>
</tr>
<tr>
<td>Did not reach full potential, n (%) (n = 556)</td>
<td>418 (75.2)</td>
<td>405 (72.8)</td>
<td>383 (68.9)</td>
<td>394 (70.9)</td>
<td>345 (62.1)</td>
<td>325 (58.5)</td>
<td>246 (44.2)</td>
<td>153 (27.5)</td>
<td>59 (10.6)</td>
<td>20 (3.6)</td>
<td></td>
</tr>
<tr>
<td>Remaining respondents (n = 187)</td>
<td>142 (75.9)</td>
<td>128 (68.4)</td>
<td>125 (66.8)</td>
<td>108 (57.8)</td>
<td>110 (58.8)</td>
<td>84 (44.9)</td>
<td>58 (31.0)</td>
<td>40 (21.4)</td>
<td>11 (5.9)</td>
<td>6 (3.2)</td>
<td></td>
</tr>
</tbody>
</table>
Supplemental Figure 1.

A. Unable to achieve educational goals
- Missed school: 19% Strongly Agree, 16% Agree, 13% Undecided, 10% Disagree, 26% Strongly Disagree, 14% Does Not Apply
- US (n = 473)
  - Unable to work full time: 16% Strongly Agree, 14% Agree, 15% Undecided, 12% Disagree, 28% Strongly Disagree, 10% Does Not Apply
  - Unable to work part time: 16% Strongly Agree, 14% Agree, 15% Undecided, 12% Disagree, 28% Strongly Disagree, 10% Does Not Apply
  - Could not work at preferred job: 32% Strongly Agree, 14% Agree, 13% Undecided, 12% Disagree, 21% Strongly Disagree, 7% Does Not Apply
  - Missed work: 40% Strongly Agree, 28% Agree, 7% Undecided, 8% Disagree, 5% Strongly Disagree, 5% Does Not Apply
  - Lost a job: 20% Strongly Agree, 10% Agree, 10% Undecided, 6% Disagree, 35% Strongly Disagree, 20% Does Not Apply
  - Earned less money: 37% Strongly Agree, 15% Agree, 9% Undecided, 8% Disagree, 9% Strongly Disagree, 16% Does Not Apply

B. Unable to achieve educational goals
- Missed school: 20% Strongly Agree, 23% Agree, 13% Undecided, 10% Disagree, 21% Strongly Disagree, 11% Does Not Apply
- Non-US (n = 269)
  - Unable to work full time: 32% Strongly Agree, 15% Agree, 11% Undecided, 13% Disagree, 18% Strongly Disagree, 10% Does Not Apply
  - Unable to work part time: 18% Strongly Agree, 14% Agree, 17% Undecided, 9% Disagree, 25% Strongly Disagree, 14% Does Not Apply
  - Could not work at preferred job: 27% Strongly Agree, 23% Agree, 11% Undecided, 9% Disagree, 18% Strongly Disagree, 13% Does Not Apply
  - Missed work: 48% Strongly Agree, 28% Agree, 10% Undecided, 5% Disagree, 7% Strongly Disagree, 2% Does Not Apply
  - Lost a job: 15% Strongly Agree, 11% Agree, 10% Undecided, 8% Disagree, 31% Strongly Disagree, 21% Does Not Apply
  - Earned less money: 36% Strongly Agree, 15% Agree, 13% Undecided, 8% Disagree, 19% Strongly Disagree, 6% Does Not Apply
Survey.

MyEndometriosisTeam Survey – Life Course Impact Survey

Introduction

Part of our mission at MyEndometriosisTeam is to help build awareness and understanding of the impact that endometriosis can have on daily life. Creating a better understanding of what other women with endometriosis go through is important to many members. The aim of this study is to understand real-life experiences of women living with chronic endometriosis. This includes how it may influence life choices and any long-lasting effect it has. This survey should take approximately 8 minutes to complete. Your participation is completely voluntary, and your responses are anonymous. MyEndometriosisTeam never shares any personally identifying information. Highlights of the findings of this research survey will be shared back with the MyEndometriosisTeam community. We are conducting this survey in collaboration with one of our pharmaceutical partners. This is one of the ways we keep MyEndometriosisTeam free while making sure your voice is heard. If you have any questions regarding the survey, please contact support@myendometriosisteam.com.

If you are 19 years of age or older, live in the United States (excluding Puerto Rico), understand the statements above and freely consent to participate in this research, click on the “Yes, I agree” button to begin the survey.

Yes, I agree
No thanks, I’d rather not participate

Section 1: Screening Questions

S1. Which of the following describes you?
   
   Male (Terminate)
   Female
S2. What is your age?

Under 19 *(Terminate)*

19-29

30-39

40-49

50-59

60 or older

S3. Which one of the following best describes your condition?

Stage 1 endometriosis

Stage 2 endometriosis

Stage 3 endometriosis

Stage 4 endometriosis

Not sure what stage of endometriosis I have

I do not have endometriosis *(Terminate)*

S4. In which country do you currently live?

United States (excluding Puerto Rico) *(Continue)*

Australia

Canada

Ireland

Netherlands

New Zealand

South Africa

United Kingdom

Other
Section 1: Endometriosis Severity

1. At what age did your endometriosis symptoms begin? (drop-down menu)

2. At approximately what age did you start your first period? (drop-down menu)

3. Thinking about when you first started to experience endometriosis symptoms, approximately how many years did it take before you were diagnosed with endometriosis? (drop-down menu)

4. Did you ever have a surgical procedure, such as a laparoscopy or laparotomy, to confirm you have endometriosis?
   - Yes
   - No
   - Not sure

5. Which one of the following best describes how often you typically feel some type of endometriosis-related pain?
   - Daily
   - A few times a week
   - Weekly
   - A few times a month
   - Monthly
   - Every few months
   - Once or twice a year
   - Never
6. Please rate how severe your endometriosis related pain has been at its worst in the last 12 months using a scale from 0 to 10, where 0=no pain and 10=worst imaginable pain. (Drop down menu).

7. Over the years, has your endometriosis related pain gotten better, gotten worse, or stayed the same?

- Gotten much better
- Gotten somewhat better
- Stayed the same
- Gotten somewhat worse
- Gotten much worse

Section 2: Impact on Quality of Life and Life Choices

8. Please indicate how much you agree or disagree with the following statements about the impact endometriosis has had on your entire life up to now.

(Please select one box for each row)

<table>
<thead>
<tr>
<th>(Please select one box for each row)</th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Neutral</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was unable to achieve my educational goals</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I missed many days of school</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I was unable to work full time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I was unable to work part time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I could not work at the job I would have preferred</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Statement</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>I missed many days of work</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I lost a job</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I earned less money than I could have</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I made fewer friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have had problems with sexual or intimate relationships</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have not dated or pursued an intimate relationship</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have delayed having or have been unable to have children</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have limited my social activities</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have not exercised or played sports as much as I would have liked</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I do not live where I would like due to my healthcare needs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I lost a lot of time in my life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have travelled less than I would have liked</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have dressed differently than I would have liked</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have used alcohol, drugs or smoked cigarettes</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have not maintained a healthy diet</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have been less outgoing</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have been less positive about the future</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have not reached my full potential in life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
9. What endometriosis-related experiences, if any, do you think have most contributed to altering your life potential in a negative way? Select all that apply. (Rotate order)

- Painful sexual intercourse
- Pelvic pain during my period
- Pelvic pain apart from during my period
- Painful periods
- Heavy period-related bleeding
- Other endometriosis related pain
- Infertility
- Depression or anxiety
- Multiple surgeries
- Prescription treatment to control endometriosis symptoms
- Other symptoms or conditions (please specify)
- Other (please specify)
- None
10. Which, if any, of these, have you experienced as a result of your endometriosis? Check all that apply. (Rotate order)

- Taken prescription medication for the pain (for example, opioids)
- Taken prescription medication to treat depression or anxiety
- Had multiple surgical procedures
- Been hospitalized overnight
- Gone to the emergency room
- Received disability income due to being unable to work
- Had a miscarriage (whether or not it was due to having endometriosis)
- Had trouble performing daily tasks
- Saw a mental health professional (eg., psychiatrist, counselor)
- Was unable to get pregnant
- Had a relationship end because I was unable to have children
- Had a relationship end because I was unable to have sex
- None of these
11. And which, if any, of these emotions, have you experienced as a result of your endometriosis? Check all that apply. (Rotate order)

I have felt…
Low self esteem
Judged by others
Inadequate
Unsexy
Insecure
Guilty
Determined
Strengthened
Hopeful
Embarrassed
Unfulfilled
Depressed
Anxious
None of these
12. Which of the following, if any, have you done to help manage the impact of endometriosis? Select all that apply. (rotate order)

- Schedule social events around my period
- Engage with other women going through the same experiences
- Talk to my friends and family about endometriosis
- Talk to my spouse or partner about my endometriosis
- Pelvic floor or other exercises to lessen pain during sex
- Make sure my doctor listens and responds to my needs
- Educate myself on new treatments
- Use non-medical methods for controlling pain (e.g., ice or heat, lubricants during sex)
- Other (please describe)
- None of these

13. Because of endometriosis, is there anything you feel you were unable to accomplish in your life? (open end)

14. Is there anything else you would like us to know about the impact endometriosis has had on your life? (open end)

Just a few last questions.

D1. Which of the following best describes the area where you live?

- Urban
- Suburban
- Rural
- Not sure / prefer not to say
D2. What is the highest level of education you have achieved?

- Less than high school
- Some high school
- High school or equivalent (e.g., GED)
- Some college, but no degree
- Associate degree
- College degree (e.g., B.A., B.S.)
- Some graduate school, but no degree
- Graduate school (e.g., M.S., M.D., Ph.D.)
- Prefer not to answer

D3. What is your current employment status?

- Working full time
- Working part time
- Unemployed, not looking for work
- Unemployed, looking for work
- Retired
- Unable to work
- Prefer not to answer
D4. Which of the following best describes your marital status?

- Single/never married
- Married
- Widowed
- Divorced or separated
- Prefer not to answer

(Skip D5 if “married” or “prefer not to answer” selected in D4)

D5. Are you currently in an intimate relationship?

- Yes
- No
- Prefer not to answer

D6. How many children, if any, do you have?

- None
- 1
- 2
- 3
- 4
- 5 or more
- Prefer not to answer

Thank you for answering these questions.