



Australian
National
University



Endometriosis Impact Questionnaire (63-item EIQ)

© Moradi M., et al.

Maryam Moradi, Melissa Parker, Anne Sneddon, Violeta Lopez, David Ellwood

- The questions in the EIQ have been developed based on 10 focus group discussions with 35 women with endometriosis. EIQ aims to measure the long term impact of endometriosis on different aspects of women's lives.
- Your valuable participation will contribute towards better understanding of the impact of endometriosis on women's lives and to better meet the needs of women with this condition.
- Please be assured that all responses are strictly confidential. Only combined data from all the questionnaires will be reported.
- Completing this questionnaire is voluntary. By completing the questionnaire you are indicating your consent to participate in the study.
- There are no right or wrong answers to any of the questions, so please respond according to your feelings and experiences about how endometriosis has affected your life.
- This questionnaire takes about 15(± 6) minutes to complete.
- If you have any questions about the questionnaire or the study please contact Maryam Moradi by email maryam.moradi.fu@gmail.com.
- Once you have completed the questionnaire please return it to us in the envelope provided.

We appreciate you filling out all dimensions to help us complete this important study.

Instructions: We ask you to complete the EIQ questionnaire by placing in every box the number which best describes how much endometriosis has affected your life over three time periods (last 12 months, 1 to 5 years ago and more than 5 years ago).

0 = Not at all

1 = A little

2 = Somewhat

3 = Quite a lot

4 = Very much

9 = Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or question is about the effect of endometriosis on working and you did not work in that time period)

Example:

Because of My Endometriosis: years ago	Last 12 months	1 to 5 years ago	More than 5
Q1. I had severe period pain.	1	3	4
Q2. I found it difficult to care for my child.	0	4	9

This woman's answer for question 2 shows she did not have any children more than 5 years ago (9), then she had a baby 3 years ago and "Because of her endometriosis" she found it difficult "Very much" (4) to care for her child, but during the last 12 months she has not had this problem at all (0). Some dimensions of the EIQ may not be relevant to you, so you could skip to the next dimension.

I have read the instructions and I am ready to begin.

Yes

Dimension 1. Physical Impact of Endometriosis (Questions marked * are mandatory)

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all

1 = A little

2 = Somewhat

3 = Quite a lot

4 = Very much

9 = Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or question is not relevant to you)

Because of My Endometriosis:

	Last 12 months	1 to 5 years ago	More than 5 years ago
Q1.* I had severe period pain.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q2.* I had pelvic pain between my periods.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q3.* I had heavy bleeding with periods.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q4.* I had irregular spotting or bleeding between my periods.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q5.* I felt tired more than usual.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q6.* I spent time in bed or lying down due to pain (e.g. period or pelvic pain).	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q7.* I had trouble sleeping.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q8.* I felt that my energy levels have decreased.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q9.* I had difficulties carrying out normal daily activities (e.g. shopping, driving).	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q10.* I had to decrease my involvement in exercise or sport.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q11.* I was bothered physically by the side effects of medical or surgical treatment/s.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q12.* I was concerned about weight gain (e.g. due to less activity caused by pain or as a side effect of treatment).	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q13.* I thought about having a hysterectomy to treat my symptoms.	<input type="text"/>	<input type="text"/>	<input type="text"/>

Dimension 1. Psychological Impact of Endometriosis (Questions marked * are mandatory)

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all

1 = A little

2 = Somewhat

3 = Quite a lot

4 = Very much

9 = Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or question is not related to you)

Because of My Endometriosis:

		Last 12 months	1 to 5 years ago	More than 5 years ago
Q14.*	I felt depressed.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q15.*	I felt uncertain because of the unpredictable nature of endometriosis and its symptoms.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q16.*	I felt uncertain about the effectiveness of my treatment/s.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q17.*	I experienced mood swings (due to my symptoms/pain or treatment side effect).	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q18.*	I felt nobody understands how I feel.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q19.*	I felt less self-confident.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q20.*	I was unhappy about my appearance (e.g. due to weight gain, surgery scar/s).	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q21.*	I felt my identity has been disrupted as a woman, partner, mother etc.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q22.*	I felt embarrassed (e.g. symptoms at work place, school, explaining to employers, colleagues or teachers).	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q23.*	I felt jealous (e.g. of others who have no pain or have had children or pain free sex).	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q24.*	I felt worried that my symptoms will get worse.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q25.*	I was worried about the effect of endometriosis on my future plans.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q26.*	I felt annoyed about the amount of painkillers I have had to take.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q27.*	I had feelings of defeat or hopelessness (e.g. not being able to deal with this disease anymore).	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q28.*	I was concerned about overuse or accidental of pain killers.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q29.*	I was not able to control my life as I would like.	<input type="text"/>	<input type="text"/>	<input type="text"/>

Dimension 1. Social Impact of Endometriosis (Questions marked * are mandatory)

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all

1 = A little

2 = Somewhat

3 = Quite a lot

4 = Very much

9 = Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or question is not relevant to you)

Because of My Endometriosis:

	Last 12 months	1 to 5 years ago	More than 5 years ago
Q30.* I reduced participation in social events like attending parties or going out with my friends.	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q31.* I decreased my leisure activities (like hobbies or going on holidays).	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q32.* I had problems with my relationships with other people (e.g. because of my mood swings or pain).	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q33.* I felt isolated.	<input type="text"/>	<input type="text"/>	<input type="text"/>

Dimension 2. Sexual and Intimate Relationships Impact of Endometriosis

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all

1 = A little

2 = Somewhat

3 = Quite a lot

4 = Very much

9 = Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or you were not sexually active or partnered in that time period)

If all the following questions about "Sexual and Intimate Relationships Impact" are not relevant to you (never been sexually active or did not have endometriosis when you had sexual relationships) please tick the box and go to the next dimension.

Because of My Endometriosis:

	Last 12 months	1 to 5 years ago	More than 5 years ago
Q34. I had pain during or after sexual activity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q35. I had bleeding or spotting during or after sexual activity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q36. I avoided sexual activity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q37. I experienced strain in my relationship with my partner/s.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q38. I was not able to maintain long term relationships with my partner/s.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q39. I was not satisfied with my sex life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q40. I had thoughts about being single due to sexual difficulties (e.g. pain or bleeding) or fertility issues.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Dimension 3. Fertility Impact of Endometriosis

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all

1 = A little

2 = Somewhat

3 = Quite a lot

4 = Very much

9 = Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or question is not relevant to you)

If all the following questions about "Fertility" are not relevant to you please tick the box, and go to the next dimension.

Because of My Endometriosis:

	Last 12 months	1 to 5 years ago	More than 5 years ago
Q41. I found it difficult to become pregnant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q42. I was worried about my fertility.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q43. I had regrets about not being able to have a child/more children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Dimension 4. Employment and Financial Impact of Endometriosis

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all

1 = A little

2 = Somewhat

3 = Quite a lot

4 = Very much

9 = Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or did not study in that time period)

If all the following questions about "Employment" are not relevant to you (never worked or did not have endometriosis when you were working) please tick the box, **answer only Question 54** and go to the next dimension.

Because of My Endometriosis:

	Last 12 months	1 to 5 years ago	More than 5 years ago
Q44. I had difficulty pursuing my preferred career.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q45. I experienced limitations in what I can do at work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q46. I reduced my working hours.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q47. I took time off work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q48. I experienced difficulty concentrating or focusing on my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q49. I think that I missed out on job promotions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q50. I was afraid of losing my job.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q51. I had to change or give up my job.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q52. I had a reduction in my income.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q53. I felt that I was unable to reach my career goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q54. I experienced financial hardship (due to the cost of diagnosis or treatment medications, surgery, infertility or lost job opportunities).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Dimension 5. Educational Impact of Endometriosis

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

- 0 = Not at all
- 1 = A little
- 2 = Somewhat
- 3 = Quite a lot
- 4 = Very much

9 =Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or did not study in that time period)

If all the following questions about "Educational Impact" are not relevant to you (did not have endometriosis when you were at school/university) please tick the box and go to the next dimension.

Because of My Endometriosis:

	Last 12 months	1 to 5 years ago	More than 5 years ago
Q55. I took time off school/studies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q56. I experienced difficulty concentrating or focusing on my studies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q57. I did not complete my study requirements on time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q58. I missed school/university exams.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q59. I needed more time to complete schooling/studies (e.g. extensions, re-enrolment).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q60. I felt that I was unable to reach my education goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Dimension 6. Lifestyle Impact of Endometriosis (Questions marked *are mandatory)

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all
 1 = A little
 2 = Somewhat
 3 = Quite a lot
 4 = Very much
 9 = Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or question is not relevant to you)

Because of My Endometriosis:

	Last 12 months	1 to 5 years ago	More than 5 years ago
Q61.* I consumed alcohol to help me cope (e.g. with my symptoms or feelings).	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q62.* I smoked cigarettes (tobacco) to help me cope (e.g. with my symptoms or feelings).	<input type="text"/>	<input type="text"/>	<input type="text"/>
Q63.* I used other illicit substances or drugs to help me cope (e.g. with my symptoms or feelings).	<input type="text"/>	<input type="text"/>	<input type="text"/>

Comments (optional)

We welcome your comments about this questionnaire (EIQ), how to improve it and/or any further comments in relation to your experiences with endometriosis.

Thank you so much for your participation in this study.

You could contact Maryam Moradi, PhD candidate by email: maryam.moradi.fu@gmail.com for any concern regarding the questionnaire.