

T O T E M S T U D Y

Time Number code

Gentle Mrs,
this questionnaire is very important in order to know what do you think about your health and about health care that you're receiving.
Answer each questionnaire's question, putting an X above the answer that correspond to your experience.
If you don't feel sure about the right answer, select always the best answer.
Thank you for your precious cooperation.

1. In general terms, would you say that your health is:

- | | | | | |
|--|--|--|--|--|
| <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="1"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="2"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="3"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="4"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="5"/> |
| <i>Excellent</i> | <i>Very good</i> | <i>Good</i> | <i>Passable</i> | <i>Bad</i> |

The following questions are connected with any activities that you should probably do during a general day. Nowadays does your health limit you during this activity?

- | | <i>yes,
limits myself
quite a lot</i> | <i>YES,
limits myself
partially</i> | <i>NO,
doesn't
not at all</i> |
|--|--|--|--|
| 2. Mild physical activities, as moving a table, hoovering or cycling | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="1"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="2"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="3"/> |
| 3. To climb up some staircases | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="1"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="2"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="3"/> |

Did you find the following problems in your job or in other daily activities, cause your physical health, in the last 4 weeks?

- | | YES | NO |
|--|--|--|
| 4. Did you yield less than you have expected | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="1"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="2"/> |
| 5. Did you limit any kind of works or activities | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="1"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="2"/> |

Did you find the following problems in your job or in other daily activities, cause your emotional state (as to feel depress or anxious), in the last 4 weeks?

- | | YES | NO |
|--|--|--|
| 6. Did you yield less than you have expected | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="1"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="2"/> |
| 7. Did you limit any kind of works or activities | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="1"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="2"/> |

8. How much did the pain disturb you in your daily activities (at home or at work) in the last for weeks?

- | | | | | |
|--|--|--|--|--|
| <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="1"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="2"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="3"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="4"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="5"/> |
| <i>Always</i> | <i>Nearly always</i> | <i>Sometimes</i> | <i>Hardly ever</i> | <i>Never</i> |

The following questions are connected with how did you feel in the last 4 weeks. Answer each question selecting the answer more similar to your state. In the last 4 weeks, for how many time did you feel....

- | | <i>Always
Hardly</i> | <i>nearly
Never
always</i> | <i>A lot
of time</i> | <i>Sometimes</i> | <i>ever</i> |
|-----------------------------|--|--|--|--|---|
| 9. ...untroubled and calm? | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="1"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="2"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="3"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="4"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="5"/> <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="6"/> |
| 10. ...full of energy? | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="1"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="2"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="3"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="4"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="5"/> <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="6"/> |
| 11. ...discouraged and sad? | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="1"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="2"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="3"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="4"/> | <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="5"/> <input style="width: 20px; height: 20px; border: 1px solid black;" type="text" value="6"/> |

12. Did your physical health or your emotional state interfere in your social activities, in family, with your friends, in the last 4 weeks?

- | | | | | |
|--------------------|---------------------------|-----------------------|-------------------------|-------------------|
| 1
<i>Always</i> | 2
<i>Nearly always</i> | 3
<i>Sometimes</i> | 4
<i>Hardly ever</i> | 5
<i>Never</i> |
|--------------------|---------------------------|-----------------------|-------------------------|-------------------|

13. Did you have pain, physical troubles or diseases in the last 4 weeks? (make a choice)

- | | |
|---|---|
| All days | 1 |
| Nearly every day | 2 |
| For about half of time | 3 |
| Many times, but for less than half the time | 4 |
| Rarely | 5 |
| Never | 6 |

14. Did you feel yourself owner of your status, thoughts, emotions or feelings in the last 4 weeks? (make a choice)

- | | |
|-------------------------------------|---|
| Yes, certainly | 1 |
| Yes, nearly completely | 2 |
| Yes, generally | 3 |
| Not too much | 4 |
| No, and that annoys me a little bit | 5 |
| No, and that annoys me a lot | 6 |

15. Have you been irritated by states of tension or because you are on edge, in the last 4 weeks? (make a choice)

- | | |
|--|---|
| Enormously, so much that I could not manage work or things that I should have done | 1 |
| Extremely | 2 |
| Quite a lot | 3 |
| Quite enough to be annoyed of it | 4 |
| A little bit | 5 |
| Not at all | 6 |

16. How much energy or vitality did you feel in the last 4 weeks? (make a choice)

- | | |
|--|---|
| Definitely full of energy, very perky | 1 |
| Enough full of energy for the majority of the time | 2 |
| I had many high peaks and low peaks in my energy and vitality | 3 |
| My level of energy or vitality has been generally low | 4 |
| My level of energy or vitality has nearly always been very low | 5 |
| I felt myself weak, empty, without energy or vitality | 6 |

17. Did you feel sad and discouraged in the last 4 weeks? (make a choice)

- | | |
|---------------|---|
| Never | 1 |
| Hardly ever | 2 |
| Sometimes | 3 |
| A lot of time | 4 |
| Nearly always | 5 |
| Always | 6 |

18. Did you feel well enough to do everything you would or should do well in the last 4 weeks? (make e choice)

- | | |
|-----------------|---|
| Yes, definitely | 1 |
|-----------------|---|

Yes, I did nearly all what I wished or I had to do	2
My health hampered me in some important activities	3
Because of my physical condition, I can just take care of my self	4
I needed some aid in order to look after myself	5
I needed some aid in order to do all or nearly all I hade to do	6

19. Did you feel so sad, discouraged or have you so many problems, to ask yourself if was it even worth going on, in the last 4 weeks? (make the choice)

Yes, enormously, so much I was very close to leave and loose everything	1
Yes, extremely	2
Yes, quite a lot	3
Yes, enough, enough to upset me	4
A little bit	5
Not at all	6

20. Was your daily life interesting for you in the last 4 weeks? (make a choice)

Never	1
Hardly ever	2
Sometimes	3
A lot of time	4
Nearly always	5
Always	6

21. Were you anxious, worried or angry in the last 4 weeks? (make a choice)

Enourmously, enough to feel quite bad	1
Extremely	2
Quite a lot	3
Enough to get upset	4
A little bit	5
Not at all	6

22. Did you feel emotionally stable in the last 4 weeks? (make a choice)

Never	1
Hardly ever	2
Sometimes	3
A lot of time	4
Nearly always	5
Always	6

23. Did you feel happy and quiet in the last 4 weeks? (make a choice)

Never	1
Hardly ever	2
Sometimes	3
A lot of time	4
Nearly always	5
Always	6

24. Did you feel tired, exhausted, knackered or worn out in the last 4 weeks? (make a choice)

Never	1
Hardly ever	2
Sometimes	3
A lot of time	4
Nearly always	5
Always	6

Now we ask you to go on with the following questions related to days prior to this follow up

25. How many times ,during the period of your follow up examinations (*make the choice for each question*)....

	<i>Always Never</i>	<i>Nearly always</i>	<i>a lot of time</i>	<i>Sometimes</i>	<i>Hardly ever</i>
Have you been reassured on your health? 6	1	2	3	4	5
Have you been tranquilized on your health? 6	1	2	3	4	5
Have you been scared because of your health? 6	1	2	3	4	5
Was your health source of anxiety for you? 6	1	2	3	4	5
Did you feel demoralized because of your health? 6	1	2	3	4	5

26. Think about the health care received, are you satisfy (*make the choice for each question*).....

	<i>Not satisfied at all</i>	<i>A little bit</i>	<i>Enough</i>	<i>Very pleased</i>	<i>Extremely</i>
About relationship with the doctors	1	2	3	4	5
About the relationship with the nurses	1	2	3	4	5
About the bureaucratic modalities in order to ask invalidity or exemptions	1	2	3	4	5 documents
About the time, elapsing between reservation of an examination (i.e. US) and its performance	1	2	3	4	5
About common spaces (i.e. dressing room, waiting room)	1	2	3	4	5
About sharing common spaces with other patients	1	2	3	4	5
About information, which were given by the doctor during the visit 1 2	3	4		5	

27. Think about the exams that you have just done (*make a choice for each question*) ...

	<i>Extremely</i>	<i>Not at all</i>	<i>A little bit</i>	<i>Very</i>	<i>much</i>
Were you worried that your condition would get worse?		1	2	3	4
Did you have physical problems or disturbances?		1	2	3	4
Did the examination interfere with your daily activities?		1	2	3	4

28. Have you been submitted to any kind of examination that you find written below, in the last 4 weeks? If you answer YES, answer also the other three questions.

Pelvi and abdomen US	NO	YES	Not at all	A little bit	Very much
-----------------------------	-----------	------------	-------------------	---------------------	------------------

	Extremely			
If yes, during the examination, were you worried that your condition get worse?			<u> 1 </u>	<u> 2 </u>
If yes, during the examination, have you had physical problems or disturbances?			<u> 1 </u>	<u> 2 </u>
If yes, did the examination affect your daily activities?			<u> 1 </u>	<u> 2 </u>
Chest, abdomen, pelvic CT	NO YES		Not at all	A little bit
	Extremely		Very	much
If yes, during the examination, were you worried that your condition get worse?			<u> 1 </u>	<u> 2 </u>
If yes, during the examination, have you had physical problems or disturbances?			<u> 1 </u>	<u> 2 </u>
If yes, did the examination affect your daily activities?			<u> 1 </u>	<u> 2 </u>
Pap Smear	NO YES		Not at all	A little bit
	Extremely		Very	much
If yes, during the examination, were you worried that your condition get worse?			<u> 1 </u>	<u> 2 </u>
If yes, during the examination, have you had physical problems or disturbances?			<u> 1 </u>	<u> 2 </u>
If yes, did the examination affect your daily activities?			<u> 1 </u>	<u> 2 </u>
CA125 (blood's examination)	NO YES		Not at all	A little bit
	Extremely		Very	much
If yes, during the examination, were you worried that your condition get worse?			<u> 1 </u>	<u> 2 </u>
If yes, during the examination, have you had physical problems or disturbances?			<u> 1 </u>	<u> 2 </u>
If yes, did the examination affect your daily activities?			<u> 1 </u>	<u> 2 </u>
An other examination	NO YES		Not at all	A little bit
			Very much	Extremely
If yes, during the examination, were you worried that your condition get worse?			<u> 1 </u>	<u> 2 </u>
If yes, during the examination, have you had physical problems or disturbances?			<u> 1 </u>	<u> 2 </u>
If yes, did the examination affect your daily activities?			<u> 1 </u>	<u> 2 </u>

 4

29. Can you show the time employed by you and your companion in occasion to the visits and the examinations? Consider the time starting from the exit from your home till your coming back. If you have done more examinations in the same day, we ask you to subdivide the time employed for each examination. For example: if you have done the Pap Smear and the Pelvi-abdomen US, in the same day, and you have employed 6 hours, you have to put 3 hours for the Pelvi-abdomen US and 3 hours for the Pas Smear.

	Time employed by you	Time employed by your companion
Specific visit	<u> </u> <u> </u> hour	<u> </u> <u> </u> hour
Pelvi and abdomen US	<u> </u> <u> </u> hour	<u> </u> <u> </u> hour
Chest, abdomen, pelvic CT	<u> </u> <u> </u> hour	<u> </u> <u> </u> hour
Pap Smear	<u> </u> <u> </u> hour	<u> </u> <u> </u> hour

CA125 (blood's examination)

hour

hour

30. Consider the time between the last follow up examination and this one: did you meet or consult another doctor (not a doctor working in this Unit) for any problem related to your endometrial disease?

NO **YES** \Rightarrow **How many times?**

31. During this first year of follow up, you might have done a blood's examinations (CA125), a chest- abdomen-pelvic CT, a pelvi and abdomen US and/or a Pap Smear. During this year, have you been submitted to other examinations connected with your endometrial disease? If yes, how many times?

Blood's examinations

Chest, abdomen, pelvic CT

Pelvi and abdomen US Pap Smear