

**Leiden Bother and Needs Questionnaire  
for patients with a Pituitary disease  
(LBNQ-Pituitary)**



Leids Universitair Medisch Centrum  
Center for Endocrine Tumors Leiden (CETL)

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This survey investigates the disease impact and potential healthcare and coaching of patients treated for pituitary gland conditions. Using the following questionnaire, we wish to map condition-related experiences of patients with a pituitary disease. We also wish to use this questionnaire to identify patients' need for both healthcare and coaching in how to deal with specific symptoms and consequences.

We would like to ask you to consider a number of statements about the consequences you (may) experience in your daily life as a result of your pituitary condition. We would like to ask you to circle/tick the answer that most closely represents your opinion. There are no right or wrong answers. If you are unsure about a given answer, try to select the answer that is most applicable.

On the next page, you can see an **example**.

**EXAMPLE**

Every question consists of three elements.

Part A consists of a statement regarding a difficult problem. You will be asked to indicate whether this statement applies to you:

As a consequence of my pituitary condition, I experience **limitations in my daily life**.

- a. ☒ YES / To a certain extent / NO (*If NO, please proceed to the next question*)

You will then be asked to indicate to what extent you experience this problem. You can do so by checking the box that most closely matches your opinion:

- b. This problem and its consequences are a burden to me.

☐ Not at all    ☒ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

Finally you will be asked to indicate how important you find it that the care you receive addresses this specific problem. You can do so by checking the box that most closely matches your opinion:

- c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

1. As a consequence of my pituitary condition, I experience **fatigue**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

2. As a consequence of my pituitary condition, I experience **physical pain**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

3. As a consequence of my pituitary condition, I experience **sleeping problems**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

4. As a consequence of my pituitary condition, I experience **problems concentrating**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

5. As a consequence of my pituitary condition, I experience **difficulties in doing several things at the same time**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

6. As a consequence of my pituitary condition, I experience **memory problems**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

7. As a consequence of my pituitary condition, I experience **difficulties letting go of certain thoughts**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

8. As a consequence of my pituitary condition, I **feel down**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

9. As a consequence of my pituitary condition, I experience **anxiety**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

10. As a consequence of my pituitary condition, I experience **mood swings**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

11. As a consequence of my pituitary condition, I have **a tendency to panic in certain situations**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

12. As a consequence of my pituitary condition, I am **more sensitive to stressful situations than before**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important



13. As a consequence of my pituitary condition, **I am worried about physical symptoms.**

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

14. As a consequence of my pituitary condition, I experience **changes in my personality.**

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

15. As a consequence of my pituitary condition, **my emotional reactions have changed.**

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

16. As a consequence of my pituitary condition, I am **more easily irritated than before**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

17. As a consequence of my pituitary condition, I experience **shame**.

a. YES / S To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

18. As a consequence of my pituitary condition, I experience **loneliness**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

19. As a consequence of my pituitary condition, I experience **guilt towards my partner/close family**.

a. YES / To a certain extent / NO / Not applicable  
(If NO or not applicable, please proceed to the next question)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

20. I do more than is actually good for me (I go beyond my own limits).

a. YES / To a certain extent / NO (If NO, please proceed to the next question)

b. I experience this as a burden:

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

21. I think that every (new) symptom is related to my pituitary condition.

a. YES / To a certain extent / NO (If NO, please proceed to the next question)

b. I experience this as a burden:

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

22. I often brood on the **causes** of my pituitary condition.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. I experience this as a burden:

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

23. I have negative thoughts about the **consequences** of my pituitary condition.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

24. I have negative thoughts about how my pituitary condition will progress.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

25. I have negative thoughts about the extent to which my pituitary condition can be kept under **control**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not	Slightly	Moderately	Considerably	Extremely
important	important	important	important	important

26. As a consequence of my pituitary condition, I experience **physical problems during sex**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not	Slightly	Moderately	Considerably	Extremely
important	important	important	important	important

27. As a consequence of my pituitary condition, I am **less interested in sex**.

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not	Slightly	Moderately	Considerably	Extremely
important	important	important	important	important

28. As a consequence of my pituitary condition, **the relationship with my partner has deteriorated.**

a. YES / To a certain extent / NO / Not applicable  
(If NO or not applicable, please proceed to the next question)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

29. As a consequence of my pituitary condition, **my circle of friends has become smaller.**

a. YES / To a certain extent / NO (If NO, please proceed to the next question)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

30. As a consequence of my pituitary condition, **I feel uncomfortable in social situations.**

a. YES / To a certain extent / NO (If NO, please proceed to the next question)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not important	Slightly important	Moderately important	Considerably important	Extremely important

31. I experience a **lack of understanding of the consequences of my pituitary condition from the people in my social circle.**

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not	Slightly	Moderately	Considerably	Extremely
important	important	important	important	important

32. As a consequence of my pituitary condition, I experience **limitations in engaging in my hobbies.**

a. YES / To a certain extent / NO (*If NO, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not	Slightly	Moderately	Considerably	Extremely
important	important	important	important	important

33. As a consequence of my pituitary condition, I experience **difficulties in performing my work.**

a. YES / To a certain extent / NO / Not applicable  
(*If NO or not applicable, please proceed to the next question*)

b. This problem and its consequences are a burden to me.

☐ Not at all    ☐ Slightly    ☐ Moderately    ☐ Considerably    ☐ Extremely

c. I find attention for this problem from my healthcare providers to be

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not	Slightly	Moderately	Considerably	Extremely
important	important	important	important	important

**Other problems that I experience:**

*(Please also indicate whether you need attention for or support to deal with these problems)*

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**Thank you very much for taking part in this survey!**