PERSuaDER-study

Questionnaire

Study number:	__ __ __ - __ __ __
Date:	____ / ____ / _____ *(dd/mm/yyyy)*

Dear participant,

You are taking part in the PERSuaDER trial. For this study we will ask you to complete a questionnaire at four occasions. The first one will be before your surgery, and then at 1, 3 and 6 months after. On behalf of the PERSuaDER team, we would like to thank you in advance for your time and effort.

The questionnaire will start on the next page. Please bear in mind that there are no “right” or “wrong” answers. Try to answer each question as sincerely as you can. The results will be processed anonymously. This means that they cannot be traced back to you. The average time needed to complete the survey is about 15 minutes.

Instructions:

The questionnaire contains multiple sets of instructions, each relevant to the questions that follow. These instructions will specify how to answer the questions and to which time period they relate to (for example: how you felt last month). Please read the instructions carefully because time periods can change throughout the questionnaire.

You can answer by ticking the box most suited to your condition. When in doubt, try to choose the answer that comes closest to your condition. Please only tick one box per question. It will be explicitly indicated if multiple answers are allowed.

If you would like to change an already filled out answer, please cross out the box ☒ and tick the right one ☒.

Are you on tube feeding? In that case some of the answers related to eating and drinking will be difficult. We ask you to anyway answer these questions as correct as possible.

If you have any questions completing the questionnaire, contact our team at:

Email: PERSuaDER@uzleuven.be
Telefoon: +32 (0) 16 345857

Under each heading, please tick the ONE box that best describes your health TODAY.

EQ1: MOBILITY

I have no problems in walking about ❑
I have slight problems in walking about ❑
I have moderate problems in walking about ❑
I have severe problems in walking about ❑
I am unable to walk about ❑

EQ2: SELF-CARE

I have no problems washing or dressing myself ❑
I have slight problems washing or dressing myself ❑
I have moderate problems washing or dressing myself ❑
I have severe problems washing or dressing myself ❑
I am unable to wash or dress myself ❑

EQ3: USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ❑
I have slight problems doing my usual activities ❑
I have moderate problems doing my usual activities ❑
I have severe problems doing my usual activities ❑
I am unable to do my usual activities ❑

EQ4: PAIN / DISCOMFORT

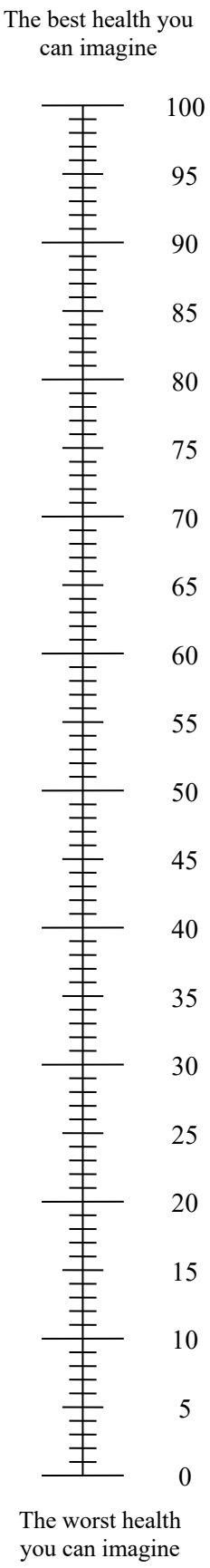
I have no pain or discomfort ❑
I have slight pain or discomfort ❑
I have moderate pain or discomfort ❑
I have severe pain or discomfort ❑
I have extreme pain or discomfort ❑

EQ5: ANXIETY / DEPRESSION

I am not anxious or depressed ❑
I am slightly anxious or depressed ❑
I am moderately anxious or depressed ❑
I am severely anxious or depressed ❑
I am extremely anxious or depressed ❑

We would like to know how good or bad your health is TODAY.
This scale is numbered from 0 to 100.
100 means the best health you can imagine.
0 means the worst health you can imagine.
Please mark an X on the scale to indicate how your health is TODAY.
Now, write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐



We are interested in some things about you and your health.
Please answer all of the questions yourself by ticking the box that best applies to you.

		Not At All	A Little	Quite a Bit	Very Much
C30-1	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	❑	❑	❑	❑
C30-2	Do you have any trouble taking a long walk?	❑	❑	❑	❑
C30-3	Do you have any trouble taking a short walk outside of the house?	❑	❑	❑	❑
C30-4	Do you need to stay in bed or a chair during the day?	❑	❑	❑	❑
C30-5	Do you need help with eating, dressing, washing yourself or using the toilet?	❑	❑	❑	❑

	During the past week:	Not At All	A Little	Quite a Bit	Very Much
C30-6	Were you limited in doing either your work or other daily activities?	❑	❑	❑	❑
C30-7	Were you limited in pursuing your hobbies or other leisure time activities?	❑	❑	❑	❑
C30-8	Were you short of breath?	❑	❑	❑	❑
C30-9	Have you had pain?	❑	❑	❑	❑
C30-10	Did you need to rest?	❑	❑	❑	❑
C30-11	Have you had trouble sleeping?	❑	❑	❑	❑
C30-12	Have you felt weak?	❑	❑	❑	❑
C30-13	Have you lacked appetite?	❑	❑	❑	❑
C30-14	Have you felt nauseated?	❑	❑	❑	❑
C30-15	Have you vomited?	❑	❑	❑	❑
C30-16	Have you been constipated?	❑	❑	❑	❑

	During the past week:	Not At All	A Little	Quite a Bit	Very Much
C30-17	Have you had diarrhea?	❑	❑	❑	❑
C30-18	Were you tired?	❑	❑	❑	❑
C30-19	Did pain interfere with your daily activities?	❑	❑	❑	❑
C30-20	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	❑	❑	❑	❑
C30-21	Did you feel tense?	❑	❑	❑	❑
C30-22	Did you worry?	❑	❑	❑	❑
C30-23	Did you feel irritable?	❑	❑	❑	❑
C30-24	Did you feel depressed?	❑	❑	❑	❑
C30-25	Have you had difficulty remembering things?	❑	❑	❑	❑
C30-26	Has your physical condition or medical treatment interfered with your family life?	❑	❑	❑	❑
C30-27	Has your physical condition or medical treatment interfered with your social activities?	❑	❑	❑	❑
C30-28	Has your physical condition or medical treatment caused you financial difficulties?	❑	❑	❑	❑

For the following questions please circle the number between 1 and 7 that best applies to you:

C30-29 How would you rate your overall health during the past week?

1 ❑	2 ❑	3 ❑	4 ❑	5 ❑	6 ❑	7 ❑
Very poor						Excellent

C30-30 How would you rate your overall quality of life during the past week?

1 ❑	2 ❑	3 ❑	4 ❑	5 ❑	6 ❑	7 ❑
Very poor						Excellent

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by ticking the box that best applies to you.

	During the past week:	**Not At All**	**A Little**	**Quite a Bit**	**Very Much**
OG-1	Have you had problems eating solid foods?	❑	❑	❑	❑
OG-2	Have you had problems eating liquidised or soft foods?	❑	❑	❑	❑
OG-3	Have you had problems drinking liquids?	❑	❑	❑	❑
OG-4	Have you had trouble enjoying your meals?	❑	❑	❑	❑
OG-5	Have you felt full up too quickly after beginning to eat?	❑	❑	❑	❑
OG-6	Has it taken you a long time to complete your meals?	❑	❑	❑	❑
OG-7	Have you had difficulty eating?	❑	❑	❑	❑
OG-8	Have you had acid indigestion or heartburn?	❑	❑	❑	❑
OG-9	Has acid or bile coming into your mouth been a problem?	❑	❑	❑	❑
OG-10	Have you had discomfort when eating?	❑	❑	❑	❑
OG-11	Have you had pain when you eat?	❑	❑	❑	❑
OG-12	Have you had pain in your stomach area?	❑	❑	❑	❑
OG-13	Have you had discomfort in your stomach area?	❑	❑	❑	❑
OG-14	Have you been thinking about your illness?	❑	❑	❑	❑
OG-15	Have you worried about your health in the future?	❑	❑	❑	❑
OG-16	Have you had trouble with eating in front of other people?	❑	❑	❑	❑
OG-17	Have you had a dry mouth?	❑	❑	❑	❑
OG-18	Have you had problems with your sense of taste?	❑	❑	❑	❑
OG-19	Have you felt physically less attractive as a result of your disease or treatment?	❑	❑	❑	❑

	During the past week:	**Not At All**	**A Little**	**Quite a Bit**	**Very Much**
OG-20	Have you had difficulty swallowing your saliva?	❑	❑	❑	❑
OG-21	Have you choked when swallowing?	❑	❑	❑	❑
OG-22	Have you coughed?	❑	❑	❑	❑
OG-23	Have you had difficulty talking?	❑	❑	❑	❑
OG-24	Have you worried about your weight being too low?	❑	❑	❑	❑
OG-25	Answer this question only if you lost any hair: If so, were you upset by the loss of your hair?	❑	❑	❑	❑

Question A1. On what date are you completing this questionnaire?

day ☐☐ month ☐☐ year ☐☐☐☐

Question A2. What is your date of birth?

day ☐☐ month ☐☐ year ☐☐☐☐

Question A3. What is your gender?

☐ Male
☐ Female

Question A4. What is the highest level of education you have completed? Look for your highest level of education and check the relevant box.

☐ I have not completed school or any education
☐ Primary or elementary school
☐ GCSE or equivalent
☐ A-Level or equivalent (age 18)
☐ Further Education (can be after age 16 or any time later in life, usually 1-2 years leading to a certificate or diploma)
☐ Master's Degree or Doctorate
☐ Higher education/ University Degree
☐ I completed other education, namely …….
……

Question A5. What is your occupation? Check the box for what best describes your primary occupation.

☐ I am at school, I study
☐ I am in paid employment
☐ I am self-employed
☐ I am a housewife/househusband
☐ I am unemployed
☐ I am disabled for working, for, … % (bodily percentage)
☐ I am retired or have taken early retirement
☐ I do something else, namely ……
……

Question A6. Do you have paid work?

☐ No
☐ Yes

You will first have questions about your job. So, about work for which you are paid. *Do you not have a paid job?* Then continue with question 10. First, read the explanatory notes above question 10.

Question 1. What is your occupation?

.....

Question 2. How many hours a week do you work? Add together all the hours for which you are paid.

…….. hours

Question 3. How many days a week do you work?

…….. days

Question 4. Have you been absent from your work in the past 4 weeks because you were ill?

☐ No
☐ Yes, I was absent for….. days
(*Only count the working days in the past 4 weeks)*

Have you checked the "Yes" box? Then answer question 5.
Otherwise continue with question 7.

Question 5. Have you been absent from your work because of being ill for longer than the entire period of 4 weeks? This refers to an uninterrupted period of absence from work.

☐ No
☐ Yes

Have you checked the "Yes" box? Then answer question 6.
Otherwise continue from question 7.

Question 6. When did you report being ill?

day ☐☐ month ☐☐ year ☐☐☐☐

Continue with question 10. *First, read the explanatory notes above question 10*.

Question 7. Have there been days over the past 4 weeks when you worked but suffered from physical or psychological problems during your work?

☐ No
☐ Yes

Have you checked the "Yes" box? Then answer questions 8 and 9. Otherwise continue with question 10. *First, read the explanatory notes above question 10.*

Question 8. On how many working days have you suffered from physical or psychological problems during your work? Just count the working days over the past 4 weeks.

……. working days

Question 9. On the days when you were suffering from problems, perhaps you were not able to do as much work as normal. On those days, how much work could you do on average? Look at the numbers below. A 10 means that you were able to do just as much as normal on those days. A 0 means that you were not able to do anything on those days. Circle the right number.

I was not able to do anything on those days					I could do around half					I was able to do just as much as normal
0	1	2	3	4	5	6	7	8	9	10

Explanatory notes You may also suffer from your physical or psychological problems during unpaid work. Sometimes you can do less as a result. For example, you cannot care properly for the children or do volunteer work. Or you may not be able to do the shopping or do gardening. **That is what the next questions are about.**

Question 10. Have there been any days on which you were able to do less unpaid work because of your physical or psychological problems? This relates to days over the past 4 weeks.

☐ No
☐ Yes

Have you checked the "Yes" box? Then answer questions 11 and 12. Otherwise go to the next section of the questionnaire.

Question 11. On how many days was this the case? Only count the days in the past 4 weeks.

…….. days

Question 12. Suppose that someone, for example your partner, a family member or an acquaintance, has helped you on these days. And did all that unpaid work for you, that you could not do. How many hours, on average, was that person busy with it on these days?

On average …….. hours on these days

We would like to know which doctors you have consulted in the past 3 months. It is about consultations for yourself. Other healthcare providers also count. For example, the physiotherapist.

Which consultations count?

- Control visits
- Appointments because you had a physical or psychological complaint
- Appointments where the doctor came to your home
- Telephone appointments
- Phone calls with the recipe line

Which consultations do not count?

- Appointments for another person, for example for your child
- Telephone calls to make an appointment

Are you unsure about the exact number of consultations? Please fill in how many consultations you have had approximately.

Question 1a. Have you consulted a general practitioner or nurse practitioner in the past 3 months?

☐ No
☐ Yes

Have you ticked "Yes"? Then answer question 1b. Otherwise, continue with question 2.

Question 1b. How many appointments did you have with your GP and/or nurse practitioner in the past 3 months?

☐ ..... appointments with a doctor
☐ ..... appointments with a nurse practitioner

Question 2. How many appointments did you have with a social worker in the past 3 months?

☐ No appointment
☐ ..... appointments

Question 3. How many appointments did you have with a physiotherapist in the past 3 months? Or with a Caesar therapist, therapist Mensendieck or a manual therapist? Add up all appointments with these therapists.

☐ No appointment
☐ ..... appointments

Question 4. How many appointments did you have with an occupational therapist in the past 3 months?

☐ No appointment
☐ …… appointments

Question 5. How many appointments did you have with a speech therapist in the past 3 months?

☐ No appointment
☐ …… appointments

Question 6. How many appointments did you have with a dietitian in the past 3 months?

☐ No appointment
☐ …… appointments

Question 7. How many appointments did you have with a homeopath in the past 3 months? Or with an acupuncturist? Add up all appointments with these healthcare providers.

☐ No appointment
☐ …… appointments

Question 8. How many appointments did you have with a psychologist in the past 3 months? Or with a psychotherapist or psychiatrist? Add up all appointments with these healthcare providers.

☐ No appointment
☐ …… appointments

Question 9 How many appointments did you have with the company doctor in the past 3 months?

☐ No appointment
☐ …… appointments

Question 10a. Have you received home care in the past 3 months?

☐ No
☐ Yes

Have you ticked "Yes"? Then answer questions 10b through 10d. Otherwise, continue with question 11.

Question 10b. What kind home care have you had in the past 3 months? You can tick more than 1 box.

☐ Housekeeping and domestic help
example: vacuuming, making bed, going for daily groceries
☐ Personal care

example: help with bathing or dressing

☐ Nursing
example: putting on a bandage, administering medication, measuring blood pressure

Question 10c. How many weeks did you have this home care? Count up all weeks in the past 3 months. *Note: a period of 3 months counts 13 weeks*.

Domestic help: ..... weeks in the past 3 months
Personal care: ..... weeks in the past 3 months
Nursing: ..... weeks in the past 3 months

Question 10d. How many hours of home care did you receive on average in these weeks?

Domestic help: on average ..... hours a week
Personal care: on average ..... hours a week
Nursing: on average ..... hours a week

Question 11a. Did you take any medication in the past 3 months?

☐ No
☐ Yes

Have you ticked "Yes"? Then fill in question 11b listing which medications you used and how much. Otherwise, continue with question 12.

Question 11b. What medication did you take in the past 3 months? By medication we mean all drugs that you have received on prescription and medication that you have bought at the pharmacy or drugstore. There are three examples below.

Pay attention: look at the package! It shows how much you had to take at each time. And how often you had to do so per day. ***Have you used more or less? Then enter how much you have actually used.***

What is the name of the medicine?	***How much did you take at each time?*** *Look at the packaging*	***How many times did you take this per day?*** *Look at the packaging*	***On how many days in the past 3 months have you used the medication?***
example 1 Metoprolol (against high blood pressure)	*example* 100 mg	*example* 1 time	*example* 90 days
example 2 Furosemide (diuretic)	*example* 40 mg	*example* 1 time	*example* 26 days (2 x per week, 13 weeks)
example 3 Hydrocortisone cream	*example* -	*example* 1	*example* 14 days
……	……	……	……

……	……	……	……
……	……	……	……
……	……	……	……
……	……	……	……
……	……	……	……
……	……	……	……
……	……	……	……

Question 12. How many times did you visit the emergency room of a hospital for the past 3 months?

☐ Not once
☐ …… times

Question 13. How many times have you been taken to the hospital with an ambulance in the past 3 months?

☐ Not once
☐ …… times

Question 14a. Did you have an appointment at the outpatient clinic of the hospital in the past 3 months? It is about appointments for yourself with a doctor. For example with the cardiologist, rheumatologist or neurologist.

☐ No
☐ Yes

Have you ticked "Yes"? Then fill in question 14b the types of doctors you have visited. And how often. There is an example in the first row. Otherwise, continue with question 15.

Question 14b. Which types of doctors have you been to in hospital for the past 3 months? And how often?

Which type of doctor did you visit in the hospital?	***How often have you been with this doctor in the past 3 months?***
example cardiologist	*example* 2 times
……	……. times

……	……. times
……	……. times
……	……. times
……	……. times
……	……. times
……	……. times
……	……. times
……	……. times
……	……. times

Question 15a. Did you visit the hospital for day care treatment during the past 3 months? So you did not stay overnight. Examples of day care treatments are blood transfusions, renal dialysis or a chemo course.

☐ No
☐ Yes

Have you ticked "Yes"? Then answer questions 15b and 15c. Otherwise, continue with question 16.

Question 15b. For what kind of treatment was this? Was this for more than one type of treatment? Then enter all types of treatments.

Treatment 1 :. .....

Treatment 2:. .....

Treatment 3:. .....

Question 15c. How many times did you have to go to the hospital for these treatments in the past 3 months?

..... times for treatment 1

..... times for treatment 2

..... times for treatment 3

Question 16a. Did you go elsewhere for a day care treatment in the past 3 months? So you did not stay overnight. For example, you went to the day care treatment centre of a residential/care centre or a psychiatric institution. Or to the day care treatment centre of a rehabilitation centre.

☐ No
☐ Yes

Have you ticked "Yes"? Then answer questions 16b and 16c. Otherwise, continue with question 17.

Question 16b. What kind of institution was this? Tick the correct answer. You can tick more than 1 box.

☐ Residential care centre or nursing home
☐ Rehabilitation centre
☐ Mental health institution
☐ Another institution, namely .....
.....

Question 16c. How many times did you have to go here in the past 3 months? Have you ticked more than one box in question 16b? Then enter the number of times you have been there for each institution below.

To a residential care or nursing home: ..... times in the past 3 months

To the rehabilitation centre: ..... times in the past 3 months

To the mental health institution: ..... times in the past 3 months

To the other institution: ..... times in the past 3 months

Question 17a. Have you been admitted to a hospital for inpatient care in the past 3 months? So you had to stay overnight. For example, because you had surgery and could not go home immediately.

☐ No
☐ Yes

Have you ticked "Yes"? Then answer questions 17b and 17c. Otherwise, continue with question 18.

Question 17b. How often have you been admitted to the hospital for inpatient care in the past 3 months?

..... times in the past 3 months

Question 17c. How long have you stayed in the hospital? Have you been in the hospital more than once in the past 3 months? Then add all the days together.

..... days in total in the past 3 months

Question 18a. Have you been admitted elsewhere for your health in the past 3 months? For example in a residential/care centre, psychiatric institution or rehabilitation centre.

☐ No
☐ Yes

Have you ticked "Yes"? Then answer questions 18b and 18c. Otherwise, go to the end of the questionnaire.

Question 18b. What kind of institution was this? You can tick more than 1 box.

☐ Residential care centre or nursing home
☐ Rehabilitation centre
☐ Mental health institution
☐ Another institution, namely .....
.....

Question 18c. How long have you been in this institution? Have you ticked more than one box in question 18b? Then fill in for each setting below how long you have been there.

Have you been anywhere more than 1 time in the past 3 months? Then add all the days together.

In the residential care centre or nursing home: ..... days in the past 3 months

In the rehabilitation centre: ..... days in the past 3 months

In the mental health institution: ..... days in the past 3 months

In the other institution: ..... days in the past 3 months

Question 19a. Have you received help from a family member or acquaintance due to your physical or psychological problems in the past 3 months?

☐ No
☐ Yes

Have you ticked "Yes"? Then answer questions 19b through 19d. Otherwise, continue with question 20.

Question 19b. What kind of help from family members or acquaintances have you had in the past 3 months? You can tick more than 1 box.

☐ Domestic help
example: vacuuming, making bed, shopping, preparing food and drinks, taking care of children
☐ Personal care
example: help with showering or dressing, help with eating and drinking or giving medicines
☐ Practical help

example: support with walking, making trips or visits to acquaintances, visits to the general practitioner or the hospital, arranging help or arranging financial affairs

Question 19c. How many weeks did you have this home care? Count up all the weeks in the past 3 months. *Note: a period of 3 months counts as 13 weeks*.

Domestic help: ..... weeks in the past 3 months

Personal care: ..... weeks in the past 3 months

Practical help: ..... weeks in the past 3 months

Question 19d. How many hours of home care did you receive on average in these weeks?

Domestic help: on average ..... hours a week

Personal care: on average ..... hours a week

Practical help: on average ..... hours a week

Question 20a. What type of transport have you used to go from home to the hospital?

- ☐ Not applicable
- ☐ Pedestrian
- ☐ Bicycle
- ☐ Car
- ☐ Public transport
- ☐ Cab
- ☐ Otherwise, namely ……

Question 20b. What was the one-way distance between your home and the hospital?

This distance was: ……. kilometres

This is the end of the questionnaire. Thank you for your time and effort! If you have any suggestions, remarks or questions regarding the questionnaire, please fill in the box below or contact our study team at:

Mail: PERSuaDER@uzleuven.be

Tel : ###

Any questions, suggestions or remarks? Please note them in the box:

For this questionnaire we used the validated EORTC OG25, QLQC30, and EuroQol-5D-5L tools.