

Quality of Life questionnaire

Version 1, 2017-04-03

## Health and Quality of Life in Men with Prostate Cancer

Thank you for taking part in this study.

A number of questions follow below (58 questions in part 1 and 17 questions in part 2). Provide the answers that best describe you and your situation. If more than one alternative is possible, the question will indicate as much. Please try to answer all the questions.

PLEASE OBSERVE that the term “active surveillance” is used in this questionnaire.

“Active surveillance” is a conservative treatment strategy for men with low-risk prostate cancer that involves close monitoring of the disease using PSA tests and repeat biopsies. When there are signs of disease progression, the patient receives curative treatment through surgery or radiotherapy. A patient is not in active surveillance if:

- 1) A decision to treat the prostate cancer by surgery or radiotherapy is taken within six months from the prostate cancer diagnosis.
- 2) Being monitored after having received treatment of any kind.

Quality of Life questionnaire

Version 1, 2017-04-03

**PART I. Demographics and questions about quality of life****General Questions**

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1. In which year were you born?  
(Give four figures, e.g. 1945)

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2. Are you currently:

- Living with spouse or partner  
 Not in a significant relationship  
 In a significant relationship, but not living together

3. Do you have children?

- No     Yes

4. Do you have grandchildren?

- No     Yes

5. Are you currently:

- Employed  
 Looking for work  
 Retired  
 On long-term sick leave  
 On disability pension

6. What is the highest level of your education?

- Basic education or equivalent  
 Upper secondary, vocational school or equivalent  
 College or university

7. **During the last 4 weeks**, how many hours per have you undertaken at least moderate physical exercise involving an elevated pulse rate (i.e. walking, cycling, swimming, etc.)?

- None  
 Less than 1 hour per week  
 1-3 hours per week  
 More than 3 and up to 7 hours per week  
 More than 7 hours per week

8. What are your smoking habits? (*Only pick one answer*)

Quality of Life questionnaire

Version 1, 2017-04-03

- Smoke everyday  
 Smoke occasionally (less than 1 cigarette per day)  
 Former smoker  
 Never smoked
9. How many units of alcohol (see example below) do you typically drink on a day when you drink alcohol?
- 0 units of alcohol per week  
 1-5 units of alcohol per week  
 6-10 units of alcohol per week  
 11-20 units of alcohol per week  
 More than 20 units of alcohol per week

In the UK, one unit of alcohol is for example:



10. How tall are you?

cm

11. How much do you weigh?

kg

12. Do you have or have you ever had any of the following illnesses? If so, which? (Tick the appropriate box for each question)

- |                                                                                                    |                             |                              |
|----------------------------------------------------------------------------------------------------|-----------------------------|------------------------------|
| A. Heart disease (e.g. angina, heart attack, or heart failure)                                     | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| B. High blood pressure                                                                             | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| C. Pains in the legs when walking owing to poor blood circulation                                  | No                          | <input type="checkbox"/> Yes |
| D. Lung disease (e.g. asthma, chronic bronchitis, or chronic obstructive pulmonary disease (COPD)) | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| E. Diabetes                                                                                        | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| F. Kidney disease                                                                                  | <input type="checkbox"/> No | <input type="checkbox"/> Yes |

Quality of Life questionnaire

Version 1, 2017-04-03

- G. Liver disease  No  Yes
- H. Stroke  No  Yes
- I. Neurological disease (e.g. Parkinson's disease or MS)  No  Yes
- J. Other type of cancer than prostate cancer (in the last 5 years)  No  Yes
- K. Depression  No  Yes
- L. Other psychological illness  No  Yes
- M. Rheumatism  No  Yes
- N. Paralysis  No  Yes
- O. HIV+ or AIDS  No  Yes

(modified from Charlson Comorbidity index Chaudhry et al 2005)

### Questions About Quality of Life

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Answer the following questions by circling the number that best fits your opinion.

13. **During the last 4 weeks**, what has your quality of life been like?

1-----2-----3-----4-----5-----6-----7  
 No quality of life Best possible quality of life

14. **During the last 4 weeks**, has your life felt meaningful?

1-----2-----3-----4-----5-----6-----7  
 Never All the time

15. **During the last 4 weeks**, what has your physical stamina been like?

1-----2-----3-----4-----5-----6-----7  
 No stamina Best possible stamina

16. **During the last 4 weeks**, what has your mental wellbeing been like?

1-----2-----3-----4-----5-----6-----7  
 No wellbeing Best possible wellbeing

Quality of Life questionnaire

Version 1, 2017-04-03

17. **During the last 4 weeks**, what has your physical health been like?

1-----2-----3-----4-----5-----6-----7  
 Worst imaginable health Best imaginable health

18. **During the last 4 weeks**, what has your self-esteem been like?

1-----2-----3-----4-----5-----6-----7  
 No self-esteem Best imaginable self-esteem

### Questions About Depression and Anxiety

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19. **During the last 4 weeks**, have you felt miserable or depressed?

1-----2-----3-----4-----5-----6-----7  
 Never All the time

20. **During the last 4 weeks**, have you experienced worry or anxiety?

1-----2-----3-----4-----5-----6-----7  
 Never All the time

21. **During the last 4 weeks**, have you had difficulties sleeping at night?

- No, never
- Yes, at least once this month
- Yes, at least once a week
- Yes, at least 3 times per week
- Yes, every night

22. **During the last 4 weeks**, have you woken during the night with feelings of worry or anxiety?

- No, never
- Yes, at least once this month
- Yes, at least once a week
- Yes, at least 3 times per week
- Yes, every night

23. **During the last 4 weeks**, have you taken any preparations to help you sleep?

- No, never
- Yes, at least once this month
- Yes, at least once a week
- Yes, at least 3 times per week

Quality of Life questionnaire

Version 1, 2017-04-03

Yes, every evening

24. **During the last 4 weeks**, have you taken any tranquilizers (anti-anxiety medications)?

- No, never  
 Yes, at least once this month  
 Yes, at least once a week  
 Yes, at least 3 times per week  
 Yes, every day

25. **During the last 4 weeks**, have you taken any anti-depressives, i.e medication against feeling low or depressed?

No     Yes

### Questions About Information and Decision on Treatment

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26. I was informed about my prostate cancer:

- At a meeting in person  
 By telephone  
 By mail  
 In another way, which? \_\_\_\_\_

27. When you were informed about your prostate cancer, were you informed in a good way?  
(Circle the number which best describes you or your situation)

1-----2-----3-----4-----5-----6-----7  
 Worst imaginable way Best imaginable way

28. Did you have a friend or relative with you when you were informed about your prostate cancer?

No     Yes

29. How much information have you received from your doctor? (For each row, tick the box that best describes your perception)

	No Information	Little Information	Quite a lot of Information	A great deal of Information
A. About prostate cancer – the illness and its course	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B. About various treatment options for prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Quality of Life questionnaire

Version 1, 2017-04-03

- C. About side effects of the various treatment options
- D. About how the various treatments could affect your quality of life
30. Which treatment options were suitable to you, according to your perception of the information you received from your doctor? (*Multiple answers are possible*)
- Active surveillance (go to checks with PSA tests and MRI examinations, treatment will become relevant if the cancer becomes more serious)
  - Surgical removal of the prostate (radical prostatectomy)
  - Radiotherapy
  - Other treatment, please specify: \_\_\_\_\_
31. How much did you influence the treatment decision-making?
- Not at all
  - A little
  - Moderately
  - Very much
32. Are you satisfied with how much you were involved in the decision-making between radiotherapy, surgery or active surveillance?
- No, I wish I had been less involved in the decision-making
  - No, I wish I had been more involved in the decision-making
  - Yes, I am satisfied with how much I was involved in the decision-making
33. How much time passed between your prostate cancer diagnosis and the treatment decision-making?
- The treatment decision was made right after I received my diagnosis
  - 1-4 weeks
  - 2-3 months
  - More than 3 months
34. In your opinion, were you given enough time to think before the treatment decision was made?
- No, I wish I had been given less time before the decision was made
  - No, I wish I had been given more time before the decision was made
  - Yes, I was given enough time before the decision was made
35. In your opinion, did the right amount of time pass between the treatment decision-making and the treatment start?
- Not applicable*, I have not received treatment for my prostate cancer
  - No, I wish there had been less time between the treatment decision-making and the treatment start

Quality of Life questionnaire

Version 1, 2017-04-03

- No, I wish there had been more time between treatment decision and treatment start
- Yes, I am satisfied with the amount of time that passed between treatment decision-making and the treatment start
36. What type of doctor(s) did you discuss your prostate cancer with before the treatment decision was made?
- Urologist (doctor that performs prostate cancer surgery)
- Oncologist (doctor that gives radiotherapy treatment)
- Other type of doctor
37. Do you have access to a nurse navigator?
- No    Yes    I don't know
38. Where have you searched for information about prostate cancer? (NB! Several alternatives possible.)
- I have not searched for information about prostate cancer
- Internet
- Radio
- TV
- Newspapers
- Patient brochures
- Patients association
- Friends or family
- If elsewhere, please specify: \_\_\_\_\_

### Questions About Your Treatment

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39. Which alternatives below describes your situation? (Cross of one alternative)
- I am currently on active surveillance (i.e. my prostate cancer is closely monitored using PSA tests and repeat biopsies and curative treatment is initiated if the disease progresses)
- I started on active surveillance but have since received curative treatment
- I received treatment directly (within 6 months from my prostate cancer diagnosis)
40. If you have received treatment for prostate cancer, which treatment(s) have you received up to date?
- (NB! Several alternatives are possible. You may, for example, have undergone an operation and radiotherapy, radiotherapy and hormone treatment, or just hormone treatment.)
- I have not had any treatment. I am on active surveillance
- Removal of the whole prostate gland (so-called radical prostatectomy)
- Radiotherapy of the prostate gland
- Hormone treatment in connection with radiotherapy of the prostate gland
- Only hormone treatment by injection (so-called GnRH-analogue)
- Only hormone treatment with pills (e.g. Bicalutamide, or Casodex)



Quality of Life questionnaire

Version 1, 2017-04-03

- Testicles have been removed by means of operation
41. If you were on active surveillance for prostate cancer but later received treatment, or if you are still on active surveillance - which of the following alternative(s) influenced the decision?
- Not applicable, I was never on active surveillance, I received treatment directly
- A.** I am/was not particularly worried about the prostate cancer
- I completely agree  
 I largely agree  
 I agree a little  
 I do not agree at all
- B.** I did not want to risk leaking urine
- I completely agree  
 I largely agree  
 I agree a little  
 I do not agree at all
- C.** I did not want to risk impairing my sexual function
- I completely agree  
 I largely agree  
 I agree a little  
 I do not agree at all
- D.** I did not want to risk getting bowel problems
- I completely agree  
 I largely agree  
 I agree a little  
 I do not agree at all
- E.** I preferred not undergoing any treatment
- I completely agree  
 I largely agree  
 I agree a little  
 I do not agree at all
- F.** I wanted to postpone any treatment until it was deemed necessary
- I completely agree  
 I largely agree  
 I agree a little  
 I do not agree at all
- G.** I felt uneasy about the available treatment strategies (surgery and radiotherapy)
- I completely agree  
 I largely agree  
 I agree a little

Quality of Life questionnaire

Version 1, 2017-04-03

- I do not agree at all

**H.** My doctor recommended active surveillance

- I completely agree  
 I largely agree  
 I agree a little  
 I do not agree at all

42. What do you believe will happen in the future when it comes to your prostate cancer? (*Cross of one alternative.*)

- I believe that my disease will progress/recur and require treatment within 2 years  
 I believe that my disease will progress/recur and require treatment within 5 years  
 I believe that my disease will progress/recur and require treatment within 10 years  
 I believe that my disease is harmless

43. If you were on active surveillance but then received treatment, please answer the following questions (A to C).

- Not applicable, I was never on active surveillance, I received treatment directly

**A.** For how long were you on active surveillance?

- Less than a year  
 1-2 years  
 2-3 years  
 3-5 years  
 More than 5 years

**B.** Why was the active surveillance terminated and treatment initiated? (*NB! Several alternatives possible.*)

- The PSA level was rising  
 The prostate biopsies showed a more aggressive tumour  
 The initiative was mine and had nothing to do with the PSA level or prostate biopsies  
 The initiative was my doctor's and had nothing to do with the PSA level or prostate biopsies  
 If other reason, please specify: \_\_\_\_\_

**C.** If it was your initiative to terminate active surveillance and start treatment but the reason for this was not that the tumour was progressing, what was the reason: (*NB! Several alternatives possible.*)

- I was worried  
 My partner was worried  
 My friends were worried  
 I wanted to avoid further biopsies  
 I wanted to avoid the repeated PSA tests  
 I just wanted to have treatment done  
 Other reason

Quality of Life questionnaire

Version 1, 2017-04-03

If other reason, please describe it:

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44. Are you worried that your medical problems, if you have any, are related to prostate cancer?

- Not at all
- A little
- Moderately
- Very much

45. Do you believe that you will die from prostate cancer?

- No
- Yes

46. Have you told anyone about your prostate cancer? (NB! Several alternatives possible.)

- I have not told anyone about my prostate cancer
- Partner
- Children
- Grandchildren
- Close friend(s)
- Colleague(s)
- Other person(s)

47. If you are concerned about telling others about your prostate cancer, what are the reasons for this? (NB! Several alternatives possible.)

- Not applicable, I do not hesitate to tell others about the prostate cancer
- It felt too private
- I did not want to worry others
- I believe that people would act differently towards me if I told them about the prostate cancer
- I believe that telling others would affect my career
- Other reason

If other reason, please describe it:

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### Questions About Your Prostate Cancer Checks

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48. Who monitors your prostate cancer? (NB! Several alternatives possible.)

- Doctor
- Nurse

Quality of Life questionnaire

Version 1, 2017-04-03

49. When was your last prostate cancer check?
- Less than one week ago
  - Less than one month ago
  - Less than three months ago
  - More than three months ago
50. When did you last take a PSA test?
- Less than one week ago
  - 1-4 weeks ago
  - 1-3 months ago
  - More than three months ago
51. When is your next scheduled PSA test?
- In less than one week
  - In 1-4 weeks
  - In more than one month
  - I don't know
52. In connection with your prostate cancer check, do you feel reminded of your cancer disease?
- Not at all
  - A little
  - Moderately
  - Very much
53. In connections with your prostate cancer check, do you feel worried about what the PSA test will show?
- Not at all
  - A little
  - Moderately
  - Very much
54. In connection with your prostate cancer checks, do you feel worried about needing to take new tissue samples (biopsies) from your prostate (if you are on active surveillance)?
- Not applicable, I have received treatment for prostate cancer
  - Not at all
  - A little
  - Moderately
  - Very much
55. In connection with your prostate cancer check, do you feel worried that your prostate cancer has spread (metastasized) to a different part of your body?
- Not at all

Quality of Life questionnaire

Version 1, 2017-04-03

- A little
- Moderately
- Very much

56. If you feel worried in connection with your prostate cancer check, how long does the worry last?

- Not applicable, I am not worried before the prostate cancer check
- Only a day or so, at the time of the prostate cancer check
- From the day I receive the invitation to the time of the prostate cancer check
- From before I receive the invitation
- I am always, more or less, worried

57. Has your prostate cancer diagnosis had an affect on your life style in any way, and if so, in what areas?

- |    |                                             |                                             |                                    |                                          |
|----|---------------------------------------------|---------------------------------------------|------------------------------------|------------------------------------------|
| A. | Type of food                                | <input type="checkbox"/> I eat less healthy | <input type="checkbox"/> Unchanged | <input type="checkbox"/> I eat healthier |
| B. | Exercise                                    | <input type="checkbox"/> I exercise less    | <input type="checkbox"/> Unchanged | <input type="checkbox"/> I exercise more |
| C. | Interest in social activities/relationships | <input type="checkbox"/> Less               | <input type="checkbox"/> Unchanged | <input type="checkbox"/> More            |
| D. | Interest in religion/philosophy             | <input type="checkbox"/> Less               | <input type="checkbox"/> Unchanged | <input type="checkbox"/> More            |

58. How has prostate cancer affected your economic situation?

- Impaired
- Unchanged
- Improved

## PART II. Questionnaire for Symptoms (EPIC-26)

The next few questions concern problems you may be experiencing.  
(Tick the appropriate box for each question)

I. **Over the past 4 weeks**, how often has your urine leaked?

- More than once a day
- About once a day
- More than once a week
- About once a week
- Rarely or never

Quality of Life questionnaire

Version 1, 2017-04-03

2. Which of the following alternatives best describes how well you have been able to control your urinating **during the last 4 weeks?**

- No urinary control whatsoever  
 Drip all the time  
 Drip a little occasionally  
 Full control

3. On average **over the last 4 weeks**, how many incontinence pads or adult diapers have you used per day owing to urine leakage?

- None  
 1 per day  
 2 per day  
 3 or more per day

4. How large a problem, if any, have the following symptoms been **during the last 4 weeks?** (Cross of one alternative for each sub-question.)

	None	Very Little	Little	Moderate	Large
A. Dripping or leaking urine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B. Pain or burning on urination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C. Bleeding with urination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D. Weak urine stream or incomplete emptying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E. Need to urinate frequently during the day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Overall, how large a problem has urination been for you **during the last 4 weeks?** (Tick the box that best describes your perception.)

- No problem  
 Very little problem  
 Little problem  
 Moderate problem  
 Large problem

6. How large a problem, if any, have the following symptoms been for you? (Cross of one alternative for each sub-question.)

None    Very Little    Little    Moderate    Large

Quality of Life questionnaire

Version 1, 2017-04-03

- A. Urgent need to empty the bowel immediately
- B. Need to empty the bowel often
- C. Inability to control the bowel function
- D. Bloody in faeces
- E. Abdominal/pelvic/rectal pain
7. Overall, how large a problem has your bowel emptying been for you **during the last 4 weeks?** (Tick the box that best describes your perception.)
- No problem
- Very little problem
- Little problem
- Moderate problem
- Large problem
8. How would you rate each of the following **during the last 4 weeks?** (Cross of one alternative for each sub-question.)
- |                                             | Very Poor<br>to Non-existent | Poor                     | Moderate                 | Good                     | Very Good                |
|---------------------------------------------|------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| A. Your ability to get an erection          | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| B. Your ability to achieve orgasm (climax)? | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
9. How would you describe the usual quality of your erections **during the last 4 weeks?** (Tick the box that best describes your perception.)
- None at all
- Not firm enough for any sexual activity
- Firm enough for masturbation and foreplay only
- Firm enough for intercourse
10. How would you describe the frequency of your erections **during the last 4 weeks?** (Tick the box that best describes your perception.)
- I NEVER obtained an erection when desired
- Less than half of the times I wanted an erection
- Around half of the times I wanted an erection
- More than half of the times I wanted an erection
- Whenever I wanted an erection
11. Overall, how would you rate your sexual capability **during the last 4 weeks?**

Quality of Life questionnaire

Version 1, 2017-04-03

12. (Tick the box that best describes your perception.)

- Very poor  
 Poor  
 Moderate  
 Good  
 Very good

12. How large a problem have you had with your sexual capability **during the last 4 weeks?**  
 (Tick the box that best describes your perception)

- No problem  
 Very little problem  
 Little problem  
 Moderate problem  
 Large problem

13. How large a problem, if any, have the following symptoms been for you during the last 4 weeks?  
 (Cross of one alternative for each sub-question)

	None	Very little problem	Little problem	Moderate problem	Large problem
A. Hot flushes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B. Tenderness/ swelling in chest	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C. Feeling low	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D. Lacking energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E. Change in body weight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. Which of the following medications/sexual aids have you tried and how did they work? (Cross of one alternative for each sub-question)

	Have not tried	Tried but it did not help	Helped but not using it now	Helps and I use it now and then	Helps and I always use it in connection with sexual activity
A. Viagra, Sildenafil, Cialis, Levitra or other medications? If other pills, please give name: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B. Bondil (gel in urethra)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C. Caverject (injection in the penis)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D. Vacuum pump?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E. Other? If so, please state what: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. How long did your erection usually last with the aid of medication/sexual aid during the last 4 weeks?  
 (Tick the box that best describes your perception)

- Not relevant, I do not use medications or sexual aids



Quality of Life questionnaire

Version 1, 2017-04-03

- Non-existent
- Insufficient for any kind of sexual activity
- Sufficient for masturbation and foreplay
- Sufficient for intercourse

16. Are you **satisfied** with your sexual life?  
(Circle the number which best describes you or your situation)

1-----2-----3-----4-----5-----6-----7  
Not at all satisfied Completely satisfied

**Finally, we would like to ask you**

17. Overall, how satisfied are you with the medical care you have received as a prostate cancer patient?  
(Personalised service, information, etc.)

(Circle the number which best describes you or your situation)

1-----2-----3-----4-----5-----6-----7  
Not satisfied at all Completely satisfied

Is there anything else that you think is important concerning your illness that we have failed to ask about? Please write and tell us!

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**THANK YOU FOR YOUR ANSWERS!**