Filled in by the registry secretariat

Patient number: ☐☐☐☐☐☐ **Time point:** ☐☐☐

Please fill in the date the questionnaire was completed: (Year-Month-Day):

☐☐☐☐-☐☐-☐☐

e.g. 2005-05-15

Personal Identification Number (Year-Month-Day-Control number)

☐☐☐☐-☐☐-☐☐-☐☐☐☐

e.g. 1945-06-28-8519

Please answer the questions by marking the appropriate level with ☒ how you experienced your symptoms during the *last month.*
Some questions may be answered with multiple ☒

Questions regarding information/participation

	Not at all	A little	Quite a bit	Very much
1. Did the doctor explain the risks and benefits with the treatment/examination in a way that you understood?	☐	☐	☐	☐
2. Did the information you received before the treatment/examination harmonize with how you felt afterwards?	☐	☐	☐	☐
3. Did you feel that you participated in decisions regarding your care and treatment, as much as you wanted to?	☐	☐	☐	☐

During your current disease course or treatment, how much information have you received on:

	Not at all	A little	Quite a bit	Very much
4. The diagnosis of your disease?	☐	☐	☐	☐
5. The extent of your disease?	☐	☐	☐	☐
6. The possible side-effects of your treatment?	☐	☐	☐	☐
7. The expected effects of the treatment on disease symptoms?	☐	☐	☐	☐

8. The effects of the treatment on sexual activity?	☐	☐	☐	☐

General questions regarding your health

9. How would you rate your overall health?	Very poor	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	Excellent
10. How would you rate your overall quality of life?	Very poor	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	Excellent

	Not at all	A little	Moderately	A lot
11. How much does your prostate cancer disease or its treatment affect your daily activities?	☐	☐	☐	☐
12. Are you worried because of your prostate cancer disease?	☐	☐	☐	☐

Questions regarding the urinary tract

	Not at all	A little	Moderately	A lot
13. Do you have problems from the urinary tract?	☐	☐	☐	☐
14. Do you have a weak urinary stream?	☐	☐	☐	☐
15. Do you have frequent urges to urinate?	☐	☐	☐	☐
16. How much do your urinary problems affect your daily activities?	☐	☐	☐	☐
17. How much urine do you leak?	☐	☐	☐	☐

18. Do you have urinary leakage?	☐ Never	☐ Sometimes leak when coughing or sneezing, and/or use of pads during certain physical activity, e.g. sporting activity, gardening	☐ Always use pads (except sometimes at night) but they are not always wet	☐ Always use pads that need to be changed because they are wet	☐ Continuous leakage and use of pads or diapers that need to be changed continuously

19. How often do you leak urine?	☐ I do not leak urine ☐ At least once a month ☐ At least once a week ☐ At least 3 times per week ☐ At least once a day ☐ At least twice a day

20. On which occasion(s) do you have urinary leakage? (Multiple answers possible)	☐ I do not leak urine ☐ When coughing, sneezing and/or laughing ☐ When lifting heavy objects ☐ When changing position (lying-sitting, sitting-standing) ☐ When going for walks ☐ When feeling an urge to urinate ☐ I leak urine without any exertion

21. How many pads do you use per 24 hours because of urinary leakage?	☐ I do not use any pads ☐ Less than 1 per 24 hours ☐ About 1 per 24 hours ☐ About 2 per 24 hours ☐ About 3-4 per 24 hours ☐ About 5 or more per 24 hours

22. If you use pads: what type/size of pads do you use because of urinary leakage?	☐ Toilet paper ☐ Attends 1 (40ml) ☐ Attends 2 (60ml) ☐ Molimed Active (80ml) ☐ Tena 1 (100ml) ☐ Tena 2 (160ml) ☐ Molimed protect (200ml) ☐ Abriman Slipguard (300ml) ☐ Other/I do not know

23. If you were to spend the rest of your life with your urinary function the way it is now, how would you feel about that?	☐ It would not bother me at all ☐ It would bother me a little ☐ It would bother me a moderate amount ☐ It would bother me a lot

Questions regarding bowel function

	Not at all	A little	Moderately	A lot
24. Do you have any problems with your stools?	☐	☐	☐	☐
25. Do you have to rush to the toilet because you have the urge to pass stools?	☐	☐	☐	☐
26. Do you have any leakage of stools?	☐	☐	☐	☐
27. Do you have mucus in your stools?	☐	☐	☐	☐
28. Do you have blood in your stools?	☐	☐	☐	☐
29. How much do your bowel problems affect your daily activities?	☐	☐	☐	☐
30. How much stool do you leak?	☐	☐	☐	☐

31. How often do you leak stools?

- ☐ I do not leak stools
- ☐ At least once a month
- ☐ At least once a week
- ☐ At least 3 times per week
- ☐ At least once a day
- ☐ At least twice a day

32. How many pads do you use per 24 hours because of leakage of stools?

- ☐ I do not use any pads
- ☐ Less than 1 per 24 hours
- ☐ About 1 per 24 hours
- ☐ About 2 per 24 hours
- ☐ About 3-4 per 24 hours
- ☐ About 5 or more per 24 hours

33. On which occasion(s) do you have leakage of stools?
(Multiple answers possible)

- ☐ I do not leak stools
- ☐ When coughing, sneezing and/or laughing
- ☐ When lifting heavy objects
- ☐ When changing position (lying-sitting, sitting-standing)
- ☐ When passing gas
- ☐ When going for walks
- ☐ When feeling an urge to pass stools
- ☐ I leak stools without any exertion

34. If you use pads: what type of pads do you use because of leakage of stools?	☐ Toilet paper ☐ Tena for men ☐ Sanisoft (carbon filter) ☐ Other/I do not know

35. If you were to spend the rest of your life with your bowel function the way it is now, how would you feel about that?	☐ It would not bother me at all ☐ It would bother me a little ☐ It would bother me a moderate amount ☐ It would bother me a lot

Questions about sex life

36. Do you have a partner?	☐ Yes ☐ No

	Not at all	A little	Moderately	A lot
37. Do you have any problem with your sex life?	☐	☐	☐	☐

38. Are you sexually active?	☐ Yes, continue to **question 40a** ☐ No

39. If you are not sexually active, how come? Please answer the question, and then continue to **question 43**	☐ Little or no sexual desire ☐ Erection problems ☐ My partner has little or no sexual desire

40a. Have you used any potency aids during sexual activity?	☐ No ☐ Yes, Injection/syringe treatment (e.g. Caverject) ☐ Yes, An applicator with a medicated pellet that is inserted into the urethra (e.g. Bondil) ☐ Yes, Pill (e.g.. Viagra, Cialis, Levitra) ☐ Yes, Vacuum pump ☐ Yes, Other 40b **If Yes, how often**? ☐ Sometimes ☐ Oftentimes ☐ Always

41. When was the last time you were sexually active?	☐ Last week ☐ Last month ☐ Last six months ☐ Last 12 months ☐ Not during the last 12 months

42. If you responded that you are sexually active- how often do you experience orgasm?	☐ Never	☐ Occasionally	☐ Fewer than half of the time	☐ About half of the time	☐ More than half of the time	☐ Always or almost always

43. If you were to spend the rest of your life with your sexual function the way it is now, how would you feel about that?	☐ It would not bother me at all ☐ It would bother me a little ☐ It would bother me a moderate amount ☐ It would bother me a lot

Please mark with ☒ the alternative that best describes your situation as it is **WITHOUT** any potency aids.

Mark only one answer for each question.

	Very low or no	Low	Moderate	High	Very high
44. During the last 6 months, how do you rate your confidence that you could get and keep an erection?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

45. During the last 6 months, when you had erections with sexual stimulation, how often were your erections hard enough for penetrating your partner?	No sexual activity	Almost never / never	A few times (less than half of the time)	Sometimes (about half of the time)	Most times (more than half of the time)	Almost always / always
	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

46. During the last 6 months, during sexual intercourse, how often were you able to maintain your erection after you had penetrated your partner?	Did not attempt intercourse	Almost never / never	A few times (less than half of the time)	Sometimes (about half of the time)	Most times (more than half of the time)	Almost always / always
	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

47. During the last 6 months, how difficult was it to maintain your erection to completion of intercourse?	Did not attempt intercourse	Extremely difficult	Very difficult	Difficult	Slightly difficult	Not difficult
	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

SATISFACTION 48. During the last 6 months, when you attempted sexual intercourse, how often was it satisfactory for you?	Did not attempt intercourse	Almost never / never	A few times (less than half of the time)	Sometimes (about half of the time)	Most times (more than half of the time)	Almost always / always
	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

THIS FORM IS ONLY FILLED IN IF YOU HAVE RESPONDED THAT YOU **USE** POTENCYAIDS.

Mark only one answer for each question.	Very low or no	Low	Moderate	High	Very high
49. During the last 6 months, how do you rate your confidence that you could get and keep an erection?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

50. During the last 6 months, when you had erections with sexual stimulation, how often were your erections hard enough for penetrating your partner?	No sexual activity	Almost never / never	A few times (less than half of the time)	Sometimes (about half of the time)	Most times (more than half of the time)	Almost always / always
	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

51. During the last 6 months, during sexual intercourse, how often were you able to maintain your erection after you had penetrated your partner?	Did not attempt intercourse	Almost never / never	A few times (less than half of the time)	Sometimes (about half of the time)	Most times (more than half of the time)	Almost always / always
	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

52. During the last 6 months, how difficult was it to maintain your erection to completion of intercourse?	Did not attempt intercourse	Extremely difficult	Very difficult	Difficult	Slightly difficult	Not difficult
	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

SATISFACTION 53. During the last 6 months, when you attempted sexual intercourse, how often was it satisfactory for you?	Did not attempt intercourse	Almost never / never	A few times (less than half of the time)	Sometimes (about half of the time)	Most times (more than half of the time)	Almost always / always
	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

THANK YOU FOR YOUR PARTICIPATION!