NPCR National Prostate Cancer Register of Sweden

To be filled in by the registry secretariat

Patient no: ☐☐☐☐☐☐ **Time:** ☐☐☐

Date of completion of questionnaire: (Year- Month- Day):

☐☐☐☐-☐☐-☐☐

e.g. 2016-05-15

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

☐☐☐☐-☐☐-☐☐-☐☐☐☐

e.g. 1945-06-28-8519

Answer by marking with ☒ the level that best reflects your experiences *during the past month.*

Questions about information/participation

	Not at all	Some	Moderately	Much/Very
1. Do you feel that you participated in the decisions about your care and treatment as much as you wanted?	☐	☐	☐	☐

2. Do you have a named contact nurse?	☐ Yes	☐ No	☐ I do not know

During your present illness or treatment, how much information have you received about:

	Not at all satisfying	To some extent satisfying	Moderately satisfying	Very satisfying
3. Possible side effects of your treatment?	☐	☐	☐	☐
4. The effect of the treatment on your sex life?	☐	☐	☐	☐

General questions about your health:

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

	Not at all	A little	Moderately	Much/Very
7. How much does your prostate cancer illness or treatment affect your daily activities?	☐	☐	☐	☐
8. Do you feel worried?	☐	☐	☐	☐

Questions about your urination, *during the past month:*

	Not at all	A little	Moderately	Much/Very
9. Are you happy with how your urination function?	☐	☐	☐	☐
10. Is your urine stream weak?	☐	☐	☐	☐
11. Do you experience urinary urgency?	☐	☐	☐	☐
12. How much urine leakage do you experience?	☐	☐	☐	☐

13. Do you have urine leakage?	☐ Never	☐ I leak sometimes when coughing, sneezing, and/or I use a pad when I must exert myself, e.g., sports, work in the garden or yard	☐ I use pads all the time (except possibly during the night), but they are not always wet	☐ I use pads all the time and must change them because they are wet	☐ I leak continuously and need large pads or diapers that must be changed continuously

14. How many pads do you use per 24 hours due to urinary leakage?

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

15. If you were to live the rest of your life with your urinary tract function just as it is now, how would you experience this?

- ☐ It would not bother me at all
- ☐ It would bother me a little
- ☐ It would bother me moderately
- ☐ It would bother me very much

Questions about bowel function, *during the past month:*

	Not at all	A little	Moderately	Much/Very
16. Are you happy with how your bowel works?	☐	☐	☐	☐
17. Do you experience urgency to defecate?	☐	☐	☐	☐
18. Do you have mucus in your stool?	☐	☐	☐	☐
19. Do you have blood in your stool?	☐	☐	☐	☐
20. How much faecal leakage do you experience?	☐	☐	☐	☐

21. Do you have faecal incontinence?	☐ Never	☐ I leak sometimes when I cough, sneeze laugh, lift heavy or when I stand up from a sitting position	☐ I leak when letting gas	☐ I use a pad/diaper continuously that must be changed because they are dirty	☐ I leak continuously and need large pads or diapers that must be changed continuously

22. How many pads do you use per 24 hours due to faecal leakage?	☐ I do not use pads ☐ Less than 1 per 24 hours ☐ Approximately 1 per 24 hours ☐ Approximately 2 per 24 hours
23. If you were to live the rest of your life with your defecation function just as it is now, how would you experience this?	☐ It would not bother me at all ☐ It would bother me a little ☐ It would bother me moderately ☐ It would bother me very much

Questions about your sexual life, *during the past month*

	Not at all	A little	Moderately	Much/Very
24. Are you happy with your sexual life?	☐	☐	☐	☐

25. Do you have a partner?	☐ Yes ☐ No
26. Are you sexually active (with or without a partner)?	☐ Yes, go to **question 28a** ☐ No

27. If you are not sexually active, what is the reason? Answer the question and then proceed to **question 30**	☐ Little or no desire ☐ Problems with erection ☐ My partner has little or no desire ☐ Other cause/causes

28a. Have you used some kind of potency restoration method for sexual activity?	☐ No ☐ Yes, self-injection treatment (e.g. Caverject) ☐ Yes, substance inserted into the urethra (e.g. Bondil) ☐ Yes, pills (e.g. Viagra, Cialis, Levitra) ☐ Yes, vacuum pump ☐ Yes, other 28b **If Yes, how often**? ☐ Sometimes ☐ Most of the times ☐ Always

29. How is your erection? (Answer even if you use Viagra, Sildenafil or Cialis)	☐ Non-existent ☐ Insufficient for any kind of sexual activity ☐ Sufficient for masturbation and foreplay ☐ Sufficient for intercourse

Mark with ☒ the alternative best describing your situation regardless of whether you use any potency restoration method
Mark only one alternative per question.

	Very weak or non-existent	Weak	Median	Strong	Very strong
30. How would you asses your faith in getting and keeping an erection the past month?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

	No sexual activity has occurred	Never or almost never	Less than half of the times	Half of the times	More than half of the times	Almost always or always
31. How often after sexual stimulation has your erection, during the past month, been enough for penetration?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

32. How often have you, during intercourse, been able to keep your erection after penetration the past month?	No attempts of intercourse have occurred	Almost never or never	Less than half of the times	Half of the times	More than half of the times	Almost always or always
	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

33. How difficult have you found it to keep your erection until the end of the intercourse the past month?	No attempts of intercourse have occurred	Very great difficulties	Great difficulties	Difficult	Some difficulties	No difficulties
	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

SATISFACTION 34. When you have tried to have intercourse in <u>the past month</u>, how often have you experienced it as satisfying?	No attempts of intercourse have occurred	Almost never or never	Less than half of the times	Half of the times	More than half of the times	Almost always or always
	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

35. If you were to live the rest of your life with your sexual function just as it now is, how would you experience this?	☐ It would not bother me at all ☐ It would bother me some ☐ It would bother me moderately ☐ It would bother me much

Thank you for your cooperation!

National Prostate Cancer Register of Sweden

FOR MORE INFORMATION ABOUT THE QUESTIONNAIRE CONTACT:

Your treating clinic or National Prostate Cancer Register web page: www.npcr.se