Study Number | | | | | | |

MAPS

Men After Prostate Surgery

12 month Questionnaire

CONFIDENTIAL

MAPS TRIAL

MEN'S HEALTH AFTER PROSTATE SURGERY

Thank you for helping us with our research into urinary incontinence after prostate surgery. We would be very grateful if you could complete and return this questionnaire.

Thank you for taking the time to help us with our research.

ISRCTN No:87696430
Version 2 October 2005

12m Q

HOW TO FILL IN THIS QUESTIONNAIRE

Most questions can be answered by putting numbers or a tick in the appropriate box or boxes. Please print your answers carefully within the boxes like this:

2	7	OR	M	I	K	E	OR	✓

If you make a mistake, shade out the wrong box completely and tick the correct one like this

e.g. If you ticked often but meant to answer sometimes:

OFTEN		**SOMETIMES**	✓	**NEVER**	

Please try to complete the whole questionnaire.

There are no right or wrong answers.

Sometimes the box you tick tells you to skip forward so that you miss out questions which do not apply to you.

In some questions we would like you to think about different time periods, such as during the last week, during the last 4 weeks or since your prostate operation. Please check the time periods carefully.

Some of the questions ask for answers in your own words, please write these in the boxes provided.

You do not have to answer any question if you do not want to.

Thank you for your help.

SECTION A – URINE SYMPTOMS

When you answer these questions, please think about how you have been in the **LAST WEEK.**

A1 **How often do you leak urine?**
*(Tick **ONE** box only)*

- Never ☐
- About once a week or less often ☐
- Two or three times a week ☐
- About once a day ☐
- Several times a day ☐
- All the time ☐

A2 **We would like to know how much urine <u>you think</u> leaks.**
How much urine do you <u>usually</u> leak (whether you wear protection or not)?
*(Tick **ONE** box only)*

- None ☐
- A small amount ☐
- A moderate amount ☐
- A large amount ☐

A3 **Overall, how much does leaking urine interfere with your everyday life?**
Please choose a number between 0 (not at all) and 10 (a great deal)
*(Tick **ONE** box only)*

Not at all	0	1	2	3	4	5	6	7	8	9	10	A great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	

A4 **If you have not leaked urine in the last week, in which month did you last leak urine?**

(Please enter month and year): **M M** ☐☐ / **Y Y Y Y** ☐☐☐☐

If you do not leak urine now, please go to question **A12**

Otherwise, please go to question **A5**

In the following questions (**A5** to **A9**), we would like to find out when you leak urine.
When you answer these questions, please think about how you have been in the **LAST WEEK.**

A5 **Does urine leak when you cough, sneeze, or are physically active or exercising?**
*(Tick **ONE** box only)*

- Never ☐
- About once a week or less often ☐
- Two or three times a week ☐
- About once a day ☐
- Several times a day ☐
- All the time ☐

A6 **When you feel the need to urinate, do you have to rush urgently to the toilet?**
*(Tick **ONE** box only)*

- Never ☐
- About once a week or less often ☐
- Two or three times a week ☐
- About once a day ☐
- Several times a day ☐
- All the time ☐

A7 **Does urine leak when you have to rush urgently to the toilet?**
*(Tick **ONE** box only)*

- Never ☐
- About once a week or less often ☐
- Two or three times a week ☐
- About once a day ☐
- Several times a day ☐
- All the time ☐

A8 **Does urine leak when you have finished urinating and are dressed?**
*(Tick **ONE** box only)*

- Never ☐
- About once a week or less often ☐
- Two or three times a week ☐
- About once a day ☐
- Several times a day ☐
- All the time ☐

When you answer these questions, please think about how you have been in the **LAST WEEK.**

A9 **Does urine leak at times other than shown in your answers to questions A5, A7 or A8?**
*(Tick **ONE** box only)*

Yes ☐ *Go to **A9a*** No ☐ *Go to **A10***

A9a **If Yes, please give details of when you leak:**

A10 **Do you wear a pad or other protection because of leaking urine?**
*(Tick **ONE** box only)*

Yes ☐ *Go to **A9a*** No ☐ *Go to **A10***

A10a **If Yes, how many pads do you wear in an average day (24 hours)?**

Enter **TOTAL** number of pads you wear in 24 hours ☐☐

A10b **Of these pads, how many do you pay for yourself?**
If you do not pay for them, please enter zero (0) in the boxes

Enter number of pads **YOU PAY FOR** yourself ☐☐

A11 **Do you use pads or protectors on your chair or bed in case you leak urine?**
*(Tick **ONE** box only)*

Yes ☐ *Go to **A11a*** No ☐ *Go to **A12***

A11a **If Yes, how many chair or bed pads do you use in an average day (24 hours)?**

Enter **TOTAL** number of chair and bed pads you use in 24 hours ☐☐

A11b **Of these chair or bed pads, how many do you pay for yourself?**
If you do not pay for them, please enter zero (0) in the boxes

Enter number of chair and bed pads **YOU PAY FOR** yourself ☐☐

A12 **How often do you usually pass urine during the daytime?**

Enter number of times ☐☐

A13 **How often do you usually have to get up at night to pass urine?**

Enter number of times ☐☐

When you answer these questions, please think about how you have been in the **LAST WEEK.**

A14 **Are you using a permanent catheter (inside your bladder) to collect your urine?**

Yes ☐ No ☐

A14 **Do you ever use an external (sheath) catheter to collect your urine?**

Yes ☐ No ☐

SECTION B – CARE YOU HAVE RECEIVED

When you answer these questions, please think about the care you have received **IN THE LAST 3 MONTHS.**

B1 **Have you seen your family doctor (GP) in the last 3 months?**

Yes ☐ *Go to **B1a*** No ☐ *Go to **B2***

B1a **If Yes, approximately how often have you seen your family doctor (GP) in the last 3 months?**

Enter number of times seen GP **for leaking urine** ☐☐

Enter number of times seen GP **for any other reason** ☐☐

B2 **Have you seen a nurse (from your doctor's practice) in the last 3 months?**

Yes ☐ *Go to **B2a*** No ☐ *Go to **B3***

B2a **If Yes, approximately how many times have you seen a nurse from your doctor's practice in the last 3 months?**

Enter number of times seen nurse **for leaking urine** ☐☐

Enter number of times seen nurse **for any other reason** ☐☐

B3 **In the last 3 months, have you seen NHS HOSPITAL staff <u>for leaking urine</u>?**

If yes, enter number of visits

I have seen a hospital doctor **about leaking urine**	Yes ☐ →	Number of visits	☐☐
	No ☐		
I have seen a hospital nurse **about leaking urine**	Yes ☐ →	Number of visits	☐☐
	No ☐		
I have seen a hospital physiotherapist **about leaking urine**	Yes ☐ →	Number of visits	☐☐
	No ☐		

When you answer these questions, please think about the care you have received **IN THE LAST 3 MONTHS.**

B4 **In the last 3 months, have you received any PRIVATE TREATMENT (which you had to pay for yourself) for leaking urine?**

If Yes, enter number of visits

I have seen a private doctor **about leaking urine**	Yes ☐ →	Number of visits	☐☐
	No ☐		
I have seen a private nurse **about leaking urine**	Yes ☐ →	Number of visits	☐☐
	No ☐		
I have seen a private physiotherapist **about leaking urine**	Yes ☐ →	Number of visits	☐☐
	No ☐		

B5 **In the last 3 months, have you been admitted to hospital because of leaking urine?**

Yes ☐ *Go to **B5a*** No ☐ *Go to **B6*** ☐☐

B5a **If you were admitted in the last 3 months, how many nights did you stay in hospital?**

Enter number of nights in hospital ☐☐

B5b **In the last 3 months, have you had an operation for leaking urine?**

Yes ☐ *Go to **B5c*** No ☐ *Go to **B6***

B5c **If Yes, please give the name or type of operation and the date:**

B6 **In the last 3 months, have you taken any medications (from a doctor, or direct from the chemist's) for leaking urine?**

Yes ☐ *Go to **B6a*** No ☐ *Go to **B7***

B6a **If Yes, please give details of medication received in the last 3 months for leaking urine.**
_____Please give drug names (e.g. detrusitol, duloxetine):

When you answer these questions, please think about the care you have received **IN THE LAST 3 MONTHS.**

B7 **Have you had any other treatment or advice for leaking urine in the last 3 months (other than the operation you named in B5c or the drugs you listed in B6a)?**

Yes ☐ *Go to **B7a*** No ☐ *Go to **B8***

B7a **If Yes, please give details of other treatment or advice received in the last 3 months for leaking urine:**

B8 **Are you in paid employment?**

Yes ☐ *Go to **B8a*** No ☐ *Go to **Section C***

B8a **If Yes, approximately how many days off sick have you had <u>for any reason</u> in the last 3 months?**

☐☐☐ days

SECTION C – BOWEL SYMPTOMS

This section is about your bowel symptoms and control of your stool (also called bowel motions or faeces). Many people experience bowel symptoms some of the time. When you answer these questions (**C1** to **C6**), please think about how you have been in the **LAST WEEK.**

C1 **How often do you lose control of or leak stool?**
*(Tick **ONE** box only)*

Never ☐
Occasionally ☐
Sometimes ☐
Most of the time ☐
All of the time ☐

C2 **If you do, how much does this bother you?**
Please choose a number between 0 (not at all) and 10 (a great deal)
*(Tick **ONE** box only)*

Not at all ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 A great deal

When you answer these questions, please think about how you have been in the **LAST WEEK.**

C3 **When you feel the need to open your bowels, do you have to rush urgently to the toilet?**
*(Tick **ONE** box only)*

- Never ☐
- Occasionally ☐
- Sometimes ☐
- Most of the time ☐
- All of the time ☐

C4 **When you have to rush urgently, do you ever lose control of or leak stool?**
*(Tick **ONE** box only)*

- Never ☐
- Occasionally ☐
- Sometimes ☐
- Most of the time ☐
- All of the time ☐

C5 **Do you ever lose control of or leak stool WITHOUT first feeling that you have to rush urgently?**
*(Tick **ONE** box only)*

- Never ☐
- Occasionally ☐
- Sometimes ☐
- Most of the time ☐
- All of the time ☐

C6 **If stool leaks, is this usually solid, liquid or both?**
*(Tick **ONE** box only)*

- Doesn't leak ☐
- Liquid only ☐
- Solid only ☐
- Liquid and solid ☐

C7 **Are you currently receiving ANY treatment or advice for leaking stool?**

Yes ☐ *Go to **C7a*** No ☐ *Go to **C8***

C7a **If Yes, please give details of treatment or advice received for leaking stool:**

C8 **Do you have any of these other bowel problems?**
*(Tick **ALL** boxes that apply to you)*

Ulcerative colitis ☐
Crohn's disease ☐
Irritable bowel syndrome ☐
Constipation ☐

C9 **Are you currently receiving ANY treatment or advice for any of these other bowel problems?**

Yes ☐ *Go to **C9a*** No ☐ *Go to **Section D***

C9a **If Yes, please give details of treatment or advice received for other bowel problems:**

SECTION D – OTHER HEALTH ISSUES

This section is about exercise, weight and other issues to do with your health. When you answer these questions, please think about how you have been in the **LAST WEEK.**

D1 **Have you done any general exercise or fitness activity?**

Yes ☐ *Go to **D2*** No ☐ *Go to **D3***

D2 **If Yes, what sort of exercise have you done?** *(Tick **all** boxes that apply)*

Walking ☐ Swimming ☐ Gardening ☐
Running ☐ Going to the gym ☐ Other *(please give details in D2a)* ☐

D2a **Please give details of other exercise:**

When you answer these questions, please think about how you have been in the **LAST WEEK.**

D3 **Since your prostate operation, have you changed how you exercise?**
*(Tick **ONE** box only)*

- No, I have made no changes ☐
- I take LESS exercise than I did ☐
- I take MORE exercise than I did ☐

D4 **Have you done any pelvic floor exercises over the last week?**

Yes ☐ *Go to **D5*** No ☐ *Go to **D6*** Don't know what these are ☐ *Go to **D9***

D5 **If Yes, on how many days in the last week did you do any pelvic floor exercises?**
*(Tick **ONE** box only)*

- Every day ☐
- 5 to 6 days ☐
- 3 to 4 days ☐
- 1 to 2 days ☐

D5a **On average, how many contractions did you do each day when you did any pelvic floor exercises?**

Enter number of contractions ☐☐☐ Don't Know ☐

D6 **Do you deliberately contract your pelvic floor a little while you are walking about?**
*(Tick **ONE** box only)*

No ☐ Rarely ☐ Sometimes ☐ Often ☐ Always ☐

D7 **Do you deliberately contract your pelvic floor before you do something that would cause you to leak urine? (e.g. cough, sneeze, exercise, lift etc)**
*(Tick **ONE** box only)*

No ☐ Rarely ☐ Sometimes ☐ Often ☐ Always ☐

D8 **If you do, does contracting your pelvic floor stop leakage of urine?**
*(Tick **ONE** box only)*

Yes, completely ☐ Reduces the amount ☐ No ☐

When you answer these questions, please think about how you have been in the **LAST WEEK.**

D9 **Please could you enter your current weight?**
If you are not sure what it is, please give your best guess.
(Please use whichever units you are familiar with)

	Stones	Pounds	**OR**	Kilograms
What is your average weight now?				

D10 **Since your prostate operation (one year ago), have you made any changes to the amount of fluid you drink?** *(Please tick **ALL** that apply)*

I have made no changes		*Go to **D11***
	Yes	**No**
I drink more fluids		
I drink more cranberry juice		
I take fewer drinks with caffeine		
I drink less fluid in the evenings		
I have made other changes *(please give details in **D10a**)*		

D10a **I have made these other changes to the amount of fluid I drink:** *(please give details)*

D11 **Since your prostate operation, have you made any changes to your diet or the sort of food you eat?** *(Please tick **ALL** that apply)*

I have made no changes		*Go to **D12***
	Yes	**No**
I eat a more balanced diet		
I eat more fruit and vegetables		
I eat more foods containing fibre eg. wholemeal bread or brown rice		
I eat less food containing lots of fat or sugar		
I have made other changes *(please give details in **D11a**)*		

D11a **I have made these other changes to my diet:** *(please give details)*

When you answer these questions, please think about how you have been in the **LAST WEEK.**

D12 Since your prostate operation, have you tried to lose any weight?

No, I do not need to lose weight ☐ *Go to **D13***

No, I haven't tried to lose weight ☐ *Go to **D13***

	Yes	No
I do extra exercise to help me lose weight	☐	☐
I went on a weight reducing diet	☐	☐
I have tried to lose weight in other ways *(please give details in **D12a**)*	☐	☐

D12a I have tried these other ways of losing weight: *(please give details)*

D13 Since your prostate operation, have you avoided or reduced the amount of heavy lifting you do (e.g. lighter gardening, less heavy shopping or lifting less)?

Yes ☐ No ☐

D14 Do you smoke?

Yes ☐ *Go to **D14b*** No ☐ *Go to **D15***

D14b If Yes, have you changed your smoking habit?
*(Please tick **ALL** that apply)*

No, I have not changed my smoking habit ☐ *Go to **D15***

	Yes	No
I have stopped smoking	☐	☐
I have reduced the amount I smoke	☐	☐

When you answer these questions, please think about how you have been in the **LAST WEEK.**

D15 **Are you affected by any chest / respiratory symptoms (e.g. cough, asthma, bronchitis)?**

Yes ☐ *Go to **D16*** No ☐ *Go to **E1***

D16 **Since your prostate operation, have you tried to reduce your chest / respiratory symptoms?**
*(Please tick **ALL** that apply)*

No, I have not tried to reduce my symptoms ☐ *Go to **E1***

	Yes	No
I have made sure that I am taking the correct medication for my condition(s)	☐	☐
I have spoken to my doctor to make sure that that my treatment is up-to-date	☐	☐
I have made other changes *(please give details in **D16a**)*	☐	☐

D16a **I have made other changes to help problems related to my chest symptoms:** *(please give details)*

SECTION E – DESCRIBING YOUR OWN HEALTH TODAY

The next two sections (E and F) are about your general health.

By placing a tick in one box in each group below, please indicate which statements best describe your own health state **TODAY**.

E1 **Mobility**

I have no problems in walking about ☐
I have some problems in walking about ☐
I am confined to bed ☐

E2 **Self-care**

I have no problems with self-care ☐
I have some problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

E3 **Usual activities** *(such as work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities ☐
I have some problems with performing my usual activities ☐
I am unable to perform my usual activities ☐

By placing a tick in one box in each group below, please indicate which statements best describe your own health state **TODAY**.

E4 Pain/discomfort

- I have no pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have extreme pain or discomfort ☐

E5 Anxiety/depression

- I am not anxious or depressed ☐
- I am moderately anxious or depressed ☐
- I am extremely anxious or depressed ☐

SECTION F – GENERAL HEALTH SF12 ©

The following questions ask for your views about your health **in the LAST 4 WEEKS,** how you feel and how well you are able to do your usual activities.

Answer every question by selecting the answer as indicated.
If you are unsure about how to answer a question please give the best answer you can.

F1 In general, would you say your health is:
*(Tick **ONE** box only)*

- Excellent ☐
- Very good ☐
- Good ☐
- Fair ☐
- Poor ☐

F2 During a typical day does your health limit you in moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf? If so, how much?
*(Tick **ONE** box only)*

- Yes, limited a lot ☐
- Yes, limited a little ☐
- No, not limited at all ☐

F3 During a typical day does your health limit you in climbing several flights of stairs? If so, how much?
*(Tick **ONE** box only)*

- Yes, limited a lot ☐
- Yes, limited a little ☐
- No, not limited at all ☐

F4 **During the <u>past 4 weeks,</u> how often have you accomplished less than you would have liked in your work or other regular daily activities as a result of your physical health?**
*(Tick **ONE** box only)*

- All of the time ☐
- Most of the time ☐
- Some of the time ☐
- A little of the time ☐
- None of the time ☐

F5 **During the <u>past 4 weeks,</u> how often have you been limited in performing any kind of work or other regular daily activities as a result of your physical health?**
*(Tick **ONE** box only)*

- All of the time ☐
- Most of the time ☐
- Some of the time ☐
- A little of the time ☐
- None of the time ☐

F6 **During the <u>past 4 weeks,</u> how often have you accomplished less than you would have liked in your work or any other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**
*(Tick **ONE** box only)*

- All of the time ☐
- Most of the time ☐
- Some of the time ☐
- A little of the time ☐
- None of the time ☐

F7 **During the <u>past 4 weeks,</u> how often have you done work or other activities less carefully than usual as a result of any emotional problems (such as feeling depressed or anxious)?**
*(Tick **ONE** box only)*

- All of the time ☐
- Most of the time ☐
- Some of the time ☐
- A little of the time ☐
- None of the time ☐

F8 **During the past 4 weeks how much did pain interfere with your normal work (both outside the home and housework)?**
*(Tick **ONE** box only)*

- Not at all ☐
- A little bit ☐
- Moderately ☐
- Quite a bit ☐
- Extremely ☐

F9 **How much during the past 4 weeks have you felt calm and peaceful?**
*(Tick **ONE** box only)*

- All of the time ☐
- Most of the time ☐
- Some of the time ☐
- A little of the time ☐
- None of the time ☐

F10 **How much during the past 4 weeks did you have a lot of energy?**
*(Tick **ONE** box only)*

- All of the time ☐
- Most of the time ☐
- Some of the time ☐
- A little of the time ☐
- None of the time ☐

F11 **How much during the past 4 weeks have you felt downhearted and depressed?**
*(Tick **ONE** box only)*

- All of the time ☐
- Most of the time ☐
- Some of the time ☐
- A little of the time ☐
- None of the time ☐

F12 **During the <u>past 4 weeks</u> how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc)?**
*(Tick **ONE** box only)*

- All of the time ☐
- Most of the time ☐
- Some of the time ☐
- A little of the time ☐
- None of the time ☐

SECTION G – SEXUAL MATTERS

We would also like to find out about your sexual function and activity. When you answer these questions, please think about how you have been in the LAST 4 WEEKS.

You do not have to answer any question if you do not want to.

G1 **Do you get erections?** *(Tick **ONE** box only)*

- Yes, with normal stiffness ☐
- Yes, with reduced stiffness ☐
- Yes, with severely reduced stiffness ☐
- No, erection not possible ☐

G1a **If you have a problem with erection, how much does this bother you?**
Please choose a number between 0 (not at all) and 10 (a great deal)
*(Tick **ONE** box only)*

	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10	
Not at all												A great deal

G2 **Do you ejaculate?** *(Tick **ONE** box only)*

- Yes, normal quantity of semen ☐
- Yes, but reduced quantity of semen ☐
- Yes, but significantly reduced quantity of semen ☐
- Yes, but no semen comes out ☐
- No ejaculation ☐

G2a **If you have a problem with ejaculation, how much does this bother you?**
Please choose a number between 0 (not at all) and 10 (a great deal)
*(Tick **ONE** box only)*

	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10	
Not at all												A great deal

When you answer these questions, please think about how you have been in the LAST 4 WEEKS.

G3 **Do you have pain or discomfort during ejaculation?** *(Tick **ONE** box only)*

- No pain or discomfort ☐
- Yes, slight pain or discomfort ☐
- Yes, moderate pain or discomfort ☐
- Yes, severe pain or discomfort ☐

G3a **If you have pain or discomfort, how much does this bother you?**
Please choose a number between 0 (not at all) and 10 (a great deal)
*(Tick **ONE** box only)*

Not at all	0	1	2	3	4	5	6	7	8	9	10	A great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	

G4 **Have you taken any medications for sexual problems?**

Yes ☐ No ☐

G5 **Have you used a vacuum device for sexual problems?**

Yes ☐ No ☐

G6 **Do you have an active sex life (with or without a partner)?**

Yes ☐ *Go to **G8*** No ☐ *Go to **G9***

G7 **Do you leak urine during sex?**

Yes ☐ No ☐ Don't Know ☐

G8 **Has your sex life changed compared with before your prostate operation one year ago?**
*(Tick **ONE** box only)*

- It has stayed the same ☐
- It is better ☐
- It is worse ☐

*Now go to **Section H***

When you answer these questions, please think about how you have been, in the LAST 4 WEEKS.)

G9 **If you DO NOT have an active sex life, is this for any of these reasons?**
*(Please tick **ALL** boxes that apply)*

- Because of my urinary symptoms ☐
- Because of my bowel symptoms ☐
- Because of my prostate operation ☐
- Because of medical treatment (e.g. drugs or medication) ☐
- For another reason ☐

SECTION H – FINALLY…

H1 **How satisfied were you with the treatment you received <u>for leaking urine</u> since your prostate operation?**
Please choose a number between 0 (very unsatisfied) and 10 (very satisfied)
*(Tick **ONE** box only)*

Very unsatisfied											Very satisfied
☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10	

H2 **Do you have any other comments about the MAPS Study, or the care you have received <u>for leaking urine?</u>**

Date you filled in this questionnaire D D / M M / Y Y Y Y

Your date of birth D D / M M / Y Y Y Y

THANK YOU

Thank you very much for your time and patience in filling in this questionnaire.

The information you have given us will be extremely useful in helping us carry out research into men's health after prostate surgery.

It will be treated with the strictest confidence and kept securely.

Please send the questionnaire back to us in Aberdeen in the envelope provided.

Please could you confirm your phone number:

Thank you again for your help

If you would like any further information or have any queries about the study, please contact:

The MAPS Study Office in Aberdeen (Tel: 01224 551103)

This study is taking place in centres across the UK but the questionnaires are being processed in Aberdeen at the Health Services Research Unit, Polwarth Building, Foresterhill, ABERDEEN, AB25 2ZD.