

User Guide for Prostate Care Questionnaire

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1. Using this guide

This guide has been written for the benefit of all users, whether or not they have previous experience of conducting questionnaire surveys. The guide explains the purpose of the Prostate Care Questionnaires, and how to use them. Easy-to-use software has been designed to allow the data from the questionnaires to be entered and analysed.

It is vital that the guide is read before starting to use the questionnaires because you will need to decide which patients you want to survey and which questionnaire and/or which sections you want to use. It is important to plan the survey properly so that you are clear what will be involved. This will require an understanding of the process as a whole and include addressing the following questions:

- which questionnaire(s) will be used?
- which patients will be surveyed?
- who will be responsible for administering the questionnaire?
- who will load the software/have access to the database?
- who will use the software to enter, store and analyse data?

We have tried to make the whole process as flexible as possible so that different sized surveys of patients and carers can be undertaken at different phases of their care pathway. However, in all surveys a commitment at the start of the process to act on the findings will be essential for the process to be worthwhile.

Note on terminology used

There is no agreed upon word to describe the person who is connected to the patient and who may provide support or care. We have used the terms “carer” and also “partner/relative/friend”.

2. The purpose of the questionnaires

The questionnaires are designed to collect data on patients’ experiences of prostate cancer care. Services for patients with prostate cancer should deliver effective care in a way that meets the preferences of the patients themselves,

and the aim of these questionnaires is to allow services to be reviewed so that health care professionals can see to what extent they are meeting the needs of patients. Carers may play an important part in supporting their partner/relative/friend and helping them to cope. As well as being affected by the patient's physical and emotional well being, carers may have their own needs. Consequently, we have also developed questionnaires to help health care professionals assess how well the needs of carers are being met so that carers can cope themselves as well as support and care for their partner/relative/friend.

3. How the questionnaires have been developed

The questionnaires have been developed by the Department of Health Sciences at the University of Leicester, in collaboration with the National Centre for Social Research. Funding was via the NHS Service Delivery and Organisation programme. The following process was followed:

- Research to inform the format and content of the measure: a literature review; a questionnaire survey of Cancer Networks; interviews with patients, their carers, and health care professionals
- Drafting and revising the questionnaires in line with comments from patients and health care professionals
- Piloting and testing the questionnaires in hospitals for validity, reliability and sensitivity to change
- Finalising the questionnaire and accompanying software for data entry and analysis

The questionnaires have been rigorously developed and tested to ensure that the results are valid, reliable and sensitive to change. The questionnaires and accompanying software are being made available for use (free of charge) throughout the NHS.

4. How to use the questionnaires

Before starting the patient and carer survey it will be necessary to check if ethical approval is required, as well as any local Research and Governance requirements. It should be noted that patient and carer consent is gained via

the completion of the questionnaire, and as things stand in 2007 it is not necessary to have a separate written consent form.

a. Deciding which questionnaire to use

The questionnaire has been designed to follow the patients' care pathway and have a section to capture demographic information about the patient completing the questionnaire to allow analysis of whether any unmet needs are associated with patients' characteristics (e.g. age, ethnicity, presence of a carer). The carers' questionnaires have been designed for use alongside the patients' questionnaires and it is recommended that you survey the experiences of the carers of the patients at the same time you are surveying the patients. This will provide valuable information on the role of carers and whether their needs are being met. The patient questionnaire has six sections and the carer questionnaire has four sections which are listed in the table below.

<p style="text-align: center;">PCQ-P</p> <p style="text-align: center;">PROSTATE CARE</p> <p style="text-align: center;">QUESTIONNAIRE FOR PATIENTS</p>	<p style="text-align: center;">PCQ-C</p> <p style="text-align: center;">PROSTATE CARE</p> <p style="text-align: center;">QUESTIONNAIRE FOR</p> <p style="text-align: center;">PARTNERS/RELATIVES/FRIENDS</p>
<p>Section A: The first time you saw the doctor or nurse about your possible prostate problem</p> <p>Section B: Having tests for possible prostate cancer at the hospital</p>	<p>Section A: Your experiences when your partner/relative/friend was tested for possible prostate cancer</p>
<p>Section C: Getting the diagnosis and making the treatment decision</p>	<p>Section B: Your experiences while getting his diagnosis and making the treatment decision</p>
<p>Section D: Your treatment</p> <p>Section E: Monitoring (checking) you</p>	<p>Section C: Your experiences during the treatment and monitoring of your partner/relative/friend for prostate cancer</p>
<p>Section F: About you and your health</p>	<p>Section D: About you and your health</p>

The sections can be used in any combination (**always providing that Section F about the respondents is included**) so it is important to take time to decide which one you are going to use. For example, you could choose to collect data on patients' current experience of treatment and monitoring by using Sections D and E for the patient and Section C for the carer to identify if there are any changes to service delivery that should be considered. Alternatively you may have recently made some changes to your service when patients come to the hospital for tests and so could use these sections to assess the impact of these changes.

There is a **short version** of both the patient questionnaire (PCQ-Ps) and carer questionnaire (PCQ-Cs) which covers all the phases of the care pathway and include questions from the longer questionnaires as well as some questions about their overall experience of care.

<p style="text-align: center;">PCQ-Ps</p> <p style="text-align: center;">PROSTATE CARE QUESTIONNAIRE FOR PATIENTS</p> <p style="text-align: center;">(Short Questionnaire)</p>	<p style="text-align: center;">PCQ-Cs</p> <p style="text-align: center;">PROSTATE CARE QUESTIONNAIRE FOR PARTNERS/RELATIVES/FRIENDS</p> <p style="text-align: center;">(Short Questionnaire)</p>
<ul style="list-style-type: none"> • Tests for possible prostate cancer at the GP's practice or local assessment centre before you were referred to hospital • Having tests for possible prostate cancer at the hospital • Getting the diagnosis and making the treatment decision • Your treatment • Monitoring (checking) you • General/overall questions • About you and your health 	<ul style="list-style-type: none"> • Your experiences during the tests for possible prostate cancer at the hospital • Your experiences while getting his diagnosis and making the treatment decision • Your experiences during the treatment • Your experiences during his monitoring • General/overall questions • About you and your health

This provides an overview of patients' experiences of care and may be used to highlight aspects of care that patients value and others where there are unmet needs. You may choose to use the short questionnaire as an alternative to the longer versions, to identify which area of care requires attention. The appropriate section(s) from the longer questionnaires could then be used to investigate further.

b. Deciding which patients to survey

It is important that whichever questionnaire is used that the patients should have completed that phase of the care pathway within a time frame that will enable them to accurately recall their experience of care. Ideally patients should receive a questionnaire before they have started the next phase of their care so for example, patients would receive Section A (The first time you saw the doctor or nurse about your possible prostate problem) before they receive their diagnosis. This would avoid patients' responses being influenced by experiences of a later stage of care. Obviously this will not always be possible for all patients surveyed, as for example some patients receiving Section C (Getting the diagnosis and making the treatment decision) may have started their treatment straight away. If this is the case then it would be desirable for patients to receive the questionnaire before they have completed the next phase of care. It will be your decision as to how many patients you are going to survey, but the following issues should be considered:

- What resources are available?
- How are the questionnaires going to be distributed?
- How quickly are the results needed?

One final point to consider at this stage is do you want to survey all patients, or only those who were NHS patients. If you are not going to include patients who received their care privately, you will need to devise a way of excluding them (e.g. putting a sticker on the front of the questionnaire indicating that it is a survey of NHS care).

c. Administering the questionnaire

First, you will need to enter the hospital name on the front of the questionnaire in the space provided so that the patient can refer to the name when answering some of the questions. The questionnaire number should also be entered in the space provided on the front of the questionnaire so that you know which ones have been returned and can remind non-responders. (Remember to keep a list of the numbers of the questionnaires and who they have been given/sent to.) Consideration needs to be given to how the questionnaire will be distributed and returned. The two main alternatives are:

i. **Postal:** posting the questionnaire to patients is often the quickest way of surveying patients, particularly when there are large numbers involved. Patients' lists will need to be accessed to identify suitable patients and checked to ensure that patients are aware they have been tested for prostate cancer or diagnosed with prostate cancer and are still alive. Mail merge can be used to produce labels of patients' names and addresses. All the packs (see Box 1 below for contents) should be sent out at the same time so that a reminder letter to non-responders can also be sent out in one posting, 10 -14 days later.

Box 1: The set of documents patients should receive

1. A questionnaire
2. A covering letter from the patient's consultant explaining the purpose of the survey
3. An information sheet which includes explanations of why they are being asked to take part, what will happen to the data, who has approved the study, the risks and benefits of participating and contact details for further information.
4. A pre paid addressed envelope
5. A carer's pack (containing a questionnaire, covering letter from their partner/relative's consultant, an information sheet and pre paid addressed envelope)

ii. **Handout:** the questionnaires can also be handed out to patients, for example as they visit the hospital for an appointment. This is often suitable for smaller numbers of patients, and it is a good idea to calculate the number that could be handed out per consultant or nurse per week to judge whether this is

an appropriate method of distribution. It is suggested that patients are invited to take the questionnaires home with them for completion and post them back as research suggests that respondents may be influenced by completing them at the hospital.

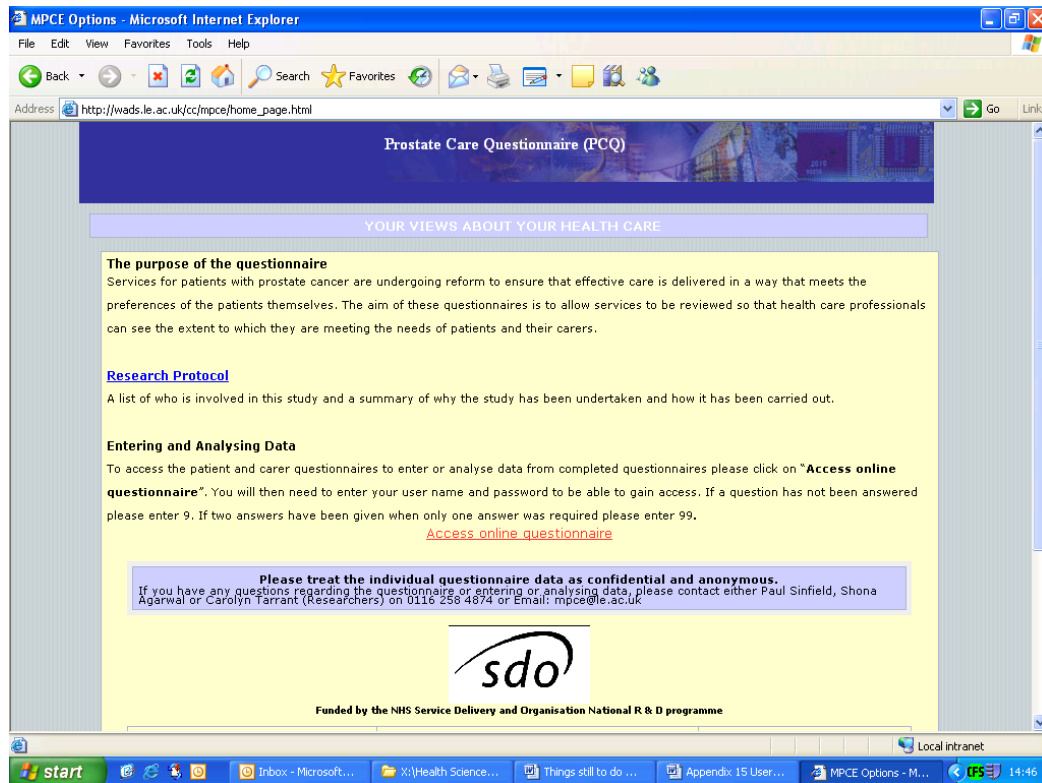
Whichever method of distributing the questionnaire is used the same set of documents needs to accompany the questionnaire (see Box 1).

5. How to use the software

The software has been developed to make it as easy as possible to access the database and enter and analyse the data by authorised users. This section of the User Guide includes 'screen captures' to illustrate the screen you will see when you use the software (although there may be some minor variations between the screen saver and the website if any further modifications have taken place).

a. Accessing the database via the website

To enter data from the questionnaires to the database or analyse the previously entered data use the Prostate Care Questionnaire (PCQ) website at http://wads.le.ac.uk/cc/mpce/home_page.html



To access the PCQ website you must have the following PC configuration to enable the use of the full functionality of the website.

Recommendations:

Microsoft Windows XP Professional version 2002 with Service Pack 2 , and Windows Internet Explorer Version 6.0 with Service Pack 2.

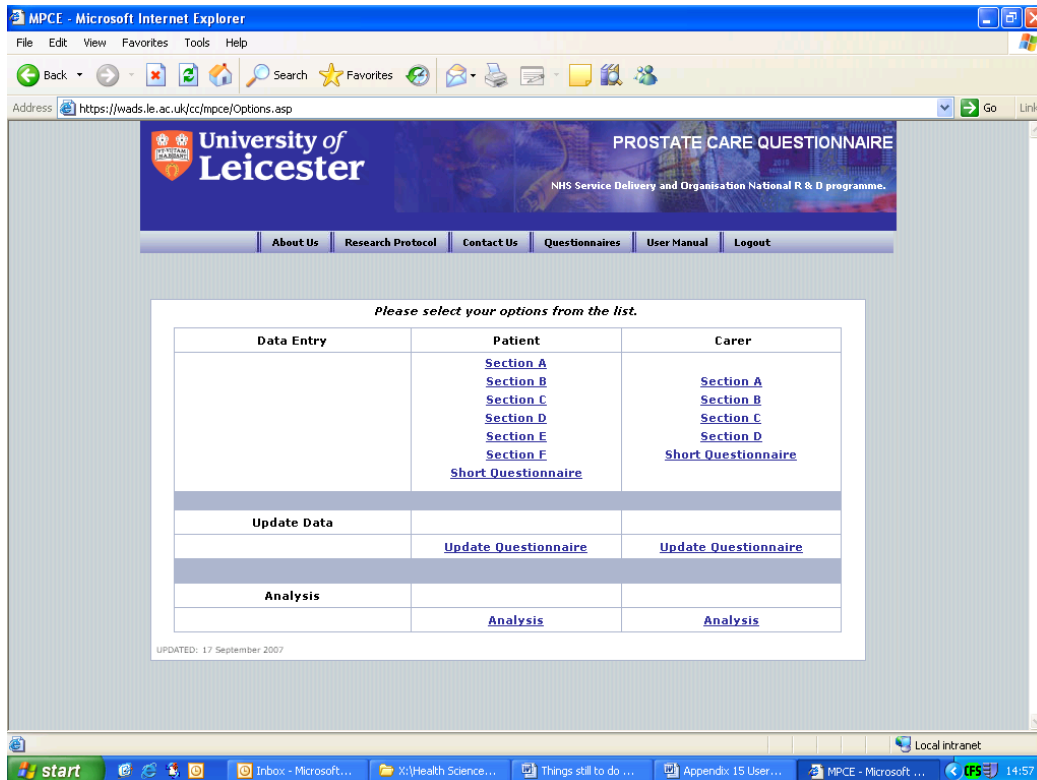
- **Login**

1. On the home web page click on the Access online questionnaire link to open the login page (see below).
2. Enter your hospital name and the 8 character password provided by the survey administrator and then click on the submit button.



Options

On a successful login, the option web page will become available (see below).



The options page is divided into three sections.

Select one of the following tasks:

- Data Entry: allows the operator to select the appropriate Questionnaire section to enter new data
- Update Data: allows the operator to edit existing data or complete unfinished data entry on any questionnaire previously entered
- Analysis: allows the operator to interrogate the database with standard report options

Select the Questionnaire type:

- Patient
- Carer

Select either the appropriate section of the full questionnaire (A, B, C, D, E or F), or if using the Short Questionnaire select Short Questionnaire.

b Entering data

Select the appropriate section of the questionnaire, or the short questionnaire, that you wish to enter data from, and follow the steps below:

- i. Enter the Hospital ID and the Questionnaire ID (**the last three digits only**) from the questionnaire. This will allow you to identify the questionnaire for editing if required at a later stage.
- ii. Use the tab key to move from the top to the bottom of the form.
- iii. If no box has been ticked (missing answer) please enter "9".
- iv. If two boxes have been ticked when only one box should have been ticked please enter "99".
- v. Use the mouse to tick boxes (and to remove ticks).
- vi. If one of the answers has been ticked that precludes all the other answers (eg. none of these) then it will not allow you to tick other boxes
- vii. Please record any written comments made by patients and carers at the end of the appropriate section irrespective of where they occur in the section. Please also record the question number that the comment refers to. Any accompanying written material (e.g. letters should be kept for reference for example when results are discussed).
- viii. On completion click the Submit button.

ix. A confirmation page indicates successful data entry to the database.

The questionnaire update page:

MPCE Patient Ver 4.1 Section A - Microsoft Internet Explorer

Address: <https://wads.le.ac.uk/cc/mpce/InputA.asp>

University of Leicester

PROSTATE CARE QUESTIONNAIRE
NHS Service Delivery and Organisation National R & D programme.

Contact Us Options Questionnaires User Manual Logout

Patient Section A

The first time you saw the doctor or nurse about your possible prostate problem.

If a question is not answered in the questionnaire then use option 9 from the drop down box or tick the No Data box to indicate no answer has been provided.
If two answers have been given when only one was required use option 99 from the drop down box.
Please record any written comments made by patients and carers at the end of the appropriate section irrespective of where they occur in the section. Please also record the question number that the comments refer to.

Hospital ID & Questionnaire ID

To identify each Hospital and questionnaire for future updates please provide Hospital ID and Questionnaire ID.

*required fields

Hospital ID* Questionnaire ID*

A1 Where did you go for the FIRST TIME about your possible prostate problem? 9

A2 What was your reason for going to the GP's practice/local assessment centre?

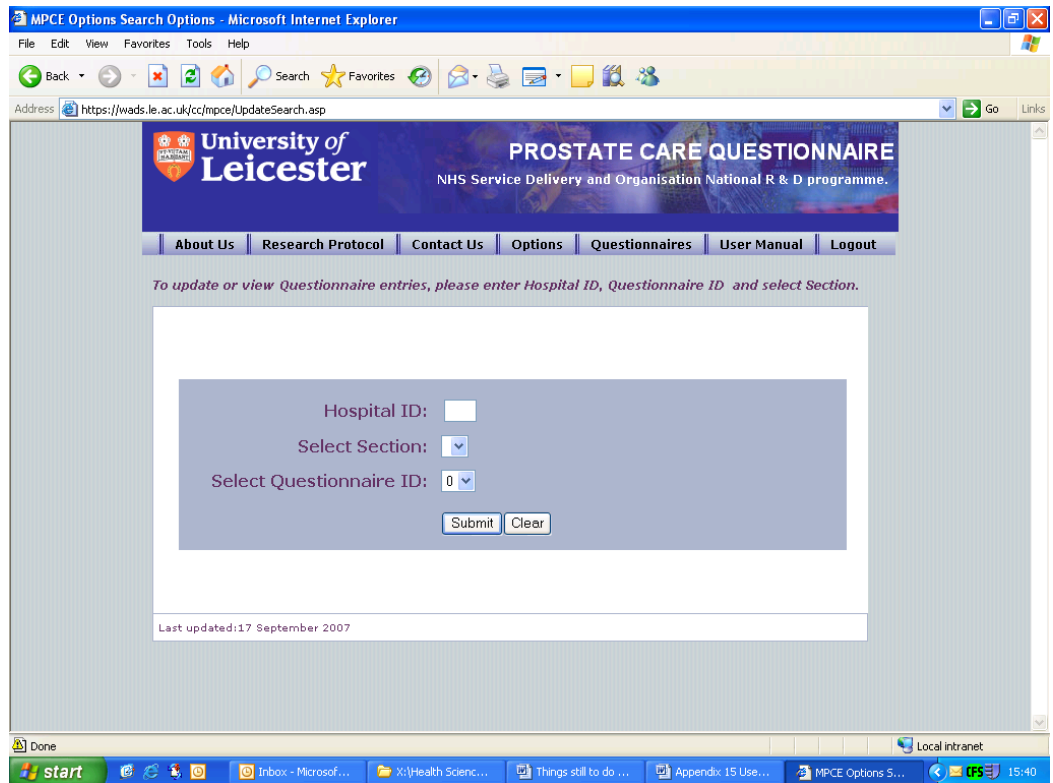
Health Problem General Health Check Risk of prostate cancer Other No Data

You will need to decide on the length of time that you will allow for questionnaires to be returned and the data entered to ensure that the responses are all referring to the same period of service.

c. Updating/Editing existing questionnaires

- i. Determine whether it is the Full or Short Version of the Questionnaire type and a patient or carer one from the front cover
- ii. Click on the Update Questionnaire link

Diagram below shows the questionnaire update page.



- iii. Select the Section from drop down box.
- iv. Select the Questionnaire ID from the drop down box (only previously entered questionnaires ID are displayed).
- v. Click on Submit button to begin search.
- vi. The edit questionnaire form is a replica of the data entry form but now displaying the previously entered data.
- vii. On completion click the submit button to store the edited data to the database.

d. Storing data

Complete the data entry for each of the questionnaires that are returned. The data that you have entered will be automatically stored. When you have finished entering data please select the Logout button at the top of the page. Please remember that patient anonymity should be maintained, and that responses should only be reported in aggregated form.

e. Analysing data

When all the data from the completed questionnaires has been entered out time should be taken to consider whether you wish to check the accuracy of the data entry. A simple way of doing this is to select randomly a proportion of the questionnaires (e.g. 10%) and check responses in the questionnaires against the data entered in the database. Record the number of errors (if any) and decide if you are satisfied with the level of accuracy. You must be confident that the data entered does reflect the responses given and will not lead to unsafe conclusions.

The software automatically produces tables from the data entered showing the number of respondents and the percentages for each answer option in each question. The web analysis pages are refreshed on an hourly basis at five past the hour.

6. Reporting the findings of the survey

Once you have the results from the survey you may wish to draw up a brief report which includes

- the questionnaire used and where patients are on the care pathway
- number of patients surveyed, time scale and response rate
- findings of the survey
- proposed action plan

It is important that all affected staff are aware of the findings and ideally have an opportunity to contribute or comment on any proposed action to be taken. It is also recommended that thought be given to how best to provide feedback to patients, so that they are aware that their input has been worthwhile and that where appropriate, action is being taken to maintain or improve levels of service delivery.

7. Taking action and reviewing its impact

It is suggested that service delivery is reviewed periodically from the patients' and carers' perspective using the questionnaires to monitor, for example, the impact of changes that have been made.

8. Carers

In Section 3 above, the surveying of the carers of patients with prostate cancer was mentioned. The carers' pack referred to in Box 1 contains a similar set of materials as for the survey of patients. We recommend that carers are surveyed at the same time as patients by distributing the carers' pack enclosed in the patients' pack. This means that there is no additional work involved in the distribution and it enables the patient to decide whether or not they wish to pass the pack to their carer if they have one. This explanation is given on a label to be stuck on the front of the carers' pack. Reminders are only sent to patients. The software will work in exactly the same way as for patients, and the same process should be followed for entering and analysing data, as well as reporting the findings and taking action that may be appropriate.

9. Troubleshooting

The questionnaires and accompanying software have been thoroughly tested and should not cause any operating problems. However, if you do have a problem with login consult your hospital IT Administrator to establish if it is a problem with the hospital system or a software problem. If it is a software problem then please contact the please contact the SDO office who supplied the software.

10. Further information

For further information about scoring the questionnaires please see Appendix 22 of the report on the sdo website

THE PROSTATE CARE QUESTIONNAIRE FOR PARTNERS/RELATIVES/FRIENDS (SHORT VERSION)

This questionnaire booklet is divided into six sub-sections:

- Your experiences during the tests for possible prostate cancer at the hospital
- Your experiences while getting his diagnosis and making the treatment decision
- Your experiences during his treatment
- Your experiences during his monitoring (checking)
- General/overall questions
- About you and your health

- You have been given/sent this questionnaire booklet because we want to find out about **your experiences when your partner/relative/friends was tested and/or treated for prostate cancer**. The information you give will be used to review and improve services.
- While every effort is made to ensure this questionnaire is not given/sent to anyone whose partner/relative/friend has not been tested for prostate cancer as with any administrative system, errors may occur. If you have been given/sent this questionnaire by mistake, please tick this box . Please accept our apologies and return it to us.
- We estimate that this questionnaire should take about 10 minutes to complete.
- Please answer as many questions as you can. Your answers will be treated in strict confidence: please do not give your name.
- **If you have any questions regarding the questionnaire, please contact the person named on the information sheet.**

N.I.H.R



Funded by the NHS Service Delivery
and Organisation National R & D programme

This questionnaire was designed by:



YOUR EXPERIENCES DURING THE TESTS FOR POSSIBLE PROSTATE CANCER AT THE HOSPITAL

1. Were you provided with information about the tests your partner/relative/friend would be having at the hospital (e.g. what the tests would involve, what after effects there might be)?

Please tick one box

Yes, I was given enough information

 1

Yes, but I would have liked more information

 2

No, I was not given any information

 3

2. Did the doctor or nurse explain that these tests were to find out if your partner/relative/friend had prostate cancer?

Please tick one box

Yes, the explanation was clear

 1

Yes, but the explanation could have been clearer

 2

No explanation was given

 3

YOUR EXPERIENCES WHILE GETTING HIS DIAGNOSIS AND MAKING THE TREATMENT DECISION

3. Did you feel that the doctor or nurse gave the diagnosis in a considerate way?

Please tick one box

Yes, very considerately

 1

Yes, but it could have been more considerate

 2

No, not really

 3

4. Did the doctor or nurse explain which treatment options were open to your partner/relative/friend?

Please tick one box

Yes, the explanation was clear

 1

Yes, but the explanation could have been clearer

 2

No explanation was given

 3

-
5. Did the doctor or nurse involve you as much as you wanted in the decision about which treatment you partner/relative/friend was to have?

Please tick one box

- Yes, I was involved as much as I wanted 1
- No, I was involved more than I wanted 2
- No, I would have liked to have been more involved 3

YOUR EXPERIENCES DURING HIS TREATMENT

6. Which treatment has your partner/relative/friend most recently had?

Please tick as many boxes as apply

- Prostatectomy**
Surgery to remove the prostate, including key hole surgery/da vinci (robotic surgery)
- Radiotherapy** (completed/ongoing)
- Hormone therapy** (completed/ongoing)
A series of injections or tablets (e.g. Zoladex)
- Brachytherapy**
A type of internal radiation therapy in which radioactive materials are placed in direct contact with the tissue being treated.
- Cryotherapy**
A technique that uses an extremely cold liquid or instrument to freeze and destroy abnormal cells.
- HIFU** (High Intensity Focused Ultrasound)
- Other**
- No immediate treatment** (e.g. active monitoring)

IF NO IMMEDIATE TREATMENT, PLEASE GO TO QUESTION

7. Before your partner/relative/friend started treatment, did the doctor or nurse give you information about the treatment to help you feel prepared (e.g. what the treatment would involve, what he should/should not do during his treatment)?

Please tick one box

- Yes, we had enough information 1
- Yes, but we would have liked more information 2
- No, we did not have any information 3

8. Were you kept up to date:

Please tick one box in EACH row in the table

	Yes	To some extent	No
A With the progress of the treatment?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
B With how well the treatment was going?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃

9. Did the doctor or nurse give you any information about caring for him (e.g. continence, wound care, problems with sex, managing pain)?

Please tick one box

- Yes, I was given enough information ₁
- Yes, but I would have liked more information ₂
- No, I was not given any information ₃

10. When he left hospital or finished his treatment were you or your partner/relative/friend given equipment or supplies that were needed (e.g. continence pads, painkillers)?

Please tick one box

- Yes, we were given enough ₁
- Yes, but we would have liked more ₂
- No, we were not given any ₃
- We did not need any ₄

11. Did the doctor or nurse organise the aftercare services that were needed for your partner/relative/friend (e.g. district nurse, physiotherapist, home help)?

Please tick one box

- Yes, we got the aftercare services when we needed them ₁
- Yes, but not as soon as we needed them ₂
- No, we did not get the aftercare services we needed ₃
- We did not need any aftercare services ₄

YOUR EXPERIENCES DURING HIS MONITORING (CHECKING)

12. Did the doctor or nurse explain why there is a need for regular tests to check his condition (e.g. PSA blood test)?

Please tick one box

Yes, the explanation was clear ₁

Yes, but the explanation could have been clearer ₂

No explanation was given ₃

13. Has the doctor or nurse explained what the test results mean (e.g. what the PSA score means)?

Please tick one box

Yes, the test results have been explained clearly ₁

Yes, but the test results could have been explained more clearly ₂

No explanation has been given ₃

GENERAL/OVERALL QUESTIONS

14. Were you advised that it might be helpful to go with your partner/relative/friend to his hospital appointments?

Please tick one box

Yes ₁ No ₂

15. Were you given the WRITTEN information you needed (e.g. about the diagnosis, about the treatment options)?

Please tick one box

Yes, I was given enough information ₁

Yes, but I would have liked more information ₂

No, I was not given any information ₃

16. Were you given information about who you could contact about advice or support (e.g. specialist nurse, patient/carer support group, cancer charity)?

Please tick one box

Yes, I was given enough information ₁

Yes, but I would have liked more information ₂

No, I was not given any information ₃

ABOUT YOU AND YOUR HEALTH

THIS INFORMATION WILL HELP PUT YOUR ANSWERS IN CONTEXT, AND SHOW WHETHER DIFFERENT GROUPS OF PEOPLE HAVE DIFFERENT EXPERIENCES

19. Please identify who passed you this questionnaire.

Please tick one box

- Partner/husband ₁
Other relative ₂
Friend ₃
Other ₄

20. Overall, how good or bad is your general health today, in your opinion?

Please tick one box

- Very good ₁
Good ₂
Fair ₃
Poor ₄
Very poor ₅

21. Which age range are you in?

Please tick one box

- Up to 54 ₁ 55 – 64 ₂ 65 – 74 ₃ 75 or over ₄

22. Do you have someone to support and/or care for you (e.g. husband/relative)?

Please tick one box

- Yes ₁ No ₂

23. Which ethnic group do you belong to?

Please tick one box

- White ₁ Black or Black British ₂ Asian or Asian British ₃
Mixed ₄ Chinese ₅ Other ethnic group ₆

24. Is your accommodation:

Please tick one box

Owner-occupied/mortgaged? ₁

Rented or other arrangements? ₂

25. Which of the following best describes you?

Please tick one box

Employed (full or part time, including self-employed) ₁

Unemployed and looking for work ₂

At school or full time education ₃

Unable to work due to long term sickness ₄

Looking after your home/family ₅

Retired from paid work ₆

Other (*please describe below*) ₇

.....

.....

.....

**Thank you very much for completing this questionnaire booklet.
Please return the questionnaire booklet within one week if
possible, in the pre-paid envelope provided.**

Hospital Name:

Questionnaire number:

THE PROSTATE CARE QUESTIONNAIRE FOR PATIENTS (PCQ-P)

This questionnaire booklet is divided into six sections:

Section A: The first time you saw the doctor or nurse about your possible prostate problem

Section B: Having tests for possible prostate cancer at the hospital

Section C: Getting the diagnosis and making the treatment decision

Section D: Your Treatment

Section E: Monitoring (checking) you

Section F: About you and your health

- You have been given/sent this questionnaire booklet because we want to find out about **your experience of being tested and/or treated for prostate cancer**. The information you give will be used to review and improve services.
- While every effort is made to ensure this questionnaire is not given/sent to anyone who has not been tested for prostate cancer as with any administrative system, errors may occur. If you have been given/sent this questionnaire by mistake, please tick this box . Please accept our apologies and return it to us.
- We estimate that each section should take about 5 minutes to complete.
- Please answer as many questions as you can. Your answers will be treated in strict confidence: please do not give your name.
- **If you have any questions regarding the questionnaire, please contact the person named on the information sheet.**
- **Please return the completed questionnaire booklet. Thank you for your help.**

N.I.H.R



Funded by the NHS Service Delivery
and Organisation National R & D programme

This questionnaire was designed by:



PCQ-P • September 2007

SECTION A THE FIRST TIME YOU SAW THE DOCTOR OR NURSE ABOUT YOUR POSSIBLE PROSTATE PROBLEM.

A1. Did you go to the GP's practice/local assessment centre about your possible prostate problem?

Please tick one box

Yes, to the GP's practice

 ₁

Yes, to the local assessment centre/clinic

 ₂

No (e.g. I was already in hospital)

 ₃

IF NO, PLEASE GO TO QUESTION A17

A2. What was your reason for going to the GP's practice/local assessment centre?

Please tick as many boxes as apply

I had a health problem (e.g. problems with urinating, urinating frequently, blood in urine, back pain)

Part of a general health check

I thought I might be at risk of prostate cancer (e.g. family history)

Other (e.g. as a result of unrelated health problems/investigations)

A3. Did the doctor or nurse take your concerns seriously?

Please tick one box

Yes

 ₁

To some extent

 ₂

No, not really

 ₃

I did not have any concerns

 ₄

A4. Were you given information about being tested for prostate cancer (e.g. what the tests would involve, pros and cons of being tested)?

Please tick one box

Yes, I was given enough information

 ₁

Yes, but I would have liked more information

 ₂

No, I was not given any information

 ₃

A5. Did the doctor or nurse explain what would happen if the results were abnormal?

Please tick one box

Yes

 ₁

No

 ₂

A6. Did the doctor or nurse offer you any WRITTEN information about being tested for prostate cancer?

Please tick one box

Yes ₁ No ₂

A7. Were you given a choice about whether you wanted to be tested for prostate cancer?

Please tick one box

Yes ₁
To some extent ₂
No, not really ₃

A8. Did the doctor or nurse give you a PSA blood test and/or a Digital Rectal Examination at the GP's practice/local assessment centre before you were referred to hospital?

Please tick one box in EACH row in the table

A PSA blood test	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂
B Digital Rectal Examination (where a doctor or nurse feels your prostate using their finger)	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂

IF YOU HAVE TICKED NO TO PSA BLOOD TEST AND DIGITAL RECTAL EXAMINATION, PLEASE GO TO QUESTION A12

A9. Did the doctor or nurse explain that the tests were trying to find out whether you might have prostate cancer?

Please tick one box

Yes, the explanation was clear ₁
Yes, but the explanation could have been clearer ₂
No explanation was given ₃

A10. Did the doctor or nurse explain your test results (e.g. what the results meant, how reliable the results were)?

Please tick one box

Yes, the explanation was clear ₁
Yes, but the explanation could have been clearer ₂
No explanation was given ₃

A11. Did the doctor or nurse give you your test results in a considerate way?

Please tick one box

- Yes ₁
- To some extent ₂
- No, not really ₃

A12. How long was it from your FIRST VISIT to the GP's practice/local assessment centre until the doctor DECIDED TO refer you to the hospital?

Please tick one box

- Not more than 2 weeks ₁
- More than 2 weeks and up to 4 weeks ₂
- More than 4 weeks and up to 6 weeks ₃
- More than 6 weeks ₄
- I was not referred to hospital ₅

IF YOU WERE NOT REFERRED TO HOSPITAL, PLEASE GO TO QUESTION A17

A13. How did you feel about the time the GP's practice/local assessment centre TOOK TO DECIDE to refer you to the hospital?

Please tick one box

- Too short ₁
- About right ₂
- Too long ₃

A14. Did the doctor or nurse explain that you were being referred to hospital to find out if you had prostate cancer?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

A15. Were you told at the GP's practice how soon you would be seen at the hospital?

Please tick one box

- Yes ₁ No ₂

A16. Were you given a choice of :

Please tick one box in EACH row in the table

A Which hospital you wanted to go to?	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂
B The date and time you wanted to be seen?	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂

A17. Please write any comments you would like to make here (e.g. any problems, anything that could have been done better or anything that was done particularly well).

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SECTION B HAVING TESTS FOR POSSIBLE PROSTATE CANCER AT THE HOSPITAL

B1. Who referred you for tests/further tests at the hospital?

Please tick one box

- GP ₁
- Doctor at the local assessment centre ₂
- Hospital doctor ₃
- Other ₄

B2. Which tests did you have at the hospital named on the front of this questionnaire?

Please tick as many boxes as apply

- Biopsy/TRUS
- Urine flow
- PSA blood test
- Digital Rectal Examination (where a doctor or nurse feels the prostate using their finger)
- Scans (e.g. MRI, Bone, CT)
- I did not have any tests at this hospital

**IF YOU DID NOT HAVE ANY TESTS AT THIS HOSPITAL,
PLEASE GO TO QUESTION B20**

**PLEASE ANSWER THE FOLLOWING QUESTIONS FROM YOUR
EXPERIENCE OF BEING TESTED AT THE HOSPITAL NAMED ON THE
FRONT OF THE QUESTIONNAIRE**

B3. How long did you wait between the date you were referred by your GP's practice/local assessment centre and the date of your first appointment at the hospital?

Please tick one box

- Not more than 2 weeks ₁
- More than 2 weeks and up to 4 weeks ₂
- More than 4 weeks and up to 6 weeks ₃
- More than 6 weeks ₄

B4. How did you feel about the length of time you had to wait for your first appointment at the hospital?

Please tick one box

- Too short ₁
- About right ₂
- Too long ₃

B5. Were you advised that it might be helpful if someone (e.g. wife/partner, relative) could attend the hospital appointment with you when you went for your tests?

Please tick one box

- Yes ₁ No ₂

B6. Before you were tested at the hospital, were you given information about the tests to help you feel prepared (e.g. what your tests would involve, what you should/should not do before your tests)?

Please tick one box

- Yes, I was given enough information ₁
- Yes, but I would have liked more information ₂
- No, I was not given any information ₃

B7. Did you experience any of the following problems with your hospital visit(s)?

Please tick as many boxes as apply

- Appointment cancelled or postponed
- Getting there (e.g. transport)
- Parking (e.g. finding a parking space, too expensive)
- Kept waiting (e.g. more than 30 minutes)
- Inconvenient appointment time
- Medical notes not available
- Cleanliness
- I did not have any of these problems

B8. How would you rate the hospital facilities?

Please tick one box in **EACH** row in the table

	Very Good	Good	Satisfactory	Poor	Not applicable/ Don't Know
A Waiting Area	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B Availability of refreshment	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
C Toilets	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
D Rooms where the tests were carried out (e.g. cleanliness, privacy)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

B9. Did you have enough privacy while the doctor or nurse was examining/testing you?

Please tick one box

Yes ₁ No ₂

B10. Did the doctor or nurse explain that these tests were to find out if you had prostate cancer?

Please tick one box

Yes, the explanation was clear ₁

Yes, but the explanation could have been clearer ₂

No explanation was given ₃

B11. Did the doctor or nurse explain to you what each test would involve?

Please tick one box in **EACH** row in the table

	Yes, the explanation was clear	Yes, but the explanation could have been clearer	No explanation was given	I didn't have these tests
A Biopsy/TRUS	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
B Urine flow	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C PSA blood test	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
D Digital Rectal Examination (where a doctor or nurse feels the prostate using their finger)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
E Scans (e.g. MRI, Bone, CT)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

B12. Did the doctor or nurse explain to you that the biopsy might be painful?

Please tick one box

- Yes, I was prepared for the level of pain ₁
- Yes, but I was unprepared for the level of pain ₂
- No explanation was given ₃
- I did not have a biopsy ₄

IF YOU DID NOT HAVE A BIOPSY, PLEASE GO TO QUESTION B15

B13. When you had your most recent biopsy were you offered a local anaesthetic?

Please tick one box

- Yes ₁ No ₂

B14. Did the doctor or nurse explain that the biopsy may cause after effects (e.g. bleeding, infection)?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

B15. Did the doctor or nurse explain to you how long you would have to wait for your test results?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

B16. Did the doctor or nurse explain to you what would happen next (e.g. the arrangements for getting your test results)?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

B17. Did the doctor or nurse offer you any support while you were waiting for your test results (e.g. someone to talk to about any concerns that you had)?

Please tick one box

- Yes ₁ No ₂

SECTION C GETTING THE DIAGNOSIS AND MAKING THE TREATMENT DECISION

C1. Where were you given your diagnosis?

Please tick one box

At the hospital named on the front of the questionnaire ₁

At another hospital (please write the details below) ₂

Name of the hospital

Town/City

At the GP's practice ₃

C2. How long did you have to wait from your first appointment for tests at the hospital, until you got your diagnosis?

Please tick one box

Not more than 2 weeks ₁

More than 2 weeks and up to 4 weeks ₂

More than 4 weeks and up to 6 weeks ₃

More than 6 weeks ₄

C3. How did you feel about the length of time you had to wait to get your diagnosis?

Please tick one box

About right ₁

Too long ₂

C4. Were you advised that it might be helpful if someone (e.g. wife/partner, relative) could attend the hospital appointment with you to get your diagnosis?

Please tick one box

Yes ₁ No ₂

C5. Did you have enough privacy when you discussed your diagnosis?

Please tick one box

Yes ₁ No ₂

C6. Were you diagnosed with prostate cancer?

Please tick one box

Yes ₁ No ₂

IF NO, PLEASE GO TO QUESTION C30

C7. Were you given your diagnosis in a considerate way?

Please tick one box

- Yes, very considerately ₁
- Yes, but it could have been more considerate ₂
- No, not really ₃

C8. Did the doctor or nurse explain how aggressive the cancer was likely to be?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

C9. Did the doctor or nurse explain whether or not the cancer had spread outside the prostate?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

C10. After getting your diagnosis, did the doctor or nurse offer you the chance to talk to a specialist nurse?

Please tick one box

- Yes ₁ No ₂

C11. How did you feel about the length of time you had to wait to discuss your diagnosis with the specialist nurse?

Please tick one box

- Too short ₁
- About right ₂
- Too long ₃
- I did not discuss my diagnosis with the specialist nurse ₄

C12. Were you given any WRITTEN information about your diagnosis?

Please tick one box

- Yes ₁ No ₂

C13. Where was it decided which treatment you were to have?

Please tick one box

At the hospital named on the front of the questionnaire ₁

At another hospital (please write the details below) ₂

Name of the hospital

Town/City

At the GP's practice ₃

C14. How did you feel about the length of time between being given your diagnosis and discussing your treatment options?

Please tick one box

Too short ₁

About right ₂

Too long ₃

C15. Did the doctor or nurse explain which treatment options were open to you?

Please tick one box

Yes, the explanation was clear ₁

Yes, but the explanation could have been clearer ₂

No explanation was given ₃

C16. Did the doctor or nurse explain what these treatment options would involve?

Please tick one box

Yes, the explanation was clear ₁

Yes, but the explanation could have been clearer ₂

No explanation was given ₃

C17. Did the doctor or nurse explain the possible side effects or consequences of these treatment options?

Please tick one box

Yes, the explanation was clear ₁

Yes, but the explanation could have been clearer ₂

No explanation was given ₃

C18. Did the doctor or nurse explain what could be done about the possible side effects?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

C19. Did the doctor or nurse explain why other treatment options were not open to you?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

C20. Did the doctor or nurse give you any WRITTEN information about:

Please tick one box in EACH row in the table

A The treatment options?	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂
B The possible side effects or consequences of the treatment options?	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂
C What could be done about the side effects?	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂

C21. Did the doctor or nurse make you feel that you could ask any questions you wanted to?

Please tick one box

- Yes ₁
- To some extent ₂
- No, not really ₃

C22. How did you feel about the length of time you had to consider your treatment options before the treatment decision was made?

Please tick one box

- Too short ₁
- About right ₂
- Too long ₃

C23. Did the doctor or nurse involve you as much as you wanted in the decision about which treatment to have?

Please tick one box

- Yes, I was involved as much as I wanted ₁
- No, I was involved more than I wanted ₂
- No, I would have liked to have been more involved ₃

C24. Did the doctor or nurse give you the help you wanted to make the treatment decision (e.g. by finding out what was important to you, by giving you his/her opinion)?

Please tick one box

- Yes, I had as much help as I wanted ₁
- No, I would have liked more help ₂
- I was not involved in making the decision about which treatment to have ₃

C25. Who decided which type of treatment you were to have?

Please tick as many boxes as apply

- Me
- My wife/partner
- Hospital doctor*
- Hospital nurse*
- Another person

* including when they have consulted their team

C26. Were you confident that the treatment decision was the best one for you?

Please tick one box

- Yes, I was fully confident ₁
- Yes, but I had some doubts ₂
- No, I was not confident ₃

C27. Did the doctor or nurse tell you that you could change your mind about which treatment to have?

Please tick one box

- Yes ₁ No ₂

C28. Did the doctor or nurse give you information about who to contact for advice or support (e.g. specialist nurse, patient support group, charity)?

Please tick one box

- Yes, I was given enough information ₁
- Yes, but I would have liked more information ₂
- No, I was not given any information ₃

C29. Have staff worked well together in giving your diagnosis and deciding which treatment to have (e.g. information about you passed on, no unnecessary delays)?

Please tick one box

- Yes ₁
- To some extent ₂
- No, not really ₃

C30. Please write any comments you would like to make here (e.g. any problems, anything that could have been done better or anything that was done particularly well).

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SECTION D YOUR TREATMENT

D1. Which treatment have you most recently had?

Please tick as many boxes as apply

Prostatectomy

Surgery to remove the prostate, including key hole surgery/da vinci (robotic surgery)

Radiotherapy (completed/ongoing)

Radiation delivered from outside the body and focused on the tumor through the skin

Hormone therapy (completed/ongoing)

A series of injections or tablets (e.g. Zoladex)

Brachytherapy

A type of internal radiation therapy in which radioactive materials are placed in direct contact with the tissue being treated.

Cryotherapy

A technique that uses an extremely cold liquid or instrument to freeze and destroy abnormal cells.

HIFU (High Intensity Focused Ultrasound)

A minimally invasive therapy delivered using a transrectal probe under ultrasound guidance

Other

No immediate treatment (e.g. active monitoring)

IF NO IMMEDIATE TREATMENT PLEASE GO TO QUESTION D24

D2. Thinking about your most recent visit for treatment, did you go to the hospital or the GP's practice?

Please tick one box

The hospital named on the front of the questionnaire

 1

Another hospital (please write the details below)

 2

Name of the hospital

Town/City

The GP's practice

 3

D3. How long did you have to wait from the decision about which treatment to have to the start of the treatment?

Please tick one box

Not more than 2 weeks

 1

More than 2 weeks and up to 4 weeks

 2

More than 4 weeks and up to 6 weeks

 3

More than 6 weeks

 4

D4. How did you feel about the length of time you had to wait for your treatment to start?

Please tick one box

- Too short ₁
- About right ₂
- Too long ₃

D5. Before you started your treatment, did the doctor or nurse give you information about the treatment to help you feel prepared (e.g. what your treatment would involve, what you should/should not do during your treatment)?

Please tick one box

- Yes, I was given enough information ₁
- Yes, but I would have liked more information ₂
- No, I was not given any information ₃

D6. Did the doctor or nurse offer you information about what you could do that might help at this stage (e.g. diet, exercises)?

Please tick one box

- Yes ₁ No ₂

D7. Were you advised that it might be helpful if someone (e.g. partner, relative) could go with you when you went for treatment?

Please tick one box

- Yes ₁ No ₂

D8. During the course of your treatment were you able to discuss any concerns about your treatment with the doctor or nurse?

Please tick one box

- Yes, I was able to discuss any concerns ₁
- No, I was not able to discuss any concerns ₂
- I did not have any concerns ₃

D9. Did you experience any of the following problems with your visit(s) for treatment?

Please tick as many boxes as apply

- Appointment cancelled or postponed
- Getting there (e.g. transport)
- Parking (e.g. finding a parking space, too expensive)
- Kept waiting (e.g. more than 30 minutes)
- Inconvenient appointment time
- Medical notes not available
- Cleanliness
- I did not have any of these problems

D10. How would you rate the following?

Please tick one box in EACH row in the table

	Very Good	Good	Satisfactory	Poor	Not applicable/ Don't Know
A Treatment	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B Nursing	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C Food/drink	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
D Rooms where you had treatment (e.g. privacy, noise, cleanliness)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
E Ward (e.g. privacy, noise, cleanliness, comfort)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

D11. While you were being treated, do you think that the doctors and nurses did everything they could to help with your pain or discomfort (e.g. give you enough medication)?

Please tick one box

- Yes, all of the time 1
- Yes, some of the time 2
- No, none of the time 3
- I was not in pain/discomfort 4

D12. Did the doctor or nurse explain how well the treatment was going/had gone?

Please tick one box

- Yes, the explanation was clear 1
- Yes, but the explanation could have been clearer 2
- No explanation was given 3

D13. Before you left the hospital or finished your treatment did the doctor or nurse explain to you what would happen next (e.g. arrangements for follow-up)?

Please tick one box

- Yes, the explanation was clear 1
- Yes, but the explanation could have been clearer 2
- No explanation was given 3
- I have not finished treatment 4

D14. Before you left the hospital or finished your treatment were you given an explanation about what to expect (e.g. the potential side effects and how long they might last, recovery time)?

Please tick one box

- Yes, the explanation was clear 1
- Yes, but the explanation could have been clearer 2
- No explanation was given 3
- I have not finished treatment 4

D15. Did the doctor or nurse discuss with you how to manage any potential side effects of the treatment (e.g. continence, problems with sex, pain)?

Please tick one box

- Yes 1
- To some extent 2
- No, not really 3

D16. When you left hospital or finished your treatment were you given equipment or supplies to help you care for yourself (e.g. continence pads, painkillers)?

Please tick one box

- Yes, I was given enough 1
- Yes, but I would have liked more 2
- No, I was not given any 3
- I did not need any 4

D17. When you left hospital or finished your treatment were you told how to get further equipment or supplies that you needed to help you care for yourself (e.g. continence pads, painkillers)?

Please tick one box

- Yes ₁
- No ₂
- I did not need any ₃

D18. Did the doctor or nurse organise the aftercare services that you needed (e.g. district nurse, physiotherapist, home help)?

Please tick one box

- Yes, I got the aftercare services when I needed them ₁
- Yes, but not as soon as I needed them ₂
- No, I did not get the aftercare services I needed ₃
- I did not need any aftercare services ₄

D19. Did the doctor or nurse give you any information about who to contact for advice or support (e.g. specialist nurse, patient support group)?

Please tick one box

- Yes, I was given enough information ₁
- Yes, but I would have liked more information ₂
- No, I was not given any information ₃

D20. Did the doctor or nurse offer you any financial information on welfare or benefits?

Please tick one box

- Yes ₁ No ₂

D21. At the end of your treatment in hospital were you contacted by your GP's practice?

Please tick one box

- Yes, within a week of finishing treatment ₁
- Yes, it was more than a week after finishing treatment ₂
- No, my GP's practice did not contact me ₃
- I have not finished my treatment (e.g. I am still having hormone therapy) ₄

SECTION E MONITORING (CHECKING) YOU

- E1. Do you have regular tests for prostate cancer e.g. PSA blood test, Digital Rectal Examination (where a doctor or nurse feels your prostate using their finger)?

Please tick one box

Yes ₁ No ₂

IF NO, PLEASE GO TO QUESTION E14

- E2. Where do you usually have these tests?

Please tick one box

At the hospital named on the front of the questionnaire ₁

At another hospital (please write the details below) ₂

Name of the hospital

Town/City

At the GP's practice ₃

- E3. Have you been offered a choice of where to have these tests (e.g. GP's practice, hospital)?

Please tick one box

Yes ₁ No ₂

- E4. Did the doctor or nurse explain why you have these regular tests?

Please tick one box

Yes, the explanation was clear ₁

Yes, but the explanation could have been clearer ₂

No explanation was given ₃

- E5. How often are you CURRENTLY tested for prostate cancer?

Please tick one box

Every month ₁

Every three months ₂

Every four months ₃

Every six months ₄

Every year ₅

Other ₆

E6. Has the doctor or nurse reassured you that the length of the wait between the tests for prostate cancer is appropriate for you?

Please tick one box

Yes ₁ No ₂

E7. Where do you usually discuss your test results?

Please tick one box

At the hospital named on the front of the questionnaire ₁

At another hospital (please write the details below) ₂

Name of the hospital

Town/City

At the GP's practice ₃

E8. Were you offered a choice of how to be given your test results (e.g. face-to-face, by telephone, in a letter)?

Please tick one box

Yes ₁ No ₂

E9. Has the doctor or nurse explained your test results (e.g. what the PSA score means, how reliable the PSA score is)?

Please tick one box

Yes, the explanation was clear ₁

Yes, but the explanation could have been clearer ₂

No explanation was given ₃

E10. Has the doctor or nurse give you any information about who to contact for advice or support (eg. specialist nurse, patient support group)?

Please tick one box

Yes, I was given enough information ₁

Yes, but I would have liked more information ₂

No, I was not given any information ₃

E11. Has the doctor or nurse offered you information about what you could do that might help at this stage (e.g. diet, exercises)?

Please tick one box

Yes ₁ No ₂

SECTION F ABOUT YOU AND YOUR HEALTH
THIS INFORMATION WILL HELP PUT YOUR ANSWERS IN
CONTEXT, AND SHOW WHETHER DIFFERENT GROUPS OF
PEOPLE HAVE DIFFERENT EXPERIENCES

F1. Overall, how good or bad is your general health today, in your opinion?

Please tick one box

- Very good ₁
Good ₂
Fair ₃
Poor ₄
Very poor ₅

F2. Which age range are you in?

Please tick one box

- Up to 54 ₁ 55 – 64 ₂ 65 – 74 ₃ 75 or over ₄

F3. Do you have someone to support and/or care for you (e.g. wife/relative)?

Please tick one box

- Yes ₁ No ₂

F4. Which ethnic group do you belong to?

Please tick one box

- White ₁ Black or Black British ₂ Asian or Asian British ₃
Mixed ₄ Chinese ₅ Other ethnic group ₆

F5. Is your accommodation:

Please tick one box

- Owner-occupied/mortgaged? ₁
Rented or other arrangements? ₂

F6. Which of the following best describes you?

Please tick one box

- Employed (full or part time, including self-employed) 1
- Unemployed and looking for work 2
- In full time education 3
- Unable to work due to long term sickness 4
- Looking after your home/family 5
- Retired from paid work 6
- Other (*please describe below*) 7

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**Thank you very much for completing this questionnaire booklet.
Please return the questionnaire booklet within one week if possible, in the pre-paid envelope provided.**

THE PROSTATE CARE QUESTIONNAIRE FOR PATIENTS: SHORT VERSION (PCQ-P_s)

This questionnaire booklet is divided into seven sub-sections:

Tests for possible prostate cancer at the GP's practice or local assessment centre before you were referred to the hospital

Having tests for possible prostate cancer at the hospital

Getting the diagnosis and making the treatment decision

Your treatment

Monitoring (checking) you

General/overall questions

About you and your health

- You have been given/sent this questionnaire booklet because we want to find out about **your experience of being tested and/or treated for prostate cancer**. The information you give will be used to review and improve services.
- While every effort is made to ensure this questionnaire is not given/sent to anyone who has not been tested for prostate cancer as with any administrative system, errors may occur. If you have been given/sent this questionnaire by mistake, please tick this box . Please accept our apologies and return it to us.
- We estimate that this questionnaire should take about 10-15 minutes to complete.
- Please answer as many questions as you can. Your answers will be treated in strict confidence: please do not give your name.
- **If you have any questions regarding the questionnaire, please contact the person named on the information sheet.**
- **Please return the completed questionnaire booklet. Thank you for your help.**

N.I.H.R



Funded by the NHS Service Delivery
and Organisation National R & D programme

This questionnaire was designed by:



University of
Leicester

TESTS FOR POSSIBLE PROSTATE CANCER AT THE GP'S PRACTICE OR LOCAL ASSESSMENT CENTRE BEFORE YOU WERE REFERRED TO THE HOSPITAL

1. Did you go to the GP's practice/local assessment centre about your possible prostate problem?

Please tick one box

Yes, to the GP's practice

₁

Yes, to the local assessment centre/clinic

₂

No (e.g. I was already in hospital)

₃

IF NO, PLEASE GO TO QUESTION 5

2. Were you given information about being tested for prostate cancer (e.g. what the tests would involve, pros and cons of being tested)?

Please tick one box

Yes, I was given enough information

₁

Yes, but I would have liked more information

₂

No, I was not given any information

₃

3. Did the doctor or nurse give you a PSA blood test and/or a Digital Rectal Examination at the GP's practice/local assessment centre before you were referred to hospital?

Please tick one box in EACH row in the table

A PSA blood test	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂
B Digital Rectal Examination (where a doctor or nurse feels your prostate using their finger)	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂

IF YOU HAVE TICKED NO TO PSA BLOOD TEST AND DIGITAL RECTAL EXAMINATION, PLEASE GO TO QUESTION 5

4. Did the doctor or nurse explain your test results (e.g. what the results meant, how reliable the results were)?

Please tick one box

Yes, the explanation was clear

₁

Yes, but the explanation could have been clearer

₂

No explanation was given

₃

HAVING TESTS FOR POSSIBLE PROSTATE CANCER AT THE HOSPITAL

5. Did the doctor or nurse explain that these tests were to find out if you had prostate cancer?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

6. Did the doctor or nurse explain to you what each test would involve?

Please tick one box in **EACH** row in the table

	Yes, the explanation was clear	Yes, but the explanation could have been clearer	No explanation was given	I didn't have these tests
A Biopsy/TRUS	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
B Other tests (e.g. PSA blood test, Urine flow, Digital Rectal Examination, Scans)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

GETTING THE DIAGNOSIS AND MAKING THE TREATMENT DECISION

7. Were you advised that it might be helpful if someone (e.g. wife/partner, relative) could attend the appointment with you to get your diagnosis?

Please tick one box

- At the GP's Practice Yes ₁ No ₂ N/A ₃
- At the hospital Yes ₁ No ₂ N/A ₃

8. Were you given your diagnosis in a considerate way?

Please tick one box

- Yes, very considerately ₁
- Yes, but it could have been more considerate ₂
- No, not really ₃

9. After getting your diagnosis, did the doctor or nurse offer you the chance to talk to a specialist nurse?

Please tick one box

- Yes ₁ No ₂

10. Did the doctor or nurse explain which treatment options were open to you?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

11. Did the doctor or nurse involve you as much as you wanted in the decision about which treatment to have?

Please tick one box

- Yes, I was involved as much as I wanted ₁
- No, I was involved more than I wanted ₂
- No, I would have liked to have been more involved ₃

YOUR TREATMENT

12. Which treatment have you most recently had?

Please tick as many boxes as apply

- Prostatectomy**
Surgery to remove the prostate, including key hole surgery/da vinci (robotic surgery)
- Radiotherapy (completed/ongoing)**
Radiation delivered from outside the body and focused on the tumor through the skin
- Hormone therapy (completed/ongoing)**
A series of injections or tablets (e.g. Zoladex)
- Brachytherapy**
A type of internal radiation therapy in which radioactive materials are placed in direct contact with the tissue being treated.
- Cryotherapy**
A technique that uses an extremely cold liquid or instrument to freeze and destroy abnormal cells.
- HIFU (High Intensity Focused Ultrasound)**
A minimally invasive therapy delivered using a transrectal probe under ultrasound guidance
- Other**
- No immediate treatment (e.g. active monitoring)**

IF NO IMMEDIATE TREATMENT, PLEASE GO TO QUESTION 20

13. Before you started your treatment, did the doctor or nurse give you information about the treatment to help you feel prepared (e.g. what your treatment would involve, what you should/should not do during your treatment)?

Please tick one box

- Yes, I was given enough information ₁
- Yes, but I would have liked more information ₂
- No, I was not given any information ₃

14. Did the doctor or nurse offer you information about what you could do that might help at this stage (e.g. diet, exercises)?

Please tick one box

- Yes ₁ No ₂

15. How would you rate the following?

Please tick one box in EACH row in the table

	Very Good	Good	Satisfactory	Poor	Not applicable/ Don't Know
A Treatment	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B Nursing	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
C Food/drink	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
D Rooms where you had treatment (e.g. privacy, noise, cleanliness)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
E Ward (e.g. privacy, noise, cleanliness, comfort)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

16. Did the doctor or nurse explain how well the treatment was going/had gone?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

17. Did the doctor or nurse discuss with you how to manage any potential side effects of the treatment (e.g. continence, problems with sex, pain)

Please tick one box

- Yes ₁
- To some extent ₂
- No, not really ₃

18. When you left hospital or finished your treatment were you given equipment or supplies to help you care for yourself (e.g. continence pads, painkillers)?

Please tick one box

- Yes, I was given enough ₁
- Yes, but I would have liked more ₂
- No, I was not given any ₃
- I did not need any ₄

19. Did the doctor or nurse organise the aftercare services that you needed (e.g. district nurse, physiotherapist, home help)?

Please tick one box

- Yes, I got the aftercare services when I needed them ₁
- Yes, but not as soon as I needed them ₂
- No, I did not get the aftercare services I needed ₃
- I did not need any aftercare services ₄

MONITORING (CHECKING) YOU

20. Has the doctor or nurse reassured you that the length of the wait between the tests for prostate cancer is appropriate for you?

Please tick one box

- Yes ₁ No ₂

21. Has the doctor or nurse explained what the test results mean (e.g. what the PSA score means)?

Please tick one box

- Yes, the test results have been explained clearly ₁
- Yes, but the test results could have been explained more clearly ₂
- No explanation has been given ₃

GENERAL/OVERALL QUESTIONS

22. Were there any delays in your care before:

Please tick one box in *EACH* row in the table

	Yes	To some extent	No, not really
A You were referred to the hospital for tests?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
B You went to the hospital for tests (e.g. appointment cancelled)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
C You got your diagnosis?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
D You started your treatment?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

23. Were you given information about who to contact for advice or support (e.g. specialist nurse, patient support group, charity)?

Please tick one box

Yes, I was given enough information

 1

Yes, but I would have liked more information

 2

No, I was not given any information

 3

24. Have staff in different places worked well together when caring for you (e.g. information about you passed on, no unnecessary delays)?

Please tick one box in *EACH* row in the table

	Yes	To some extent	No, not really	Not applicable
A Between GP's practice and hospital	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
B Between hospitals	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
C Between different departments (e.g. Urology and Oncology)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

25. Please write any comments you would like to make here (e.g. any problems, anything that could have been done better or anything that was done particularly well).

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ABOUT YOU AND YOUR HEALTH

THIS INFORMATION WILL HELP PUT YOUR ANSWERS IN CONTEXT, AND SHOW WHETHER DIFFERENT GROUPS OF PEOPLE HAVE DIFFERENT EXPERIENCES

26. Overall, how good or bad is your general health today, in your opinion?

Please tick one box

- Very good ₁
- Good ₂
- Fair ₃
- Poor ₄
- Very poor ₅

27. Which age range are you in?

Please tick one box

- Up to 54 ₁ 55 – 64 ₂ 65 – 74 ₃ 75 or over ₄

28. Do you have someone to support and/or care for you (e.g. wife/relative)?

Please tick one box

- Yes ₁ No ₂

29. Which ethnic group do you belong to?

Please tick one box

- White ₁ Black or Black British ₂ Asian or Asian British ₃
- Mixed ₄ Chinese ₅ Other ethnic group ₆

30. Is your accommodation:

Please tick one box

- Owner-occupied/mortgaged? ₁
- Rented or other arrangements? ₂

31. Which of the following best describes you?

Please tick one box

- Employed (full or part time, including self-employed) 1
- Unemployed and looking for work 2
- In full time education 3
- Unable to work due to long term sickness 4
- Looking after your home/family 5
- Retired from paid work 6
- Other (*please describe below*) 7

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**Thank you very much for completing this questionnaire booklet.
Please return the questionnaire booklet within one week if
possible, in the pre-paid envelope provided.**

THE PROSTATE CARE QUESTIONNAIRE FOR PARTNERS/RELATIVES/FRIENDS (PCQ-C)

This questionnaire booklet is divided into four sections:

Section A: Your experiences when your partner/relative/friend was tested for possible prostate cancer

Section B: Your experiences while getting his diagnosis and making the treatment decision

Section C: Your experiences during the treatment and monitoring of your partner/relative/friend for prostate cancer

Section D: About you and your health

- You have been given/sent this questionnaire booklet because we want to find out about **your experiences when your partner/relative/friend was tested and/or treated for prostate cancer**. The information you give will be used to review and improve services.
- While every effort is made to ensure this questionnaire is not given/sent to anyone whose partner/relative/friend has not been tested for prostate cancer as with any administrative system, errors may occur. If you have been given/sent this questionnaire by mistake, please tick this box . Please accept our apologies and return it to us.
- We estimate that each section should take about 5 minutes to complete.
- Please answer as many questions as you can. Your answers will be treated in strict confidence: please do not give your name.
- **If you have any questions regarding the questionnaire, please contact the person named on the information sheet.**
- **Please return the completed questionnaire booklet. Thank you for your help.**

N.I.H.R



Funded by the NHS Service Delivery
and Organisation National R & D programme

This questionnaire was designed by:



PCQ-C • September 2007

SECTION A YOUR EXPERIENCES WHEN YOUR PARTNER/RELATIVE/FRIEND WAS TESTED FOR POSSIBLE PROSTATE CANCER

A1. Did your partner/relative/friend go to the GP's practice/local assessment centre about their possible prostate problem?

Please tick one box

Yes, to the GP's practice ₁

Yes, to the local assessment centre/clinic ₂

No (e.g. he was already in hospital) ₃

IF NO , PLEASE GO TO QUESTION A7

A2. Did the doctor or nurse give your partner/relative/friend any written information about being tested for prostate cancer?

Please tick one box

Yes ₁

No ₂

Don't know ₃

A3. Were you advised that it might be helpful for you to go with him to the hospital when he went for tests (e.g. verbally, in the referral letter)?

Please tick one box

Yes ₁ No ₂

A4. Did your partner/relative/friend have tests at the hospital named on the front of the questionnaire?

Please tick one box

Yes ₁ No ₂

IF NO, PLEASE GO TO QUESTION A13

A5. Did the hospital provide any information about the tests for prostate cancer (e.g. what the tests would involve, what after effects there might be)?

Please tick one box

Yes, I was given enough information ₁

Yes, but I would have liked more information ₂

No, I was not given any information ₃

A6. Did you go to the hospital with him when he went for tests?

Please tick one box

Yes, for all of them ₁

Yes, for some of them ₂

No, for none of them ₃

IF NO FOR NONE OF THEM, PLEASE GO TO QUESTION A13

A7. How would you rate the hospital facilities?

Please tick one box in EACH row in the table

	Very Good	Good	Satisfactory	Poor	Not applicable/ Don't Know
A Waiting Area	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B Availability of refreshment	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
C Toilets	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
D Rooms where the tests were carried out (e.g. cleanliness, privacy)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

A8. Were you treated considerably by the staff at the hospital?

Please tick one box in EACH row in the table

	Yes, very considerably	Yes, to some extent	No, not really
A Doctor(s)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
B Nurse(s)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
C Receptionist(s)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃

A9. Did the doctor or nurse explain that the tests were to find out if your partner/relative/friend had prostate cancer?

Please tick one box

Yes, the explanation was clear ₁

Yes, but the explanation could have been clearer ₂

No explanation was given ₃

A10. Were you told beforehand:

Please tick one box in *EACH* row in the table

A How long his test(s) would take?	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂
B That he may be in pain/upset after the biopsy?	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂

A11. Have staff in different places worked well together when testing your partner/relative/friend for prostate cancer (e.g. information about him passed on, no unnecessary delays)?

Please tick one box in *EACH* row in the table

	Yes	To some extent	No, not really	Not applicable
A Between GP's practice and hospital	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
B Between hospitals	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C Between different departments (e.g. Urology and Oncology)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

A12. Did the doctor or nurse offer you any support while you were waiting for the diagnosis (e.g. someone to talk to about any concerns you had)?

Please tick one box

Yes ₁ No ₂

A13. Please write any comments you would like to make here (e.g. any problems, anything that could have been done better or anything that was done particularly well).

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SECTION B YOUR EXPERIENCES WHILE GETTING HIS DIAGNOSIS AND MAKING THE TREATMENT DECISION

B1. Where was your partner/relative/friend given his diagnosis?

Please tick one box

At the hospital named on the front of the questionnaire ₁

At another hospital (please write below the details) ₂

Name of the hospital

Town/City

At the GP's practice ₃

B2. Were you advised that it might be helpful for you to go with him when he went for the diagnosis (e.g. verbally, in the referral letter)?

Please tick one box

Yes ₁ No ₂

B3. Were you in the room with your partner/relative/friend when he was given his diagnosis?

Please tick one box

Yes ₁ No ₂

IF NO, PLEASE GO TO QUESTION B8

B4. Was your partner/relative/friend diagnosed with prostate cancer?

Please tick one box

Yes ₁ No ₂

IF NO, PLEASE GO TO QUESTION B26

B5. Did you feel that the doctor or nurse gave the diagnosis in a considerate way?

Please tick one box

Yes, very considerately ₁

Yes, but it could have been more considerate ₂

No, not really ₃

B6. Did the doctor or nurse explain how aggressive the cancer was likely to be?

Please tick one box

Yes, the explanation was clear ₁

Yes, but the explanation could have been clearer ₂

No explanation was given ₃

B7. Did the doctor or nurse explain whether or not the cancer had spread outside the prostate?

Please tick one box

Yes, the explanation was clear

 ₁

Yes, but the explanation could have been clearer

 ₂

No explanation was given

 ₃

B8. Did the doctor or nurse provide you or your partner/relative/friend with any WRITTEN information about the diagnosis?

Please tick one box

Yes

 ₁

No

 ₂

Don't know

 ₃

B9. How did you feel about the length of time between the diagnosis being given and the treatment options being discussed?

Please tick one box

Too short

 ₁

About right

 ₂

Too long

 ₃

B10. Were you in the room with your partner/relative/friend when the treatment options were discussed?

Please tick one box

Yes ₁ No ₂

IF NO, PLEASE GO TO QUESTION B18

B11. Did the doctor or nurse explain which treatment options were open to your partner/relative/friend?

Please tick one box

Yes, the explanation was clear

 ₁

Yes, but the explanation could have been clearer

 ₂

No explanation was given

 ₃

B12. Did the doctor or nurse explain what these treatment options would involve?

Please tick one box

Yes, the explanation was clear

 ₁

Yes, but the explanation could have been clearer

 ₂

No explanation was given

 ₃

B13. Did the doctor or nurse explain the possible side effects or consequences of these treatment options?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

B14. Did the doctor or nurse explain what could be done about the possible side effects?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

B15. Did the doctor or nurse explain why other treatment options were not open to your partner/relative/friend?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

B16. Did the doctor or nurse include you in the discussion on the treatment options and possible side effects?

Please tick one box

- Yes, I was included as much as I wanted ₁
- No, I was included more than I wanted ₂
- No, I would have liked to have been more included ₃

B17. Did the doctor or nurse make you feel that you could ask any questions you wanted to?

Please tick one box

- Yes ₁
- To some extent ₂
- No, not really ₃

B18. Did the doctor or nurse give you or your partner/relative/friend with any WRITTEN information about:

Please tick one box in EACH row in the table

A The treatment options?	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂
B The possible side effects or consequences of the treatment options?	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂
C What could be done about the side effects?	Yes <input type="checkbox"/> ₁ No <input type="checkbox"/> ₂

B19. How did you feel about the length of time your partner/relative/friend had to consider their treatment options before the treatment decision was made?

Please tick one box

- Too short ₁
- About right ₂
- Too long ₃

B20. Did the doctor or nurse involve you as much as you wanted in the decision about which treatment your partner/relative/friend was to have?

Please tick one box

- Yes, I was involved as much as I wanted ₁
- No, I was involved more than I wanted ₂
- No, I would have liked to have been more involved ₃

B21. Did the doctor or nurse give you or your partner/relative/friend the help wanted to make the treatment decision (e.g. by finding out what was important to you, by giving you his/her opinion)?

Please tick one box

- Yes, we had as much help as we wanted ₁
- No, we would have liked more help ₂
- I was not involved in making the decision about which treatment to have ₃

B22. After the treatment decision had been made, did the doctor or nurse explain to you or your partner/relative/friend that the treatment decision could be changed?

Please tick one box

- Yes ₁ No ₂

B23. Did the doctor or nurse offer information about what your partner/relative/friend could do that might help at this stage (e.g. diet, exercises)?

Please tick one box

Yes ₁ No ₂

B24. Did the doctor or nurse give you information about who YOU could contact for advice or support (eg. specialist nurse, patient/carer support group, charity)?

Please tick one box

Yes, I was given enough information ₁

Yes, but I would have liked more information ₂

No, I was not given any information ₃

B25. Were you treated considerately by the staff at the hospital?

Please tick one box in **EACH** row in the table

	Yes, very considerately	Yes, to some extent	No, not really
A Doctor(s)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
B Nurse(s)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
C Receptionist(s)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃

B26. Please write any comments you would like to make here (e.g. any problems, anything that could have been done better or anything that was done particularly well).

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SECTION C YOUR EXPERIENCES DURING THE TREATMENT AND MONITORING OF YOUR PARTNER/RELATIVE/FRIEND FOR PROSTATE CANCER

C1. Which treatment did your partner/relative/friend most recently have?

Please tick as many boxes as apply

- Prostatectomy**
Surgery to remove the prostate, including key hole surgery/da vinci (robotic surgery)
- Radiotherapy (completed/ongoing)**
Radiation delivered from outside the body and focused on the tumor through the skin
- Hormone therapy (completed/ongoing)**
A series of injections or tablets (e.g. Zoladex)
- Brachytherapy**
A type of internal radiation therapy in which radioactive materials are placed in direct contact with the tissue being treated.
- Cryotherapy**
A technique that uses an extremely cold liquid or instrument to freeze and destroy abnormal cells.
- HIFU (High Intensity Focused Ultrasound)**
A minimally invasive therapy delivered using a transrectal probe under ultrasound guidance
- Other**
- No immediate treatment (e.g. active monitoring)**

IF NO IMMEDIATE TREATMENT, PLEASE GO TO QUESTION C13

C2. Thinking about his most recent visit for treatment, did he go to the hospital or the GP's practice?

Please tick one box

- The hospital named on the front of the questionnaire ₁
- Another hospital (please write below the details) ₂
- Name of the hospital
- Town/City
- The GP's practice ₃

C3. Were you advised that it might be helpful if you could go with him when he went for treatment?

Please tick one box

- Yes ₁ No ₂

C4. Before your partner/relative/friend started treatment, did a doctor or nurse give you information about the treatment to help you feel prepared (e.g. what the treatment would involve, what he should/should not do during treatment)?

Please tick one box

- Yes, I had enough information ₁
- Yes, but I would have liked more information ₂
- No, I did not have any information ₃

C5. Did you experience any of the following problems with your partner/relative/friend visit(s) for treatment?

Please tick as many boxes as apply

- Appointment cancelled or postponed
- Getting there (e.g. transport)
- Parking (e.g. finding a parking space, too expensive)
- Kept waiting (e.g. more than 30 minutes)
- Inconvenient appointment time
- Medical notes not available
- Cleanliness
- I did not have any of these problems

C6. Were you kept up to date:

Please tick one box in EACH row in the table

	Yes	To some extent	No
A With the progress of the treatment?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
B With how well the treatment was going?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃

C7. Before he left the hospital or finished his treatment did the doctor or nurse explain what would happen next (e.g. arrangements for follow-up)?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃
- He has not finished treatment (e.g. still having hormone therapy) ₄

C8. Before he left the hospital or finished his treatment were you given an explanation about what to expect (e.g. the potential side effects and how long they might last, recovery time)?

Please tick one box

- Yes, the explanation was clear 1
- Yes, but the explanation could have been clearer 2
- No explanation was given 3
- He has not finished treatment 4

C9. Did the doctor or nurse give you any information about caring for him (e.g. continence, problems with sex, managing pain)?

Please tick one box

- Yes, I was given enough information 1
- Yes, but I would have liked more information 2
- No, I was not given any information 3

C10. When he left hospital or finished his treatment were you or your partner/relative/friend given equipment or supplies that were needed (e.g. continence pads, painkillers)?

Please tick one box

- Yes, we were given enough 1
- Yes, but we would have liked more 2
- No, we were not given any 3
- We did not need any 4

C11. When he left hospital or finished his treatment were you or your partner/relative/friend told how to get further equipment or supplies (e.g. continence pads, painkillers)?

Please tick one box

- Yes 1
- No 2
- We did not need any 3

C12. Did the doctor or nurse organise the aftercare services that were needed for your partner/relative/friend (e.g. district nurse, physiotherapist, home help)?

Please tick one box

- Yes, we got the aftercare services when we needed them ₁
- Yes, but not as soon as we needed them ₂
- No, we did not get the aftercare services we needed ₃
- We did not need any aftercare services ₄

C13. Does your partner/relative/friend have regular tests for prostate cancer (e.g. PSA blood test, Digital Rectal Examination)?

Please tick one box

- Yes ₁ No ₂

IF NO, PLEASE GO TO QUESTION C16

C14. Did the doctor or nurse explain why there is a need for regular tests to check his condition (e.g. PSA blood test)?

Please tick one box

- Yes, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

C15. Has the doctor or nurse explained what the test results means (e.g. what the PSA score means)?

Please tick one box

- Yes, the test results have been explained clearly ₁
- Yes, but the test results could have been explained more clearly ₂
- No explanation has been given ₃

C16. Has the doctor or nurse given you any information about who to contact for advice or support (e.g. specialist nurse, carer support group)?

Please tick one box

- Yes, I was given enough information ₁
- Yes, but I would have liked more information ₂
- No, I was not given any information ₃

C17. Have staff in different places worked well together when caring for your partner/relative/friend for this condition (e.g. information about him passed on, no unnecessary delays)?

Please tick one box in EACH row in the table

	Yes	To some extent	No, not really	Not applicable
A Between GP's practice and hospital	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
B Between hospitals	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C Between different departments (e.g. Urology and Oncology)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

C18. Please write any comments you would like to make here (e.g. any problems, anything that could have been done better or anything that was done particularly well).

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SECTION D ABOUT YOU AND YOUR HEALTH

THIS INFORMATION WILL HELP PUT YOUR ANSWERS IN CONTEXT, AND SHOW WHETHER DIFFERENT GROUPS OF PEOPLE HAVE DIFFERENT EXPERIENCES

D1. Please identify who passed you this questionnaire.

Please tick one box

- Partner/husband ₁
Other relative ₂
Friend ₃
Other ₄

D2. Overall, how good or bad is your general health today, in your opinion?

Please tick one box

- Very good ₁
Good ₂
Fair ₃
Poor ₄
Very poor ₅

D3. Which age range are you in?

Please tick one box

- Up to 21 ₁ 22 to 54 ₂ 55 – 64 ₃ 65 – 74 ₄ 75 or over ₅

D4. Do you have someone to support and/or care for you (e.g. husband/relative)?

Please tick one box

- Yes ₁ No ₂

D5. Which ethnic group do you belong to?

Please tick one box

- White ₁ Black or Black British ₂ Asian or Asian British ₃
Mixed ₄ Chinese ₅ Other ethnic group ₆

D6. Is your accommodation:

Please tick one box

Owner-occupied/mortgaged? ₁

Rented or other arrangements? ₂

D7. Which of the following best describes you?

Please tick one box

Employed (full or part time, including self-employed) ₁

Unemployed and looking for work ₂

In full time education ₃

Unable to work due to long term sickness ₄

Looking after your home/family ₅

Retired from paid work ₆

Other (*please describe below*) ₇

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**Thank you very much for completing this questionnaire booklet.
Please return the questionnaire booklet within one week if
possible, in the pre-paid envelope provided.**

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