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APPENDIX 1

Data extraction form

Data extraction form

Phase of care: Screening, diagnosis and referral, treatment decisions, treatment, follow-up/long term treatment, relapse, palliative care, terminal care

**REF ID
Extractor ID**

**Authors
Title of article
Date of publication
Country of study**

**Relevant to topic?
*If NO why? Please do not proceed further with the form***

Quality

- **Are the aims and objectives clearly stated?**
- **Is the design clearly specified and appropriate?**
- **Do the researchers provide a clear account of the process through which findings were produced?**
- **Do the researchers display enough data to support their interpretations and conclusions?**
- **Is the method of analysis appropriate and adequately explicated?**

**Acceptable quality?
If unacceptable state reasons please state briefly reasons:
*If NO please do not proceed further with the form***

**Stated aim of the study:
Sample/participants:
Study Design:
Data collection:
Analytic approach:**

Themes

- 1
 - 2
 - 3
 - 4
 - 5
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Comments

APPENDIX 2

Summary information on
the studies included in
the literature review

Summary information on the studies included in the literature review

PAPER	METHOD OF DATA COLLECTION	SAMPLE / PARTICIPANTS	COUNTRY	PHASE OF THE CARE PATHWAY	ASPECT OF CARE	FINDINGS
Arroll B et al 2003 Prostate cancer screening: knowledge, experiences and attitudes of men aged 40-79 years. <i>The New Zealand Medical Journal</i> 116:1-8.	Telephone survey	120 men with prostate cancer	New Zealand	Screening	Information/knowledge	The majority approved of screening and were not aware of complications of treatment.
Bailey D.E. et al 2004 Uncertainty intervention for watchful waiting in prostate cancer. <i>Cancer Nursing</i> 27 (5):339-346.	Questionnaire (Randomised control trial)	41 men with prostate cancer whose treatment is watchful waiting	USA	Treatment	Coping	Intervention patients were more likely than controls to view their lives in a new light and experience a decrease in confusion.
Berglund G et al 2003 "Between men": Patient perceptions and priorities in a rehabilitation program for men with prostate cancer. <i>Patient Education and Counseling</i> 49 (3):285-292.	Questionnaire (Randomised control trial)	211 men with prostate cancer who are newly diagnosed	Sweden	Explanation of diagnosis	Information/knowledge	Patients rated the knowledge they received from the information programme as very important. Patients rated the relaxation benefits of the combined programme (physical training and information) higher than in the physical only programme.

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<p>Boberg E.W. et al 2003 Assessing the unmet information, support and care delivery needs of men with prostate cancer. <i>Patient Education and Counseling</i> 49 (3):233-242.</p>	<p>Focus group, questionnaire</p>	<p>6 focus groups (39 men with prostate cancer), 233/500 responses from men with prostate cancer to questionnaires</p>	<p>USA</p>	<p>Post initial treatment</p>	<p>Information/knowledge; support</p>	<p>Care delivery needs tended to be met, but information and support needs were less well met.</p>
<p>Boehmer U & Clark J.A. 2001 Married couples' perspectives on prostate cancer diagnosis and treatment decision-making. <i>Psycho-Oncology</i> 10 (2):147-155, 2001.</p>	<p>Focus group</p>	<p>7 men with prostate cancer and their partners (14 subjects)</p>	<p>USA</p>	<p>Explanation of diagnosis; treatment decision</p>	<p>Information/knowledge; decision-making; role of carer</p>	<p>Men did not share their prostate-related health problems or treatment decisions with their wives. Physicians affect the decision-making process and style.</p>
<p>Booker J et al 2004 Telephone first post-intervention follow-up for men who have had radical radiotherapy to the prostate: evaluation of a novel service delivery approach. <i>European Journal of Oncology Nursing</i> 8 (4):325-333.</p>	<p>Questionnaire</p>	<p>36 men with prostate cancer</p>	<p>UK</p>	<p>Post initial treatment</p>	<p>Support; relationship with healthcare professional</p>	<p>The telephone service was generally seen as convenient and time-saving. Nurse led care was acceptable.</p>

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<p>Boxhall S & Dougherty M 2003 An evaluation of a specialist nursing role for men with prostate cancer. <i>Urologic Nursing</i> 23 (2):148-152, 2003.</p>	<p>Focus group</p>	<p>30 men with prostate cancer (newly diagnosed)</p>	<p>Australia</p>	<p>Explanation of diagnosis</p>	<p>Information/knowledge; support; relationship with healthcare professional</p>	<p>A nurse was an acceptable source of information and support (patients valued the extra time they felt that they had).</p>
<p>Breau R.H. et al 2003 Assessing self-help issues for patients with prostate cancer, interstitial cystitis, erectile dysfunction and urinary diversion. <i>BJU International</i> 92 (7):736-740.</p>	<p>Interview</p>	<p>30 men with prostate cancer</p>	<p>Canada</p>	<p>Post initial treatment</p>	<p>Information/knowledge; self-help</p>	<p>Many patients would use most types of self-help if they were available.</p>
<p>Broom A 2005 The eMale - Prostate cancer, masculinity and online support as a challenge to medical expertise. <i>Journal of Sociology</i> 41 (1):87-104.</p>	<p>Interview</p>	<p>33 men with prostate cancer</p>	<p>Australia</p>	<p>Post initial treatment</p>	<p>Support</p>	<p>Online support groups provide some men with a method of managing inhibitions associated with face-to-face encounters.</p>
<p>Butler L et al 2000 Behind the scenes: partners' perceptions of quality of life post radical prostatectomy. <i>Urologic Nursing</i> 20 (4):254-258.</p>	<p>Interview</p>	<p>21 partners of men with prostate cancer</p>	<p>Canada</p>	<p>Explanation of diagnosis; treatment decision; post initial treatment</p>	<p>Information/knowledge; coping</p>	<p>Couples need information to help them in decision-making and self-care e.g. catheter care.</p>

PAPER	METHOD OF DATA COLLECTION	SAMPLE / PARTICIPANTS	COUNTRY	PHASE OF THE CARE PATHWAY	ASPECT OF CARE	FINDINGS
Chapple A et al 2002 (a) Why men with prostate cancer want wider access to prostate specific antigen testing: qualitative study. <i>BMJ</i> 325: 737-739	Interview	52 men with suspected or confirmed prostate cancer	UK	Screening	Information/knowledge; decision-making	Most men remembered the PSA test but recalled receiving little information beforehand.
Chapple A et al 2002 (b) Is 'watchful waiting' a real choice for men with prostate cancer? A qualitative study. <i>BJU International</i> 90:257-264.	Interview	50 men with prostate cancer whose treatment is watchful waiting	UK	Treatment	Decision-making; information/knowledge	Few of the men who might have chosen watchful waiting remember this being presented as a serious option. Most chose active treatments. Those who chose watchful waiting often faced pressure to seek active treatment.
Cohen H & Britten N 2003 Who decides about prostate cancer treatment? A qualitative study. <i>Family Practice</i> 20 (6):724-729.	Interview	19 men with prostate cancer who are newly diagnosed	UK	Treatment decision	Decision-making; communication	The respondents' treatment plans were mostly decided on their behalf by their clinicians, and the structure of patient follow-up did not afford men an opportunity to discuss treatment decisions further.
Crawford E.D. et al 1997 Comparison of perspectives on prostate cancer: Analyses of survey data. <i>Urology</i> 50 (3):366-372.	Telephone survey	1000 men with prostate cancer (from a patient support group)	USA	Treatment decision; post initial treatment	Information/knowledge; decision-making; support	About four fifths of patients preferred aggressive therapy for prostate cancer. Only one fifth recalled discussions on options for no therapy, life expectancy with and without therapy, patient preferences. Support groups were good providers of emotional support compared to physicians.

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Davison B.J. et al 1995 Information and decision-making preference of men with prostate cancer. <i>Oncology Nursing Forum</i> 22 (9):1401-1408.	Questionnaire	57 men with prostate cancer who are newly diagnosed	Canada	Treatment decision	Information/knowledge; decision-making	58% of men preferred a passive decision-making role. Men wanted information on disease advancement, likelihood of cure and types of treatment available.
Davison B.J. & Degner L.F. 1997 Empowerment of men newly diagnosed with prostate cancer. <i>Cancer Nursing</i> 20 (3):187-196.	Questionnaire (Randomised control trial)	60 men with prostate cancer who are newly diagnosed	Canada	Treatment decision	Information/knowledge; decision-making	Men in the intervention group assumed a significantly more active role in treatment decision-making and had lower state anxiety levels at 6 weeks post intervention.
Davison B.J et al 1999 Information and patient participation in screening for prostate cancer. <i>Patient Education and Counseling</i> 37 (3):255-263.	Interview and questionnaire (Randomised control trial)	100 men (prior to periodic health examination)	Canada	Screening	Information/knowledge; decision-making	Men who received the information prior to the Periodic health examination (PHE) assumed a significantly more active role in making a testing decision.
Davison B.J. et al 2002 Assessing information and decision preferences of men with prostate cancer and their partners. <i>Cancer Nursing</i> 25 (1):42-49.	Questionnaire	80 men with prostate cancer and their partners	Canada	Treatment decision	Information/knowledge; decision-making	Men had a preference for an active or collaborative role in decision-making. Couples identified prognosis, disease stage, treatment options and side effects as the 4 priority information needs.

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<p>Davison B.J. et al 2003 Provision of individualized information to men and their partners to facilitate treatment decision-making in prostate cancer. <i>Oncology Nursing Forum</i> 30 (1):107-114.</p>	<p>Questionnaire</p>	<p>74 men with prostate cancer (newly diagnosed) and their partners</p>	<p>Canada</p>	<p>Treatment decision</p>	<p>Decision-making</p>	<p>Individualized information to patients and their partners at the time of diagnosis was associated with lowering couples' levels of psychological distress and enabling patients to participate in decision-making.</p>
<p>Davison B.J. et al 2004 Patient evaluation of a discharge program following a radical prostatectomy. <i>Urologic Nursing</i> 24 (6):483-489.</p>	<p>Questionnaire</p>	<p>100 men with prostate cancer who had radical prostatectomy</p>	<p>Canada</p>	<p>Post initial treatment</p>	<p>Information/knowledge; self care</p>	<p>The participants were satisfied with the programme and felt that it provided them with the necessary information for recovery.</p>
<p>Dube C.E. et al 2004 Men's experiences of physical exams and cancer screening tests: a qualitative study. <i>Preventive Medicine</i> 40 (6):628-635.</p>	<p>Focus group</p>	<p>33 men discussed prostate cancer screening and 20 discussed testicular screening</p>	<p>USA</p>	<p>Screening</p>	<p>Information/knowledge; communication decision-making</p>	<p>When PSA testing was offered, discussion was often inadequate. These men desired more discussion and better sources of health information during medical encounters. Privacy was also important to patients.</p>
<p>Duke J et al 2001 The perceived needs of men diagnosed with prostate cancer. <i>Australian Epidemiology</i> 8 (2):34-40.</p>	<p>Questionnaire</p>	<p>650 men with prostate cancer (either localised or advanced cancer)</p>	<p>Australia</p>	<p>Post initial treatment</p>	<p>Information/knowledge; decision-making; support</p>	<p>High levels of needs were identified in the domains of emotional wellbeing, physical/daily living, communication and information on treatment risks and post-treatment side-effects and expectations.</p>

PAPER	METHOD OF DATA COLLECTION	SAMPLE / PARTICIPANTS	COUNTRY	PHASE OF THE CARE PATHWAY	ASPECT OF CARE	FINDINGS
<p>Eakin E.G. & Strycker L.A. 2001 Awareness and barriers to use of cancer support and information resources by HMO patients with breast, prostate, or colon cancer: Patient and provider perspectives. <i>Psycho-Oncology</i> 10 (2):103-113.</p>	<p>Questionnaire</p>	<p>501 patients with breast, colon or prostate cancer (n=151)</p>	<p>USA</p>	<p>Post initial treatment</p>	<p>Support; information/knowledge</p>	<p>Patients with prostate cancer were more likely to use a support group if they were in active treatment and had higher levels of personal support.</p>
<p>Eton D.T. et al 2005 Psychological distress in spouses of men treated for early stage prostate carcinoma <i>Cancer</i> 103 (11):2412-2418</p>	<p>Interview</p>	<p>165 couples</p>	<p>USA</p>	<p>Post initial treatment</p>	<p>Psychological distress</p>	<p>Spouses reported more cancer-specific distress than did patients, but did not differ from patients in general distress. Overall distress in spouses of early-stage patients with prostate cancer was modest, and it was more likely to be predicted by psychosocial than medical factors.</p>
<p>Feldman-Stewart D et al 2001 What questions do families of patients with early-stage prostate cancer want answered? <i>Journal of Family Nursing</i> 7 (2):188-207.</p>	<p>Questionnaire</p>	<p>22 families of men with prostate cancer (newly diagnosed)</p>	<p>Canada</p>	<p>Explanation of diagnosis</p>	<p>Information/knowledge</p>	<p>A core set of 29 information items was identified that most (>67%) respondents agreed were essential. The information priorities of the patient often differed from those of his family.</p>

PAPER	METHOD OF DATA COLLECTION	SAMPLE / PARTICIPANTS	COUNTRY	PHASE OF THE CARE PATHWAY	ASPECT OF CARE	FINDINGS
Feltwell A.K. & Rees C.E. 2004 The information-seeking behaviours of partners of men with prostate cancer: a qualitative pilot study. <i>Patient Education and Counseling</i> 54:179-185.	Focus group and interview	6 men with prostate cancer and their partners (n=12)	UK	Post initial treatment	Decision-making; role of carer	Some partners sought detailed information while other avoided information. Some failed to seek information from health care professionals as they felt disempowered and rushed for time in the consultations.
Fitch M.I. et al 1999 Survivors' perspectives on the impact of prostate cancer: implications for oncology nurses. <i>Canadian Oncology Nursing Journal</i> 9 (1):23-28.	Questionnaire	621 men diagnosed with prostate cancer	Canada	Post initial treatment	Treatment side effects; information/knowledge; self help; support	The most frequently identified problems were sexual function, side effects, fear of dying and incontinence. Most had been accurately informed about treatment but there was dissatisfaction with lack of information about emotional reactions, alternative therapies, speaking to other patients and availability of counselling and self-help groups.
Fitch M.I. et al 2000 Men's perspectives on the impact of prostate cancer: implications for oncology nurses. <i>Oncology Nursing Forum</i> 27 (8):1255-1263.	Questionnaire	120 men with recurrent prostate cancer and 845 men without recurrent disease	Canada	Further treatment and palliative care	Treatment side effects; pain; relationship with healthcare professionals; information/knowledge	Men with recurrent disease experienced: problems with side effects, anger, pain and talking with healthcare professionals. They were dissatisfied with the information they received about their medical condition and possible side effects.
Flood A.B. et al 1996 The importance of patient preference in the decision to screen for prostate cancer. <i>Journal of General Internal Medicine</i> 11 (6):342-349.	Questionnaire (Randomised control trial)	372 men seeking prostate cancer screening. 196 men visiting a general internal medicine clinic.	USA	Screening	Information/knowledge	Men who viewed the educational videotape were better informed about PSA tests, and were less likely to have a PSA test.

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Gray R.E. et al 1997 Interviews with men with prostate cancer about their self-help experience. <i>Journal of Palliative Care</i> 13:15-21.	Interview	12 men with prostate cancer involved in self-help groups	Canada	Post initial treatment	Information/knowledge; support	Participants reported their group involvement to be helpful, especially in terms of accessing information. Additional benefits included being able to talk about difficult issues, and engaging with family members around health issues.
Gray R.E. et al 1999 Presurgery experiences of prostate cancer patients and their spouses. <i>Cancer Practice</i> 7 (3):130-135.	Interview	34 men with prostate cancer (newly diagnosed and awaiting surgery)and their partners	Canada	Explanation of diagnosis	Communication: support; information/knowledge; decision-making	The diagnosis of prostate cancer came as a shock for both partners, the impact of which lessened over time; the reality of illness necessitated readdressing the marital relationship, most often resulting in a sense of renewed connection and commitment.
Gray R.E. et al 2000 Managing the impact of illness: The experiences of men with prostate cancer and their spouses. <i>Journal of Health Psychology</i> 5 (4):531-548.	Interview	34 men with prostate cancer (newly diagnosed)	Canada	Explanation of diagnosis; treatment decision	Information/knowledge; decision-making; coping; role of carer; adjustment	Managing the impact of illness included dealing with the practicalities; stopping illness from interfering with everyday life; keeping relationships working; managing feelings and making sense of it all.
Gregoire I et al 1997 The effectiveness of a professionally led support group for men with prostate cancer. <i>Urologic Nursing</i> 17 (2):58-66.	Questionnaire	54 men with prostate cancer and some family members	Canada	Post initial treatment	Information/knowledge; decision-making; coping	Participants in the support group felt they had a better understanding of their illness and perceived themselves as more involved in their treatment. Sharing their experiences with others helped provide a more positive outlook.

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<p>Gwede C.K et al 2005 Treatment decision-making strategies and influences in patients with localised prostate carcinoma <i>Cancer 104(7):1381-1390</i></p>	<p>Questionnaire</p>	<p>119 men treated with Radical prostatectomy (44%) or brachytherapy (56%)</p>	<p>USA</p>	<p>Treatment decision</p>	<p>Decision-making; satisfaction with care</p>	<p>Approximately half of patients reported difficulty (49%) and distress (45%) while making treatment decisions, but no regrets (74%) regarding the treatment choice that they made. Patients chose Brachytherapy because of Quality of Life considerations and Radical prostatectomy was chosen for “cure and complete removal of the tumour”.</p>
<p>Hack T.F et al 1999 Feasibility of an Audiotape Intervention for Patients with Cancer: A Multicenter, Randomized Controlled Pilot Study. <i>Journal of Psychosocial Oncology 17 (2):1-15.</i></p>	<p>Questionnaire Telephone interview (Randomised control trial)</p>	<p>18 men with prostate cancer (newly diagnosed) and 18 women with breast cancer</p>	<p>Canada</p>	<p>Explanation of diagnosis</p>	<p>Information/knowledge; communication</p>	<p>Recall of information was significantly greater among patients who received the audiotape. The patients who at follow-up recalled the most information had the highest degree of satisfaction with patient-physician communication.</p>
<p>Hann D.M et al 2005 Use of complementary therapies among breast and cancer patients during treatment: a multi-site study <i>Integrative Cancer Therapies 4 (4):294-300</i></p>	<p>Questionnaire</p>	<p>126 breast and 82 prostate cancer patients</p>	<p>USA</p>	<p>Treatment</p>	<p>Complementary therapies; coping and self-care</p>	<p>Significantly more breast cancer patients used CT than prostate cancer patients. Prostate cancer patients’ reasons for using complementary therapies: reduce side effects, provide hope, help people cope and reduce stress.</p>
<p>Hamilton J.B. & Sandelowski M 2004 Types of social support in African Americans with cancer. <i>Oncology Nursing Forum 31 (4):792-800.</i></p>	<p>Interview</p>	<p>13 African American men with prostate cancer and 15 women with breast cancer</p>	<p>USA</p>	<p>Post initial treatment</p>	<p>Support; information/knowledge</p>	<p>Patients valued the emotional support of “presence”; instrumental support of prayers maintaining social roles; informational support from family and friends including on managing symptoms and interpreting information from professionals.</p>

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<p>Harden J et al 2002 Couples' experiences with prostate cancer: focus group research. <i>Oncology Nursing Forum</i> 29 (4):701-709.</p>	<p>Focus group</p>	<p>22 men with prostate cancer (newly diagnosed or with metastatic disease) and 20 spouse-caregivers</p>	<p>USA</p>	<p>Post initial treatment</p>	<p>Support; information/knowledge; decision-making; coping; treatment side effects</p>	<p>Participants had a need for information and support. Both men and partners felt unprepared to manage treatment effects (urine control, sexual function, fatigue). Symptoms had a broad effect on couples, not just men.</p>
<p>Hellbom M et al 1998 Individual psychological support for cancer patients: utilisation and patient satisfaction. <i>Patient Education and Counseling</i> 34 (3):247-256.</p>	<p>Questionnaire</p>	<p>527 patients newly diagnosed with breast, colorectal, gastric and prostate cancer (n=197)</p>	<p>Sweden</p>	<p>Explanation of diagnosis</p>	<p>Support</p>	<p>A short-term problem focused Individual Psychological Support (IPS) was evaluated. The majority who received the IPS stated that their problems were addressed to a great extent, that the number of contacts was adequate and that the IPS came at the right time.</p>
<p>Heyman E.N. & Rosner T.T. 1996 Prostate cancer: an intimate view from patients and wives. <i>Urologic Nursing</i> 16:37-44.</p>	<p>Focus group and interview</p>	<p>20 men with prostate cancer and their wives</p>	<p>USA</p>	<p>Post initial treatment</p>	<p>Information/knowledge; support</p>	<p>Informational needs change over time, firstly for reassurance survival. Information should be presented several times and sources of information should be made known. Information required on coping with side effects after treatment. Contact with other survivors was beneficial.</p>
<p>Holmboe E.S. & Concato J 2000 Treatment decisions for localized prostate cancer - Asking men what's important. <i>Journal of General Internal Medicine</i> 15 (10):694-701.</p>	<p>Interview</p>	<p>102 men with prostate cancer (newly diagnosed)</p>	<p>USA</p>	<p>Treatment decision</p>	<p>Decision-making</p>	<p>Reasons for preferring a treatment were removal of tumour, evidence for radiotherapy and short duration of therapy (brachytherapy). Dislikes were risk of incontinence for prostatectomy, long duration of therapy (radiotherapy) and lack of evidence (brachytherapy). Watchful waiting was rejected through fear of future consequences.</p>

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<p>Jacobs J.R. et al 2002 Problems associated with prostate cancer: differences of opinion among health care providers, patients, and spouses. <i>Journal of Cancer Education</i> 17 (1):33-36.</p>	<p>Interview</p>	<p>5 men with prostate cancer and their 5 spouses, 5 urologic oncologists and 5 oncology nurses</p>	<p>USA</p>	<p>Treatment</p>	<p>Communication</p>	<p>Patients, partners and professionals had different opinions on problems, which may contribute to communication problems between them.</p>
<p>Jakobsson L et al 1997 Met and unmet nursing care needs in men with prostate cancer. An explorative study. Part II. <i>European Journal of Cancer Care</i> 6 (2):117-123.</p>	<p>Interview</p>	<p>11 men with prostate cancer</p>	<p>Sweden</p>	<p>Treatment</p>	<p>Relationship with healthcare professionals; satisfaction with care; information; support</p>	<p>Patients were either passive or active receivers of care. Nurses need to be aware of, and sensitive to, undertones in statements and actively seek patients' needs.</p>
<p>Johnson J.E. et al 1989 Process of coping with radiation therapy. <i>Journal of Consulting and Clinical Psychology</i> 57 (3):358-364.</p>	<p>Questionnaire (Randomised control trial)</p>	<p>84 men with prostate cancer treated with radiotherapy</p>	<p>USA</p>	<p>Treatment</p>	<p>Coping</p>	<p>The experimental group (which had information on coping with radiotherapy) experienced significantly less disruption in function during and for 3 months following radiotherapy than the comparison group.</p>
<p>Kelsey S.G. et al 2004 The experience of radiotherapy for localized prostate cancer: the men's perspective. <i>European Journal of Cancer Care</i> 13:272-278.</p>	<p>Focus group</p>	<p>27 men with prostate cancer (treated with radiotherapy or brachytherapy)</p>	<p>UK</p>	<p>Treatment</p>	<p>Information/knowledge; decision-making; relationship with healthcare professionals; support</p>	<p>There was a fragmented approach to care and treatment, and a need to evaluate the provision of information.</p>

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<p>Kronenwetter C et al 2005 A qualitative analysis of interviews of men with early stage prostate cancer: the Prostate Cancer Lifestyle Trial. <i>Cancer Nursing</i> 28 (2):99-107.</p>	<p>Interview</p>	<p>26 men with prostate cancer whose treatment is watchful waiting</p>	<p>USA</p>	<p>Explanation of diagnosis; treatment</p>	<p>Adjustment; role of carer; support</p>	<p>Diagnosis was met with either anxiety, stress, or denial. Some indication that conflict with partners was exacerbated by the diagnosis.</p>
<p>Lintz K et al 2003 Prostate cancer patients' support and psychological care needs: Survey from a non-surgical oncology clinic. <i>Psycho-Oncology</i> 12 (8):769-783.</p>	<p>Questionnaire</p>	<p>210 men with prostate cancer</p>	<p>UK</p>	<p>Treatment; post initial treatment</p>	<p>Support; information/knowledge</p>	<p>Significant unmet need existed across a number of domains in the areas of psychological and health system/information. The more commonly reported needs were 'fear about cancer spreading (44%), concerns about the worries of close family (43%) and changes in sexual feelings (41%).'.</p>
<p>Maliski S.L. et al 2002 From "death sentence" to "good cancer": Couples' transformation of a prostate cancer diagnosis. <i>Nursing Research</i> 51 (6):391-397.</p>	<p>Interview</p>	<p>20 couples (men with prostate cancer and had undergone a prostatectomy)</p>	<p>USA</p>	<p>Explanation of diagnosis; treatment</p>	<p>Adjustment; support; information/knowledge; decision-making</p>	<p>The diagnosis represented a loss of control which led couples to put themselves on a crash course on prostate cancer. The information gathered led them to believe prostate cancer was a good cancer which helped them to refocus their energies and start the quest for best treatment.</p>
<p>Manne S et al 2003 Psychoeducational group intervention for wives of men with prostate cancer. <i>Psycho-Oncology</i> 13 (1):37-46.</p>	<p>Questionnaire (Randomised control trial)</p>	<p>60 wives of men with prostate cancer</p>	<p>USA</p>	<p>Post initial treatment</p>	<p>Psychological distress; coping</p>	<p>No differences with regard to partners' general distress or cancer-specific distress, although intervention group participants reported gains in the use of positive reappraisal coping and reductions in denial coping.</p>

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Mazur D.J. & Hickman D.H. 1996 Patient preferences for management of localized prostate cancer. <i>The Western Journal of Medicine</i> 165:26.	Interview	140 men with prostate cancer (newly diagnosed)	USA	Treatment decision	Decision-making	Of the 140 patients, 53% preferred surgical treatment, 42% observation, 4% preferred the physician to make the decision and 1% preferred radiotherapy.
McGregor S 2003 (b) Information on video format can help patients with localised prostate cancer to be partners in decision-making. <i>Patient Education and Counseling</i> 49 (3):279-283.	Interview	10 healthy men and 12 men with prostate cancer (newly diagnosed)	UK	Treatment decision	Information/knowledge; decision-making	Both groups felt that video provided information in a helpful way. Patients felt that they had a clearer understanding of the disease and its treatment and were better able to be informed partners in the decision-making process.
McGregor S 2003 (a) What information patients with localised prostate cancer hear and understand. <i>Patient Education and Counseling</i> 49 (3):273-278.	Interview	10 men with prostate cancer (newly diagnosed)	UK	Treatment decision	Information/knowledge; decision-making; communication; relationship with healthcare professionals	The men were aware that they had incomplete understanding, but no one asked that information should be provided and in a language they understood. Only two men felt that the choice of treatment lay with them.
Meredith P et al 1995 Comparison of patients' needs for information on prostate surgery with printed materials provided by surgeons. <i>Quality in Health Care</i> 4 (1):18-23.	Questionnaire	4226 men with prostate cancer (undergoing prostatectomy)	UK	Treatment	Information	Much of the information distributed had considerable shortcomings and did not meet the needs and requirements of patients undergoing prostatectomy.

PAPER	METHOD OF DATA COLLECTION	SAMPLE / PARTICIPANTS	COUNTRY	PHASE OF THE CARE PATHWAY	ASPECT OF CARE	FINDINGS
Miles B.J. et al 1999 Recall and attitudes in patients with prostate cancer. <i>Urology</i> 53:169-174.	Telephone survey	421 men with prostate cancer	USA	Screening; treatment decision; post initial treatment	Information/knowledge; decision-making	Patients' recall of diagnostic procedures was poor; less than 20% remembered having a biopsy. More than 80% depended entirely on their attending urologist for informed consent and education about prostate cancer management.
Moore K.N. & Estey A 1999 The early post-operative concerns of men after radical prostatectomy. <i>Journal of Advanced Nursing</i> 29:1121-1129.	Interview	63 men with prostate cancer who had undergone a radical prostatectomy	Canada	Post initial treatment	Information/knowledge; support; relationship with healthcare professionals	Men did not receive detailed pre-operative teaching and at discharge had many knowledge gaps about catheter care, post-operative pain, incontinence and erectile dysfunction. Participants also perceived a lack of support from health care professionals.
Nathan D et al 2002 Helping low-literacy prostate cancer patients choose Rx. <i>Oncology News International</i> 11:3.	Questionnaire	30 men with prostate cancer (newly diagnosed)	USA	Treatment decision	Information/knowledge; decision-making	Patients' knowledge of prostate cancer was correlated with their level of health literacy. Race, marital status and age were not associated with prostate cancer knowledge. Patients with low levels of literacy may face significant barriers to participating in treatment decisions.
Nyman C.R. et al 2005 The patient's choice of androgen-deprivation therapy in locally advanced prostate cancer: bicalutamide, a gonadotrophin-releasing hormone analogue or orchidectomy <i>BJU International</i> 96:1014-1018	Questionnaire	150 patients	Sweden	Treatment decision	Decision-making; satisfaction with care	Most patients when fully informed (discussion and written information) were sure about their treatment choice. Almost all patients were satisfied with their treatment choice after 3 months of treatment.

PAPER	METHOD OF DATA COLLECTION	SAMPLE / PARTICIPANTS	COUNTRY	PHASE OF THE CARE PATHWAY	ASPECT OF CARE	FINDINGS
O'Rourke M.E. & Germino B.B. 1998 Prostate cancer treatment decisions: a focus group exploration. <i>Oncology Nursing Forum</i> 25:97-104.	Focus group	12 men with prostate cancer and 6 partners	USA	Treatment decision	Information/knowledge; decision-making; role of carer	Six themes were derived from the data: finding out; prostate specific antigen talk; getting the story; who decides; treatment options and looking back.
O'Rourke M.E. 1999 Narrowing the options: the process of deciding on prostate cancer treatment. <i>Cancer Investigation</i> 17:349-359.	Interview	18 men with prostate cancer (newly diagnosed) and their partners	USA	Treatment decision	Information/knowledge; decision-making	Most couples chose surgery as a treatment promising a cure. Concern about potential side effects did not deter men from choosing surgery. Information on potential for cure and risk of recurrence was important in decision-making.
O'Rourke M.E. & Germino B.B. 2000 From two perspectives to one choice: Blending couple and individual views of prostate cancer treatment selection. <i>Journal of Family Nursing</i> 6:231-251.	Interview	18 men with prostate cancer (newly diagnosed) and their partners	USA	Treatment decision	Decision-making; role of carer	Separate and couple interviews reveal the different realities that are constructed by respondents and reveal different pictures of the decision-making process.
Oliffe J 2004 Transrectal ultrasound prostate biopsy (TRUS-Bx): patient perspectives. <i>Urologic Nursing</i> 24:395-400.	Interview	30 men with prostate cancer	Australia	Testing	Communication; anxiety; pain	There was anxiety leading up to the transrectal ultrasound prostate biopsy (TRUS-Bx) and some discomfort and embarrassment during the procedure. Patients were not prepared for the levels of pain experienced, but only one reported the pain to the clinician.

PAPER	METHOD OF DATA COLLECTION	SAMPLE / PARTICIPANTS	COUNTRY	PHASE OF THE CARE PATHWAY	ASPECT OF CARE	FINDINGS
Oliffe J 2005 Being screened for prostate cancer: a simple blood test or a commitment to treatment? <i>Cancer Nursing</i> 29: 1-8	Interview	35 Anglo-Australian men	Australia	Screening; diagnosis; treatment decision	Knowledge/information; relationship with health care professionals; decision-making; complementary therapy; emotional reactions	Screening was experienced as a continuum of three tests (PSA, DRE, TRUS biopsy). Patients were shocked by the diagnosis and for most the treatment decision was about which treatment to have rather than whether to be treated.
Onel E et al 1998 Assessment of the feasibility and impact of shared decision-making in prostate cancer. <i>Urology</i> 51:63-66.	Questionnaire	111 men with prostate cancer (newly diagnosed)	USA	Treatment decision	Information/knowledge; decision-making	After the video, patients demonstrated significant increases in their understanding of treatment options to manage prostate cancer.
Petry H et al 2004 Responses and experiences after radical prostatectomy: perceptions of married couples in Switzerland. <i>International Journal of Nursing Studies</i> 41:507-513.	Interview	10 men with prostate cancer (who had undergone a radical prostatectomy) and their partners	Switzerland	Post initial treatment	Adjustment; coping; self care; treatment side-effects; role of carer	Men focused on regaining control of their lives, urinary and erectile function while wives efforts focused on being there.
Phillips C et al 2000 Early postsurgery experience of prostate cancer patients and spouses. <i>Cancer Practice</i> 8:165-171.	Interview	34 men with prostate cancer (who had undergone a prostatectomy) and their partners	Canada	Post initial treatment	Adjustment; self care; treatment side effects; support; role of carer	Hearing news about the extent of their cancer surgery influenced how patients viewed their cancer experience and in many cases their recovery. Men placed a strong emphasis on recovering their physical capacity quickly.

PAPER	METHOD OF DATA COLLECTION	SAMPLE / PARTICIPANTS	COUNTRY	PHASE OF THE CARE PATHWAY	ASPECT OF CARE	FINDINGS
Poole G et al 2001 Social support for patients with prostate cancer: The effects of support groups. <i>Journal of Psychosocial Oncology</i> 19 (2):1-16.	Questionnaire	240 men with prostate cancer	Canada	Post initial treatment	Support; coping; information/knowledge	Attendees were significantly more likely to cite other patients as sources of emotional, informational and practical support. Satisfaction with social support was significantly associated with coping and Quality of Life.
Porterfield H.A. 1997 Perspectives on prostate cancer treatment: awareness, attitudes, and relationships. <i>Urology</i> 49:102-103.	Telephone survey	1000 randomly selected members of a US patient group and 200 doctors	USA	Treatment decision	Information/knowledge; decision-making; relationship with healthcare professionals	Doctors feel more confident than patients that the patients were sufficiently informed to make treatment decisions, although the majority of patients surveyed reported they took a very active or somewhat active role in the treatment decision process.
Ptacek J.T. et al 1999 Stress and coping processes in men with prostate cancer: The divergent views of husbands and wives. <i>Journal of Social & Clinical Psychology</i> 18:299-324.	Questionnaire	57 men with prostate cancer (who had undergone radiotherapy) and their partners	USA	Post initial treatment	Coping; support; adjustment	Patients remembered coping primarily by seeking support. Wives consistently reported that their husbands experienced more stress than the husbands actually reported.
Ptacek J.T. et al 2002 The social context of coping with prostate cancer. <i>Journal of Psychosocial Oncology</i> 20:61-80.	Questionnaire	57 men with prostate cancer (who had undergone radiotherapy)	USA	Post initial treatment	Coping; support	Associations between coping, psychological distress and marital satisfaction depended on the supportive context in which survivors were coping.

PAPER	METHOD OF DATA COLLECTION	SAMPLE / PARTICIPANTS	COUNTRY	PHASE OF THE CARE PATHWAY	ASPECT OF CARE	FINDINGS
<p>Rees C.E. et al 2003 The relationship between the information-seeking behaviours and information needs of partners of men with prostate cancer: A pilot study. <i>Patient Education and Counseling</i> 49:257-261.</p>	<p>Questionnaire</p>	<p>39 partners of men with prostate cancer</p>	<p>UK</p>	<p>Post initial treatment</p>	<p>Information/knowledge</p>	<p>Positive correlations were found between participants' information-seeking behaviours and their information needs, suggesting that as individuals' propensities to seek information increased so too did their needs for information.</p>
<p>Salmenpera L et al 2001 Attitudes of patients with breast and prostate cancer toward complementary therapies in Finland. <i>Cancer Nursing</i> 24:328-334, 2001.</p>	<p>Questionnaire</p>	<p>190 men with prostate cancer</p>	<p>Finland</p>	<p>Treatment</p>	<p>Complementary therapies</p>	<p>45% of patients with prostate cancer believed that people with cancer may benefit from complementary therapies, although they did not think that the therapies could cure cancer.</p>
<p>Schapira M.M. et al 1999 Information Sources and professional consultations sought by men newly diagnosed as having prostate cancer. <i>Journal of Cancer Education</i> 14:243-247.</p>	<p>Questionnaire</p>	<p>112 men with prostate cancer (newly diagnosed)</p>	<p>USA</p>	<p>Treatment decision</p>	<p>Information/knowledge; relationship with healthcare professionals</p>	<p>Health professionals scored 4 for helpfulness (out of 5), patient education materials 3.6, electronic and print media 3.2, and lay acquaintances 3.2. Pamphlets were used widely as they were easily available, could be read when wanted.</p>

PAPER	METHOD OF DATA COLLECTION	SAMPLE / PARTICIPANTS	COUNTRY	PHASE OF THE CARE PATHWAY	ASPECT OF CARE	FINDINGS
Schapira M.M. & Vanruiswyk J 2000 The effect of an illustrated pamphlet decision-aid on the use of prostate cancer screening tests. <i>Journal of Family Practice</i> 49:418-424.	Questionnaire (Randomized control trial)	257 men aged 50-80	USA	Screening	Information/knowledge	The decision-aid was effective in improving knowledge of prostate cancer screening tests but did not change the use of these tests (PSA and DRE)
Sculpher M et al 2004 Patients' preferences for the management of non-metastatic prostate cancer: Discrete choice experiment. <i>BMJ</i> 328:382-385.	Interview	129 men with prostate cancer (non-metastatic)	UK	Treatment decision	Decision-making	When asked to assume a starting life expectancy of 5 years, the men were willing to make trade-offs between life expectancy and side effects.
Scura K.W. et al 2004 Telephone social support and education for adaptation to prostate cancer: A pilot study. <i>Oncology Nursing Forum</i> 31:335-338.	Questionnaire and telephone interview (Randomised control trial)	17 men with prostate cancer (newly diagnosed)	USA	Post initial treatment	Adjustment; support	Structured interviews with 14 of 17 subjects revealed in this pilot study that telephone social support and education were helpful in increasing adaptation to prostate cancer.
Sheridan S.L. et al 2004 Information needs of men regarding prostate cancer screening and the effect of a brief decision aid. <i>Patient Education and Counseling</i> 54:345-351.	Questionnaire	188 men	USA	Screening	Information/knowledge; decision-making	The decision aid increased the proportion of men with sufficient information to decide about testing. It also changed 20% of men's interest in testing. No single piece of information was influential to decision-making.

PAPER	METHOD OF DATA COLLECTION	SAMPLE / PARTICIPANTS	COUNTRY	PHASE OF THE CARE PATHWAY	ASPECT OF CARE	FINDINGS
Slevin T.J. et al 1999 Prostate cancer testing: behaviour, motivation and attitudes among Western Australian men. <i>Medical Journal Australia</i> 171:185-188.	Telephone survey	400 men	Australia	Screening	Information/knowledge; decision-making	Of 391 asymptomatic men, 56% recalled having been tested for prostate cancer and 43% had had a PSA test. 38% men stated that the doctor did not discuss the pros and cons of the test, 39% reported a discussion of less than 5 minutes, and 17% were given printed information.
Smith R.L. et al 2002 An evaluation of the Man to Man self-help group in Colorado and Utah. <i>Cancer Practice</i> 10:234-239.	Questionnaire, focus group	112 men with prostate cancer (newly diagnosed or post initial treatment), 66 urologists	USA	Post initial treatment	Information/knowledge; support	Participants valued the prostate cancer treatment information, physician presentations and social aspects that were offered. Non-attendance of African-American patients was due to accessing other sources of support (family, friends and church).
Steginga S.K. et al 2001 The supportive care needs of men with prostate cancer (2000). <i>Psycho-Oncology</i> 10:66-75.	Questionnaire	206 men with prostate cancer (members of a self-help group)	Australia	Post initial treatment	Information/knowledge; support; treatment side effects	One third of the sample reported a moderate to high need for help for multiple items in the sexuality, psychological and health system and information domains.
Steginga S.K. et al 2004 A prospective study of the use of alternative therapies by men with localized prostate cancer. <i>Patient Education and Counseling</i> 55:70-77.	Questionnaire	111 men with prostate cancer (newly diagnosed)	Australia	Treatment	Complementary therapies	The percentage of men using alternative therapies was 25% before treatment, 17% 2 months after treatment and 14% 12 months after treatment (and were less distressed psychologically than those not using them). Most commonly used therapies were dietary changes, vitamins and herbal and nutritional supplements.

PAPER	METHOD OF DATA COLLECTION	SAMPLE / PARTICIPANTS	COUNTRY	PHASE OF THE CARE PATHWAY	ASPECT OF CARE	FINDINGS
Templeton H & Coates V 2003 Informational needs of men with prostate cancer on hormonal manipulation therapy. <i>Patient Education and Counseling</i> 49:243-256.	Interview	90 men with prostate cancer (who were undergoing hormone manipulation therapy)	UK	Treatment	Information/knowledge; treatment side effects	These men had knowledge deficits coupled with a great desire for information. Current practice in urology was not adequately addressing their informational needs.
Templeton H.& Coates V.2004 Evaluation of an evidence-based education package for men with prostate cancer on hormonal manipulation therapy. <i>Patient Education and Counseling</i> 55:55-61.	Questionnaire (Randomised control trial)	55 men with prostate cancer (who were undergoing hormone manipulation therapy)	UK	Treatment	Information/knowledge; satisfaction with care; coping	The education package had a significant effect on knowledge, quality of life and satisfaction with care, but not on coping.
Van Tol-Geerdink J.J et al 2006 Do patients with localised prostate cancer treatment really want more aggressive treatment? <i>Journal of Clinical Oncology</i> 24(28):4581-4586	Baseline questionnaire, interview	200 patients met the inclusion criteria. 150 of them gave informed consent and were included in the study	Netherlands	Treatment decision	Decision-making	Many patients attach more weight to specific quality of life aspects than the likelihood of survival

PAPER	METHOD OF DATA COLLECTION	SAMPLE / PARTICIPANTS	COUNTRY	PHASE OF THE CARE PATHWAY	ASPECT OF CARE	FINDINGS
<p>Volk R.J. et al 1997 A randomized controlled trial of shared decision-making for prostate cancer screening. <i>Archives of Family Medicine</i> 8:333-340.</p>	<p>Interview</p>	<p>10 couples (men were asymptomatic)</p>	<p>USA</p>	<p>Screening</p>	<p>Decision-making</p>	<p>7 out of 10 husbands preferred no screening strategy, and 9 out of 10 wives preferred screening for their husbands. Guidelines for prostate cancer screening and management should consider assessing preferences on an individual couple basis.</p>
<p>Volk R.J. et al 1999 Preferences of husbands and wives for prostate cancer screening. <i>Archives of Family Medicine</i> 6:72-76, 1997.</p>	<p>Interview (Randomised control trial)</p>	<p>160 men</p>	<p>USA</p>	<p>Screening</p>	<p>Information/knowledge; decision-making</p>	<p>Patients' knowledge at baseline was poor. At 2 week follow up, videotape intervention showed a 78% improvement in knowledge questions answered correctly.</p>
<p>Weber B.A. et al 2004 The effect of dyadic intervention on self-efficacy, social support, and depression for men with prostate cancer. <i>Psycho-Oncology</i> 13:47-60.</p>	<p>Questionnaire and written logs (Randomised control trial)</p>	<p>30 men with prostate cancer (who had undergone a radical prostatectomy)</p>	<p>USA</p>	<p>Post initial treatment</p>	<p>Support; treatment side effects; self care</p>	<p>One to one support was effective in reducing depression and increasing self-efficacy in men who have undergone radical prostatectomy.</p>
<p>Wolf A.M.D. et al 1996 Preferences of elderly men for prostate-specific antigen screening and the impact of informed consent. <i>Journal of Gerontology</i> 53a:M195-M200.</p>	<p>Interview (Randomised control trial)</p>	<p>205 men (no history of prostate cancer)</p>	<p>USA</p>	<p>Screening</p>	<p>Information/knowledge</p>	<p>Those primary care patients of lower socio-economic status who received informed consent were significantly less interested in PSA screening than those who did not.</p>

PAPER	METHOD OF DATA COLLECTION	SAMPLE / PARTICIPANTS	COUNTRY	PHASE OF THE CARE PATHWAY	ASPECT OF CARE	FINDINGS
Wolf A.M.D. and Schorling J.B. 1998 The impact of informed consent on patient interest in prostate-specific antigen screening. <i>Archives Internal Medicine</i> 156:1333-1336.	Questionnaire	104 elderly men (65+) with no history of prostate cancer	USA	Screening	Information/knowledge	Informed elderly patients were significantly less interested than were uninformed patients.
Woolf S.H. et al 2005 Unwanted control: how patients in the primary care setting decide about screening for prostate cancer. <i>Patient Education and Counseling</i> 56:116-124.	Telephone survey and questionnaire	161 primary care patients	USA	Screening	Information/knowledge; decision-making	Before and after visits, patients expressed a preference for a shared approach to the PSA decision, but the actual decision involved greater patient control. Almost 25% of patients reported greater decisional control than they desired and 30% of men who wanted a shared approach made the actual decision themselves.
Wong T.F et al 2000 The impact of informed consent on patient interest in prostate-specific antigen screening. <i>Archives Internal Medicine</i> 156:1333-1336.	Questionnaire	101 men with prostate cancer	Canada	Explanation of diagnosis; treatment decision; treatment; post initial treatment.	Information/knowledge; decision-making	Over 70% wanted detailed information at all illness stages focusing on their disease, treatment, survival, self-care and empowerment. Over 60% wanted shared decision-making with their physician.

APPENDIX 3

Cancer Network Service Improvement Leads Questionnaire

**CANCER NETWORK SERVICE IMPROVEMENT LEADS
QUESTIONNAIRE**

Name of Cancer Network:

1. In your Cancer Network, have you used a measure of patient experience in the last two years?

Yes

No

Please go to Question 2

1a. Who was the measure developed by?

Ourselves

Someone else

please state who.....

(We would be grateful if you could enclose a copy of the measure when returning this questionnaire)

1b. What type of cancer patient was the measure used for

Prostate

Other

1c. What was the measure used for

Routine monitoring

Service redesign

Other, please specify _____

1d. Can you briefly describe how the measure worked

Please use the back of the questionnaire which has been left blank for any additional comments on any of the questions

1e. What were the benefits of using the measure?

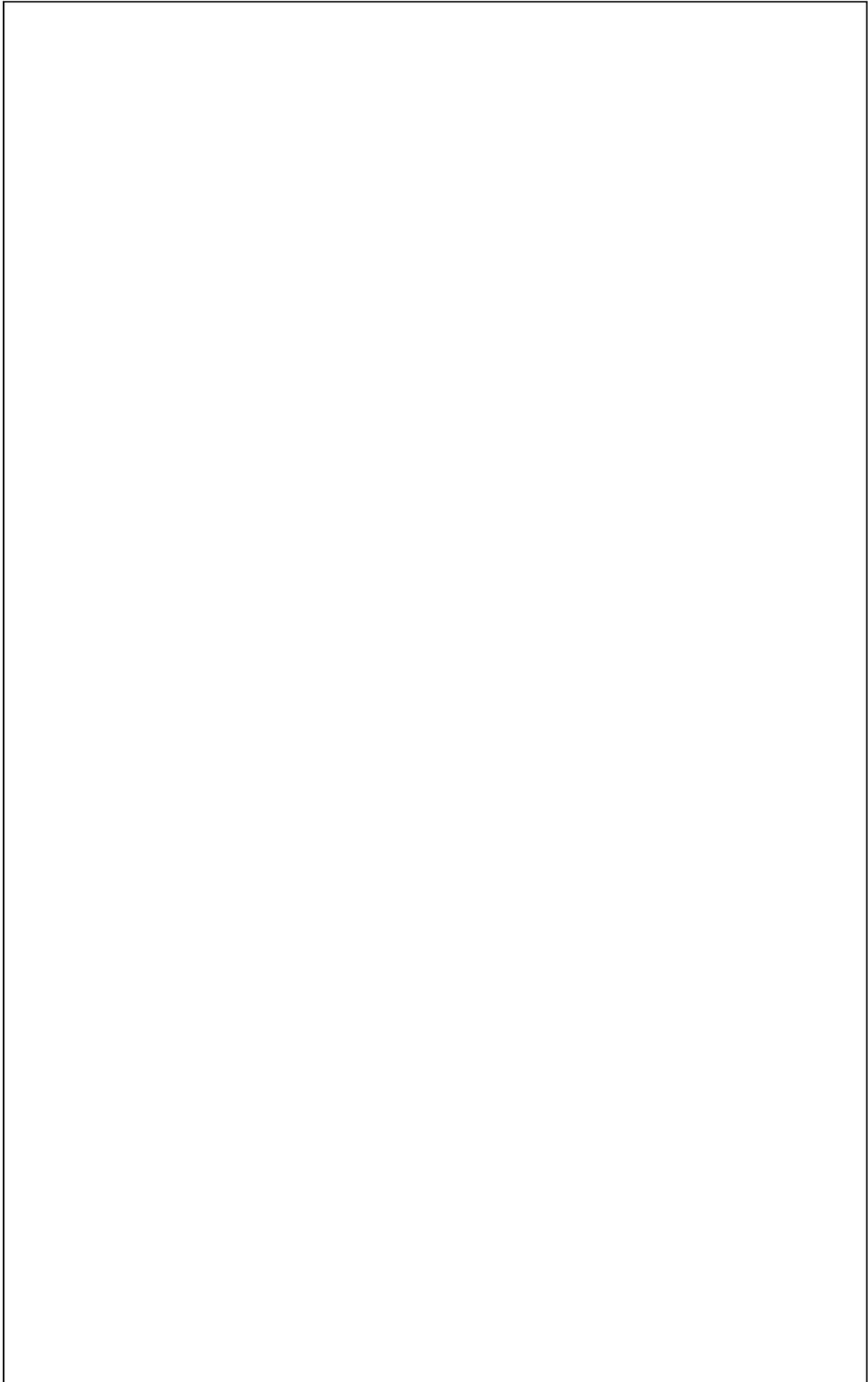
1f. Please state any problems of using the measure

Please go to Question 3

2. Please state why you have not used a measure of patient experience

3. **A new measure of patient experience for prostate cancer patients is being developed. What features do you feel a measure of patient experience of prostate cancer should have?**

e.g. format, appropriate for groups of patients with particular needs



Further comments (please indicate the question that they refer to).

4. The next stage of the study is to establish further contextual information on the use of measures of patient experience. We would like to undertake interviews of Cancer Network SILs and staff responsible for the conduct of patient experience investigations. Can you please identify five people who have been involved in using these measures who we could approach to interview.

Name	Job Title	Employing Trust (This is needed to apply for R&G approval, prior to interview)	Contact Details (telephone number, email address)
	Lead clinician		
	Lead nurse		
	Patient representative		
	SIF		
	SIL (your details)	N/A	

We will provide results from our study for dissemination to you. You can also visit the study website at: <http://www.hs.le.ac.uk/research/>

(Thank you for completing the questionnaire. Please return it in the pre-paid addressed envelope provided by Friday September 3rd.)

APPENDIX 4

Interview schedule for patient interviews

INTERVIEW SCHEDULE FOR PATIENT INTERVIEWS

Introduction

- University of Leicester/ National Centre for Social Research collaboration
- SDO funded study: Prostate cancer care: improving measures of the patient experience of care
- Study aim: to develop a measure of patient experience of care (explain).
- Check that the interviewee has consented to the interview being recorded and transcribed for analysis. This is to ensure that we don't miss anything. What you say will be anonymised and the names of the interviewees will **not** be used. Remind the patient that they can stop the interview at any point if they need to.

Key Research Objectives

- To identify the key issues important to patients at different stages of prostate cancer
- To identify key issues important to friend/relatives (interviewed separately)

BACKGROUND

Should already have information on patient's background. However, confirm for the tape recording:

- Age: grouped into under 55; 56-70; over 70
- Ethnic origin
- Stage of treatment – ask questions from the appropriate section only

- | | |
|---|--------------------------|
| 1. NEWLY DIAGNOSED PATIENTS | |
| a) CANCER IN PROSTATE ONLY | <input type="checkbox"/> |
| b) CANCER SPREAD BEYOND PROSTATE | <input type="checkbox"/> |
| 2. PATIENTS BEING ACTIVELY MONITORED WITHOUT TREATMENT | |
| a) PROSTATE CANCER NOT DIAGNOSED | <input type="checkbox"/> |
| b) PROSTATE CANCER DIAGNOSED | <input type="checkbox"/> |
| 3. PATIENTS WHO HAVE HAD CURATIVE TREATMENT | |
| a) RADICAL THERAPY (RADIOTHERAPY, BRACHYTHERAPY, CRYOTHERAPY) | <input type="checkbox"/> |
| b) RADICAL PROSTATECTOMY | <input type="checkbox"/> |
| 4. PATIENTS WHO HAVE STABILISING TREATMENT (HORMONE THERAPY) | <input type="checkbox"/> |
| 5. PATIENTS WHO NO LONGER HAVE HORMONE THERAPY | <input type="checkbox"/> |

1. NEWLY DIAGNOSED PATIENTS

I would like you to explain your experience of the aspects of care that are important to you and how they made you feel. Please comment on the things that were done well, the things that could have been done better, the things that weren't done which you would have liked. e.g. time allowed, clarity of information provided/use of jargon, staff attitudes, privacy.

Symptoms/concerns

How was your prostate problem identified? Did you have any initial symptoms? Did you have any initial concerns?

Prostate Specific Antigen Test

How did you feel about the PSA test?

Referral to hospital

How did you feel about being referred to hospital?

Experience of hospital

What was your experience at the hospital? Were you an inpatient or an outpatient?

Test results

How did you feel about how the test results were delivered?

Decision-making

Have you decided what type of treatment to have?

Other health problems

Did you have any other health problems? Were these taken into account in relation to your treatment options?

Friend/relative

Did you have a friend/relative with you at the GP surgery or hospital? Were they made welcome? Were they able to ask questions and participate in discussions/decision-making?

Other comments

Do you have any other comments on aspects of the care you received which were important to you?

Thank you for your time and the information you have given us. We will transcribe the tape recording and add it to the data from the other interviews. Would you like us to send you a copy of our findings?

2. PATIENTS BEING ACTIVELY MONITORED WITHOUT TREATMENT

I would like you to explain your experience of the aspects of care that were important to you and how they made you feel. Please comment on the things that are done well, the things that could be done better and the things that aren't done which you would like done. e.g. time allowed, clarity of information provided/use of jargon, staff attitudes, privacy.

a). Prostate cancer not diagnosed

We are particularly interested in your experience of being actively monitored, but first could you tell me briefly how you came to be tested for prostate cancer?

Possible prompts

- How was the problem identified?
- Did you understand the PSA test before/after it was given?
- What information was provided? Was it understandable?
- How did you feel about being referred to hospital?
- What was your experience at the hospital? (e.g. staff, facilities)
- How were the test results delivered?

Decision-making

Were you as involved as you wanted to be in the decision to be actively monitored?

Monitoring

How are you monitored? Are you happy with the way you are being monitored?

Friend/relatives

Did you have a friend/relative with you at the hospital? Were they made welcome? Were they able to ask questions and participate in discussions/decision-making?

Other comments

Do you have any other comments on aspects of the care you receive which are important to you?

Thank you for your time and the information you have given us. We will transcribe the tape recording and add it to the data from the other interviews. Would you like us to send you a copy of our findings?

b). Prostate cancer diagnosed

We are particularly interested in your experience of being actively monitored, but first could you tell me briefly how you came to be diagnosed with prostate cancer?

Possible prompts

- How was the problem identified?
- Did you understand the PSA test before/after it was given?
- What information was provided? Was it understandable?
- How did you feel about being referred to hospital?
- What was your experience at the hospital? (e.g. staff, facilities)
- How were the test results delivered?

Decision-making

Were you as involved as you wanted to be in the decision to be actively monitored?

Monitoring

How are you monitored? Are you happy with the way you are being monitored?

Other health problems

Did you have any other health problems? Were these taken into account in relation to your treatment options?

Friend/relatives

Did you have a friend/relative with you at the hospital? Were they made welcome? Were they able to ask questions and participate in discussions/decision-making?

Other comments

Do you have any other comments on aspects of the care you receive which are important to you?

Thank you for your time and the information you have given us. We will transcribe the tape recording and add it to the data from the other interviews. Would you like us to send you a copy of our findings?

3. PATIENTS WHO HAVE HAD CURATIVE TREATMENT

- a). Radical therapy (radiotherapy, brachytherapy, cryotherapy)**
- b). Radical prostatectomy**

I would like you to explain your experience of the aspects of care that were important to you and how they made you feel. Please comment on the things that were done well, the things that could have been done better and the things that weren't done which you would have liked. e.g. time allowed, clarity of information provided/use of jargon, staff attitudes, privacy.

We are particularly interested in your experience of your treatment, but first could you tell me briefly how you came to be diagnosed with prostate cancer?

Possible prompts

- How was the problem identified?
- Did you understand the PSA test before/after it was given?
- What information was provided? Was it understandable?
- How did you feel about being referred to hospital?
- What was your experience at the hospital? (e.g. staff, facilities)
- How were the test results delivered?

Decision-making

Were you as involved as you wanted to be in the treatment decision?

Treatment

What was your experience of the treatment? (Check what treatment the patient has had)

Discharge

Were you happy with the discharge arrangements?

Other health problems

Did you have any other health problems? Were these taken into account in relation to your treatment options?

Friend/relatives

Did you have a friend/relative with you at the GP surgery or hospital? Were they made welcome? Were they able to ask questions and participate in discussions/decision-making? Were they given information? Was it given at the right time? Was it understandable?

On going care

What do you think of the on going care arrangements?

Other comments

Do you have any other comments on aspects of the care you receive which are important to you?

Thank you for your time and the information you have given us. We will transcribe the tape recording and add it to the data from the other interviews. Would you like us to send you a copy of our findings?

4. PATIENTS WHO HAVE STABILISING TREATMENT (HORMONE THERAPY)

I would like you to explain your experience of the aspects of care that were important to you and how they made you feel. Please comment on the things that were done well, the things that could have been done better and the things that weren't done which you would have liked. e.g. time allowed, clarity of information provided/use of jargon, staff attitudes, privacy.

We are particularly interested in your experience of being treated with hormone therapy, but first could you tell me briefly how you came to be diagnosed with prostate cancer?

Possible prompts

- How was the problem identified?
- Did you understand the PSA test before/after it was given?
- What information was provided? Was it understandable?
- How did you feel about being referred to hospital?
- What was your experience at the hospital? (e.g. staff, facilities)
- How were the test results delivered?

Decision-making

Were you as involved as you wanted to be in the treatment decision?

Treatment

What sort of treatment do you have? (injections at GP surgery or injections/tablets at home)

What was your experience of the treatment?

Other health problems

Did you have any other health problems? Were these taken into account in relation to your treatment options?

Friend/relative

Did you have a friend/relative with you at the GP surgery or hospital? Were they made welcome? Were they able to ask questions and participate in discussions/decision-making?

On going care

Are you receiving any other treatment/care? (e.g. pain control)

Other comments

Do you have any other comments on aspects of the care you receive which are important to you?

Thank you for your time and the information you have given us. We will transcribe the tape recording and add it to the data from the other interviews. Would you like us to send you a copy of our findings?

5. PATIENTS WHO NO LONGER HAVE HORMONE THERAPY

I would like you to explain your experience of the aspects of care that were important to you and how they made you feel. Please comment on the things that were done well, the things that could have been done better and the things that weren't done which you would have liked. e.g. time allowed, clarity of information provided/use of jargon, staff attitudes, privacy.

Firstly, could you tell me briefly how you came to be diagnosed with prostate cancer?

Possible prompts

- How was the problem identified?
- Did you understand the PSA test before/after it was given?
- What information was provided? Was it understandable?
- How did you feel about being referred to hospital?
- What was your experience at the hospital? (e.g. staff, facilities)
- How were the test results delivered?
- Were you as involved as you wanted to be in the treatment decision?
- What sort of treatment do you have?
- Did you have any other health problems? Were these taken into account in relation to your treatment options?
- Did you have a friend/relative with you at the GP surgery or hospital? Were they made welcome? Were they able to ask questions and participate in discussions/decision-making?

On going care

Are you receiving any treatment/care? (e.g. pain control)

Other comments

Do you have any other comments on aspects of the care you receive which are important to you?

Thank you for your time and the information you have given us. We will transcribe the tape recording and add it to the data from the other interviews. Would you like us to send you a copy of our findings?

APPENDIX 5

Interview schedule for carer interviews

INTERVIEW SCHEDULE FOR CARER INTERVIEWS

Introduction

- University of Leicester/ National Centre for Social Research collaboration
- SDO funded study: Prostate cancer care: improving measures of the patient experience of care
- Explain study aim: to develop a measure of patient experience of care
- Check that the interviewee has consented to the interview being recorded and transcribed for analysis. This is to ensure that we don't miss anything. What you say will be anonymised and the names of the interviewees will **not** be used. Remind the interviewee that they can stop the interview at any point if they need to.

Key Research Objectives

- to identify key issues important to friend/relatives
- to identify the key issues important to patients at different stages of prostate cancer

Background information on the patient they care for

Record on tape:

- Age: under 55; 56-70; over 70
- Ethnic origin
- Stage of treatment– ask questions from the appropriate section only

1. NEWLY DIAGNOSED PATIENTS

- a) CANCER IN PROSTATE ONLY
- b) CANCER SPREAD BEYOND PROSTATE

2. PATIENTS BEING ACTIVELY MONITORED WITHOUT TREATMENT

- a) PROSTATE CANCER NOT DIAGNOSED
- b) PROSTATE CANCER DIAGNOSED

3. PATIENTS WHO HAVE HAD CURATIVE TREATMENT

- a) RADICAL THERAPY (RADIOTHERAPY, BRACHYTHERAPY, CRYOTHERAPY)
- b) RADICAL PROSTATECTOMY

4. PATIENTS WHO HAVE STABILISING TREATMENT (HORMONE THERAPY)

5. PATIENTS WHO NO LONGER HAVE HORMONE THERAPY

1. NEWLY DIAGNOSED PATIENTS

- a) CANCER IN PROSTATE ONLY
- b) CANCER SPREAD BEYOND PROSTATE

I would like you to explain your experience of the aspects of care that were important to you and how they made you feel. Please comment on the things that were done well, the things that could have been done better, the things that weren't done which you would have liked done. e.g. time allowed, clarity of information provided/use of jargon, staff attitudes, privacy.

- **Prostate Specific Antigen tests**
Were you there when the PSA test was done? What was your experience of the PSA tests?
- **Referral to hospital**
Were you there when the referral was made?
(If no, go to next question on anxiety)
- **Anxiety**
Did the test results/referral cause you anxiety? Was any help offered to deal with this anxiety?
- **Experience at hospital at outpatients**
What was your experience at the outpatients?
- **Other comments**

Do you have any other comments on aspects of care which are important?

Thank you for your time and the information you have given us. We will transcribe the tape recording and add it to the data from the other interviews. Would you like us to send you a copy of our findings?

2. PATIENTS BEING ACTIVELY MONITORED WITHOUT TREATMENT

a). PROSTATE CANCER NOT DIAGNOSED

We are particularly interested in the experience of being actively monitored, but first could you tell me briefly how the test for prostate cancer came about?

Possible prompts

- How was the problem identified?
- Did you understand the PSA test before/after it was given?
- What information was provided? Was it understandable?
- How were the test results delivered?

- **Referral to hospital**
Were you there when the referral was made?
(if not go onto next question on anxiety)

- **Anxiety**
Did the referral cause anxiety? Was any help offered to deal with this anxiety?

- **Experience at hospital**
What was your experience at the hospital?

- **On going care**
What does being actively monitored involve? How do you feel about this course of treatment? Do you have all the information you need? Is there any help for you? (e.g. helpline, nurse to ring)

- **Other comments**

Do you have any other comments on aspects of care which are important?

Thank you for your time and the information you have given us. We will transcribe the tape recording and add it to the data from the other interviews. Would you like us to send you a copy of our findings?

b). PROSTATE CANCER DIAGNOSED

We are particularly interested in the experience of being actively monitored, but first could you tell me briefly how the diagnosis of prostate cancer came about?

Possible prompts

- How was the problem identified?
- Did you understand the PSA test before/after it was given?
- What information was provided? Was it understandable?
- How were the test results delivered?

- **Referral to hospital**
Were you there when the referral was made?
(if not go onto next question on anxiety)

- **Anxiety**
Did the test results/referral cause anxiety? Was any help offered to deal with this anxiety?

- **Experience at hospital**
What was your experience at the hospital?

- **On going care**
What does being actively monitored involve? How do you feel about this course of treatment? Do you have all the information you need? Is there any help for you? (e.g. helpline, nurse to ring)

- **Other comments**

Do you have any other comments on aspects of care which are important?

Thank you for your time and the information you have given us. We will transcribe the tape recording and add it to the data from the other interviews. Would you like us to send you a copy of our findings?

3. PATIENTS WHO HAVE HAD CURATIVE TREATMENT

- a). RADICAL THERAPY (RADIOTHERAPY, BRACHYTHERAPY, CRYOTHERAPY)
- b). RADICAL PROSTATECTOMY

We are particularly interested in your experience, but could you first tell me briefly how the diagnosis came about?

Possible prompts

- How was the problem identified?
- Did you understand the PSA test before/after it was given?
- What information was provided? Was it understandable?
- How were the test results delivered?

- **Referral to hospital**
Were you there when the referral was made?
(if not go onto next question on anxiety)

- **Anxiety**
Did the test results/referral cause you anxiety? Was any help offered to deal with this anxiety?

- **Discharge from hospital**
Were you happy with the discharge arrangements?

- **Experience at hospital**
What was your experience at the hospital?

- **On going care**
What on going care is there? How do you feel about this?
Do you have all the information you need? Is there any help for you? (e.g. helpline, nurse to ring)

- **Other comments**

Do you have any other comments on aspects of care which are important?

Thank you for your time and the information you have given us. We will transcribe the tape recording and add it to the data from the other interviews. Would you like us to send you a copy of our findings?

4. PATIENTS WHO HAVE STABILISING TREATMENT (HORMONE THERAPY)

We are particularly interested in the experience of hormone treatment, but first could you please tell me briefly how the diagnosis came to be made?

Possible prompts

- How was the problem identified?
- Did you understand the PSA test before/after it was given? What information was provided? Was it understandable?
- Were you present when the test results were delivered? Were you clear what they were and what the implications were?
- Were you there when the referral to hospital was made? (if not go onto next question on anxiety)
- Did you suffer from anxiety at any stage in this process?
- What was your experience of the visit to the hospital outpatients? (e.g. convenience, waiting facilities, attitude of staff to you, involvement in decision-making)

- **Treatment**

What was your experience of the hormone treatment?

Possible prompts

Did you understand the treatment purpose and procedure? Had you been involved in the treatment decision? Was there a need for pain control? If so, were you happy with the pain control?

- **On going care**

What on going care is there?

Possible prompts

How do you feel about this? Do you have all the information you need? Is there any help for you? (e.g. helpline, nurse to ring)

- **Other comments**

Do you have any other comments on aspects of care which are important?

Thank you for your time and the information you have given us. We will transcribe the tape recording and add it to the data from the other interviews. Would you like us to send you a copy of our findings?

5. PATIENTS WHO NO LONGER HAVE HORMONE THERAPY

Firstly, could you please tell me briefly how the diagnosis came to be made?

Possible prompts

- How was the problem identified?
- Did you understand the PSA test before/after it was given? What information was provided? Was it understandable?
- Were you present when the test results were delivered? Were you clear what they were and what the implications were?
- Were you there when the referral to hospital was made? (if not go onto next question on anxiety)
- Did you suffer from anxiety at any stage in this process?
- What was your experience of the visit to the hospital outpatients? (e.g. convenience, waiting facilities, attitude of staff to you, involvement in decision-making)

- **Treatment**

What was your experience of the hormone treatment?

Possible prompts

Did you understand the treatment purpose and procedure? Had you been involved in the treatment decision? Was there a need for pain control? If so, were you happy with the pain control?

- **On going care**

What on going care is there?

Possible prompts

How do you feel about this? Do you have all the information you need? Is there any help for you? (e.g. helpline, nurse to ring)

- **Other comments**

Do you have any other comments on aspects of care which are important?

Thank you for your time and the information you have given us. We will transcribe the tape recording and add it to the data from the other interviews. Would you like us to send you a copy of our findings?

APPENDIX 6

Prostate Care Questionnaire - Patients PCQ-Pv1

YOUR VIEWS ABOUT PRIMARY AND SECONDARY HEALTH CARE (PCQ-P)

Pilot v1 • May 2006

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. You do not need to give your name and your answers will be treated in strict confidence. Please complete all those sections that apply to your experience of care and then post back the completed questionnaire booklet in the pre-paid envelope provided. Thank you for your help.

This questionnaire booklet is divided into six sections:

Section A: This section is about going to the GP's practice for the first time because of your possible prostate problem.

Section B: This section is about having tests/further tests for possible prostate cancer at the hospital.

Section C: This section is about discussing your test results for possible prostate cancer.

Section D: This section is about your treatment.

Section E: This section is about monitoring you.

Section F: This section is about you and your health. It will help us put your answers in context, so that we can let the NHS know if different groups of people have different requirements.



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

SECTION A

Going to the GP's practice for the first time because of your possible prostate problem.

1. Please write below the details of the GP's practice you went to?

Name of the GP's practice

Town/City

2. When you went to the GP's practice who did you see?

Please tick one box

Your GP 1

Another GP 2

A nurse 3

Other (please write below who it was) 4

.....

3. Was this the person you wanted to see?

Please tick one box

Yes 1

No 2

Did not mind who I saw 3

4. What was your reason(s) for going to the GP's practice?

Please tick as many boxes as apply

Problems with urinating

Other symptoms e.g. back pain

Part of a general health check

I thought I might be at risk of prostate cancer

Other (please write below what it was)

.....

5. Did the doctor or nurse take note of your concerns?

Please tick one box

Yes 1

To some extent 2

No, not really 3

I did not have any concerns 4

6. Overall, did you have confidence and trust in the doctor or nurse that you saw?

Please tick one box in each column

	Doctor(s)	Nurse(s)
Yes	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
To some extent	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, not really	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
No opinion/not applicable	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄

7. Did the doctor or nurse give you an explanation of what might be causing your symptoms?

Please tick one box

Yes, the explanation was clear	<input type="checkbox"/> ₁
Yes, but the explanation could have been clearer	<input type="checkbox"/> ₂
No explanation was given	<input type="checkbox"/> ₃
I did not have any symptoms	<input type="checkbox"/> ₄

The following questions are about your FIRST PSA test at the GP's practice (Prostate Specific Antigen test or blood test)

8. Did you have a PSA/blood test organised by the GP's practice?

Please tick one box

Yes	<input type="checkbox"/> ₁	
No	<input type="checkbox"/> ₂	If no, please go to Question 18

9. Where was your first PSA test carried out?

Please tick one box

At the GP's practice	<input type="checkbox"/> ₁	
At the local Assessment Centre/Clinic	<input type="checkbox"/> ₂	
At the hospital	<input type="checkbox"/> ₃	If at the hospital, please go to Question 18
Other	<input type="checkbox"/> ₄	

Please write below the details

Name

Town/City

10. Before the test, did the doctor or nurse give you an explanation of what the PSA test was trying to find out?

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 did not want/need an explanation ₄

11. Before the test, did the doctor or nurse give you an explanation of what might happen if the PSA test was abnormal?

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 did not want/need an explanation ₄

12. Before the test, did the doctor or nurse explain that the PSA test is not always accurate?

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 did not want/need an explanation ₄

13. Did the doctor or nurse offer you any written information about the PSA test?

Please tick one box

- Yes ₁
- No ₂

14. Did the doctor or nurse involve you in the decision on whether to have a PSA test?

Please tick one box

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

15. Did the doctor or nurse advise you to avoid ejaculation 24/48 hours before the PSA test?

Please tick one box

Yes ₁

No ₂

16. Did the doctor or nurse give you an explanation of the results of your PSA 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

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

Please tick one box

Yes ₁

To some extent ₂

No, not really ₃

No explanation was given ₄

The following questions are about your FIRST DRE at the GP's practice (Digital Rectal Examination or internal examination is where a doctor/nurse uses a finger to feel your prostate)

18. Did you have a DRE organised by the GP's practice?

Please tick one box

Yes ₁

No ₂ If no, please go to Question 27

19. Where was your first DRE carried out?

Please tick one box

At the GP's practice ₁

At the local Assessment Centre/Clinic ₂

At the hospital ₃ If at the hospital, please go to Question 27

Other ₄

Please write below the details

Name

Town/City

20. Before the test, did the doctor or nurse give you an explanation of what the DRE was trying to find out?

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 did not want/need an explanation 4

21. Before the test, did the doctor or nurse give you an explanation of how the DRE is carried out?

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 did not want/need an explanation 4

22. Did the doctor or nurse offer you any written information about the DRE?

Please tick one box

- Yes 1
- No 2

23. Before the test, did the doctor or nurse give you an explanation of what might happen if the DRE was abnormal?

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 did not want/need an explanation 4

24. Did the doctor or nurse involve you in the decision on whether to have a DRE?

Please tick one box

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

25. Did the doctor or nurse give you an explanation of the results of your DRE?

Please tick one box

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

26. Did the doctor or nurse give you the results of your DRE in a considerate way?

Please tick one box

- Yes ₁
- To some extent ₂
- No, not really ₃
- No explanation was given ₄

27. How long was it from your first visit to the GP's practice until he/she decided to refer you to the hospital for tests/further tests?

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 and up to 8 weeks ₄
- More than 8 weeks ₅
- I was not referred to hospital ₆

(If you were not referred to hospital, please do not answer any more questions and return the questionnaire booklet, thank you for your time).

28. How did you feel about the time the GP took to refer you to the hospital for further tests?

Please tick one box

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

29. Did the doctor or nurse give you an explanation of why you were being referred to hospital?

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 did not want/need an explanation ₄

30. Did the doctor or nurse give you a choice of :

Please tick one box on each line

- | | Yes | No |
|-------------------------------------|---------------------------------------|---------------------------------------|
| Which hospital you wanted to go to? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| How soon you wanted to be seen? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |

31. Did you have any particular needs when the referral arrangements were made (e.g. transport, time of appointment)?

Please tick one box

- Yes ₁
- No ₂ If no, please go to Question 33

If yes, please write here what they were

.....

.....

32. Were these needs taken into account when the referral arrangements were made?

Please tick one box

- Yes ₁
- No ₂

33. Did the doctor or nurse give you an explanation of how soon you would be seen at the hospital?

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 did not want/need an explanation ₄

34. Overall, did the doctor or nurse treat you with respect and dignity?

Please tick one box in each column

	Doctor(s)	Nurse(s)
Yes	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
To some extent	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, not really	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
No opinion/not applicable	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄

35. Overall, please show how good or bad your experience of care was by circling the number on the scale below.

0 1 2 3 4 5 6 7 8 9 10

Worst experience of care  Best experience of care

SECTION B

Having tests/further tests for possible prostate cancer at the hospital.

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

Please tick one box

GP ₁

Hospital doctor ₂

Other (Please write below who it was) ₃

.....

2. At which hospital did you have your first appointment?

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

3. Were you given enough information to help you with your visit to the hospital for tests?

Please tick one box

Yes ₁

No ₂

If no, please write below what information you would have liked

.....
.....

4. How long did you wait between the date you were referred 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 and up to 8 weeks ₄

More than 8 weeks ₅

5. Did you need to change your first appointment?

Please tick one box

Yes, but it wasn't a problem to change my appointment ₁

Yes, but I did have to wait much longer for an alternative appointment ₂

No, I did not need to change my appointment ₃

6. 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

If you have made more than one visit to the hospital for tests, please answer the following questions from your overall experience.

7. Did you experience any problems with your hospital visit(s)?

Please tick one box on each line

	Yes	No	Not applicable/ Don't know
Appointment cancelled or postponed	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Getting there (e.g. transport)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Finding a parking space	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Kept waiting (e.g. more than 30 minutes)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Getting time off work	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Availability of your medical notes for doctors when required	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Cleanliness	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Other (please write below what it was)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃

.....

8. How would you rate the hospital facilities?

Please tick one box on each line

	Very good	Good	Satisfactory	Poor	Not applicable/ Don't know
Waiting area	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Availability of refreshments	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Toilets	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Rooms where the tests were carried out	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

Please write any comment(s) you would like to make here

.....

.....

9. Were you treated considerately?

Please tick one box in each column

	Doctor(s)	Nurse(s)	Receptionist(s)
Yes	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
To some extent	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, not really	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
No opinion/not applicable	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄

10. Did you have enough privacy while the doctor or nurse was examining you?

Please tick one box

Yes	<input type="checkbox"/> ₁
No	<input type="checkbox"/> ₂
I was not examined	<input type="checkbox"/> ₃

11. Did the doctor or nurse give you enough privacy while you were having tests (e.g. urine flow)?

Please tick one box

Yes	<input type="checkbox"/> ₁
No	<input type="checkbox"/> ₂
I was not tested	<input type="checkbox"/> ₃

If no, please write the name(s) of the test(s) here.....

12. Did the doctor or nurse give you an explanation of the purpose of these tests?

Please tick one box on each line

	Yes, the explanation was clear	Yes, but the explanation could have been clearer	No explanation was given	I didn't have this test
TRUS/Biopsy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Urine flow	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
PSA* ¹	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
DRE* ²	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Other	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

If other, please write the name(s) of the test(s) here.....

*¹ Prostate Specific Antigen or blood test *² Digital Rectal Examination or internal examination

13. Did the doctor or nurse give you an explanation of your Gleason score? *³

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 did not want/need an explanation ₄

*³ A system of grading prostate cancer cells based on how they look under a microscope. Gleason scores range from 2 to 10 and indicate how likely it is that a tumour will spread. A low Gleason score means the cancer cells are similar to normal prostate cells and are less likely to spread; a high Gleason score means the cancer cells are very different from normal and are more likely to spread.

14. Did the doctor or nurse offer you any written information about your Gleason score?

Please tick one box

- Yes ₁
- No ₂

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

Please tick one box on each line

	Yes, the explanation was clear	Yes, but the explanation could have been clearer	No explanation was given	I didn't have this test
TRUS/Biopsy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Urine flow	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
PSA	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
DRE	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Other	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

If other, please write the name(s) of the test(s) here

.....

.....

16. 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, it was not clearly explained ₃
- I did not have a biopsy ₄ I did not have a biopsy,
please go to Question 20

17. When you had your biopsy were you offered a local anaesthetic?

Please tick one box

- Yes ₁
No ₂

18. Did the doctor or nurse explain to you that the biopsy may cause an 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

19. Were you offered any medication (e.g. antibiotics) to control any infections from your biopsy?

Please tick one box

- Yes ₁
No ₂

20. 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

21. 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

22. Did the doctor or nurse explain to you what would happen next?

Please tick one box

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

23. Overall, did you have confidence and trust in the doctors and nurses that you saw?

Please tick one box in each column

	Doctor(s)	Nurse(s)
Yes	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
To some extent	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, not really	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
No opinion/not applicable	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄

24. Overall, please show how good or bad your experience of care was by circling the number on the scale below.

0 1 2 3 4 5 6 7 8 9 10

Worst experience of care  Best experience of care

SECTION C

Discussing your test results for possible prostate cancer

1. At which hospital did you discuss your test results?

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

2. Which tests had you had at the hospital?

Please tick as many boxes as apply

TRUS/Biopsy

Urine flow

PSA*¹

DRE*²

Other

If other, please write the name(s) of the test(s) here.....
.....
.....

*¹ Prostate Specific Antigen or blood test *² Digital Rectal Examination or internal examination

The following questions refer to the test(s) that you have ticked

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

Please tick one box

Yes ₁ If yes, please go to Question 5

No ₂

4. Would you have liked a choice of how you wanted to be given your test results?

Please tick one box

Yes ₁

No ₂

5. How long did you have to wait for your test results?

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 and up to 8 weeks ₄
- More than 8 weeks ₅

6. How did you feel about the length of the time you had to wait for your test results?

Please tick one box

- Too short ₁
- About right ₂
- Too long ₃
- No opinion/not important ₄

7. Were you told that it might be helpful if someone (e.g. partner, relative) could attend the hospital appointment with you to discuss your test results?

Please tick one box

- Yes ₁
- No ₂

8. When you went back to the hospital to discuss your test results, who did you see?

Please tick one box

- A doctor (e.g. consultant, registrar) ₁
 - A nurse (e.g. a specialist prostate cancer nurse) ₂
 - Other (please write below who it was) ₃
-

9. Did you have enough privacy when you discussed your test results?

Please tick one box

- Yes ₁
- No ₂

10. Did the doctor or nurse explain the results of your tests 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 If no explanation was given please go to Question 12

11. Did the doctor or nurse explain to you your test results in a considerate way?

Please tick one box

- Yes ₁
- To some extent ₂
- No, not really ₃
- No explanation was given ₄

12. Did the test results show that you had prostate cancer?

Please tick one box

- Yes ₁ If yes, please continue to the next question
- No ₂ If no, please do not answer any more questions and return the questionnaire, thank you for your time

13. After getting your test results, did the doctor or nurse offer you the chance to talk to a specialist prostate cancer nurse?

Please tick one box

- Yes ₁
- No ₂ If no, please go to Question 16

14. How soon after the doctor or nurse gave you your test results did you discuss them with the specialist prostate cancer nurse?

Please tick one box

- Straight away ₁
- Later that same day ₂
- Within a week ₃
- Within a month ₄
- I did not discuss my test results ₅ If test results not discussed, please go to Question 16

15. How did you feel about the length of time you had to wait to discuss your test results with the specialist prostate cancer nurse?

Please tick one box

- Too short ₁
- About right ₂
- Too long ₃
- No opinion/not important ₄

16. Were you given enough written or printed information by hospital staff?

Please tick one box on each line

- | | Yes | No | I did not want/need any |
|--|---------------------------------------|---------------------------------------|---------------------------------------|
| About the results of this test/these tests | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ |
| About active treatment | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ |
| About watchful waiting/active monitoring | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ |

17. Would you have liked a break between being given your test results and discussing your treatment options?

Please tick one box

- Yes ₁
- No ₂ If no, please go to Question 19

18. How long a break would you have liked before discussing your treatment options?

Please tick one box

- 15-30 minutes ₁
- 31-60 minutes ₂
- At a further appointment the next day ₃
- At a further appointment another day ₄

19. Which treatment options were you offered?

Please tick one box on each line

- | | Yes | No |
|---|---------------------------------------|---------------------------------------|
| A planned combination of treatments (e.g. radiotherapy and hormone therapy) | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| Prostatectomy* ¹ | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| Radiotherapy | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| Hormone therapy | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| Brachytherapy* ² | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |

Cryotherapy*³

₁ ₂

Watchful waiting/active monitoring

₁ ₂

Other (please write below what it was)

₁ ₂

.....

*¹ Surgery to remove the prostate.

*² A type of internal radiation therapy in which radioactive materials are placed in direct contact with the tissue being treated.

*³ A technique that uses an extremely cold liquid or instrument to freeze and destroy abnormal skin cells that require removal.

20. Did the doctor or nurse explain these treatment options 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

I did not want/need an explanation

₄

21. Did the doctor or nurse explain the side effects or consequences of these treatment options 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

I did not want/need an explanation

₄

22. Did the doctor or nurse explain what could be done about the 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

I did not want/need an explanation

₄

23. Would you have liked an explanation of why the other treatment options were not suitable?

Please tick one box

Yes ₁

No ₂

24. Did the doctor or nurse offer you any written or printed information about:

Please tick one box on each line

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

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

Please tick as many boxes as apply

Me	<input type="checkbox"/>
My wife/partner	<input type="checkbox"/>
Hospital doctor*	<input type="checkbox"/>
Hospital nurse*	<input type="checkbox"/>
Another person (please write below who it was)	<input type="checkbox"/>
.....	

* including when they have consulted their team

26. Did the doctor or nurse involve you enough in the decision about which treatment to have?

Please tick one box

Yes, I was involved more than I wanted	<input type="checkbox"/> ₁
Yes, I was involved as much as I wanted	<input type="checkbox"/> ₂
No, I would have liked to have been more involved	<input type="checkbox"/> ₃

27. After the treatment decision had been made did the doctor or nurse tell you that you could discuss your treatment decision again?

Please tick one box

Yes	<input type="checkbox"/> ₁
No	<input type="checkbox"/> ₂

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

Please tick one box

Yes	<input type="checkbox"/> ₁
No	<input type="checkbox"/> ₂

29. Did the doctor or nurse tell you that you could get help from any of the following (e.g. advice, support)?

Please tick as many boxes as apply

- Specialist prostate cancer nurse
- Another patient to talk to
- Patients' support group
- Websites (e.g. message boards)
- Charities
- None of these
- I did not need/want any information about help
- Other (please write below who/what it was)

.....

30. Overall, did you have confidence and trust in the doctors and nurses that you saw?

Please tick one box in each column

	Doctor(s)	Nurse(s)
Yes	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
To some extent	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, not really	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
No opinion/not applicable	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄

31. Overall, please show how good or bad your experience of care was by circling the number on the scale below.



SECTION D

Your treatment

1. Which treatment have you most recently had?

Please tick one box

A planned combination of treatments
(e.g. radiotherapy and hormone therapy) 1

Prostatectomy*¹ 2

Radiotherapy 3

Hormone therapy 4

Brachytherapy*² 5

Cryotherapy*³ 6

Watchful waiting/active monitoring 7

Other (please write below what it was) 8

.....

*¹ Surgery to remove the prostate.

*² A type of internal radiation therapy in which radioactive materials are placed in direct contact with the tissue being treated.

*³ A technique that uses an extremely cold liquid or instrument to freeze and destroy abnormal skin cells that require removal.

2. Where did you have your most recent treatment?

Please tick one box

At the hospital named at 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 (please write below the details) 3

Name of the GP's practice

Town/City

3. Before you started your treatment, did a doctor or nurse help you understand the following (e.g. by giving you an explanation, providing written information)?

Please tick one box on each line

	Yes	To some extent	No not really	Not applicable
What your treatment would involve	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
The possible side effects/consequences of your treatment	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Why your treatment was starting on the date arranged	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Whether you had a choice about where the treatment took place	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
What you should do during your treatment	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
What you should not do during your treatment	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

4. While you were being treated, were you offered the opportunity to discuss any concerns about your treatment with the doctor or nurse?

Please tick one box

Yes ₁ No ₂

5. Did you experience any problems with your visit(s) for treatment?

Please tick one box on each line

	Yes	No	Not applicable/ Don't know
Appointment cancelled or postponed	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Getting there (e.g. transport)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Finding a parking space	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Kept waiting (e.g. more than 30 minutes)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Getting time off work	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Availability of your medical notes for doctors when required	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Cleanliness	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Ward noise	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Other	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃

If other, please write the name(s) of the test(s) here

.....

Please write any comment(s) you would like to make here

.....

6. Did the doctor or nurse clearly explain 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, the explanation was clear ₁
- Yes, but the explanation could have been clearer ₂
- No explanation was given ₃

7. While you were being treated, were you ever in pain or discomfort?

Please tick one box

- Yes ₁
- No ₂ If no, please go to Question 9

8. While you were being treated, were you given enough medication to control your pain or discomfort?

Please tick one box

- Yes ₁
- No ₂

9. Did the doctor or nurse tell you about any of the following sources of help for coping?

Please tick as many boxes as apply

- Specialist prostate cancer nurse
- Another patient to talk to
- Patients' support group
- Websites (e.g. message boards)
- Charities
- None of these
- I did not need/want any information about help for coping
- Other (please write below who/what it was)
-

If none of these, please go to Question 11

If I did not need/want any information about help for coping, please go to Question 11

10. Was this enough information about coping?

Please tick one box

- Yes ₁
- No ₂

11. Did the doctor or nurse offer you any information about complementary therapies (e.g. diet/diet supplements/acupuncture/massage/reflexology)?

Please tick one box

Yes ₁

No ₂ If no, please go to Question 13

12. Was this enough information about complementary therapies?

Please tick one box

Yes ₁

No ₂

If no, please write here what other information you would have liked

.....

13. Did you have your most recent treatment in hospital?

Please tick one box

Yes ₁

No ₂ If no, please go to Question 16

14. How would you rate the following?

Please tick one box on each line

	Very good	Good	Satisfactory	Poor	Not applicable/ Don't know
Nursing	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Food/drink	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Ward (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

Please write any comment(s) you would like to make here.....

.....

.....

15. While you were in the hospital as an inpatient, were your spiritual needs met (e.g. appropriate food, prayer room)?

Please tick one box

Yes ₁

To some extent ₂

No, not really ₃

I didn't have any spiritual needs ₄

Please write any comment(s) you would like to make here.....

.....

.....

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 explain what would happen after you were discharged from hospital?

Please tick one box

- Yes, the explanation was clear 1
- Yes, but the explanation could have been clearer 2
- No explanation was given 3
- Not applicable 4

18. Did the doctor or nurse offer you any written or printed information about caring for yourself at home?

Please tick one box

- Yes 1
- No 2
- Not applicable 3

19. Did the doctor or nurse tell you about a support or self-help group for people with your condition?

Please tick one box

- Yes 1
- No 2
- I did not want/need any information about support or self-help groups 3

20. Were you given equipment or supplies to use at home to help you care for yourself?

Please tick one box on each line

	Yes, I was given enough	Yes, but I would have liked more	No	I didn't need any
Catheter	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Continence pads	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Other (please write below what it was)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

.....

21. Did a doctor or nurse organise any nursing or other health services for you?

Please tick one box on each line

	Yes	No	I didn't need any
A district nurse	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
A community nurse	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
A health visitor	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
A physiotherapist	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
Another person (please write below who it was)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃

.....

22. Did the doctor or nurse tell you who to contact if you were worried about your treatment or side effects of treatment?

Please tick as many boxes as apply

Yes, I was told to contact my GP	<input type="checkbox"/>
Yes, I was told to contact the hospital	<input type="checkbox"/>
Yes, I was told to contact the specialist nurse	<input type="checkbox"/>
Yes, I was told to contact a community or district nurse	<input type="checkbox"/>
Yes, I was told to dial 999	<input type="checkbox"/>
Yes, I was told to contact someone else	<input type="checkbox"/>
(please write here who it was).....	
No, I was not told who to contact	<input type="checkbox"/>

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

Please tick one box

Yes	<input type="checkbox"/> ₁
No	<input type="checkbox"/> ₂

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

Please tick as many boxes as apply

Yes, in less than 7 days of finishing treatment	<input type="checkbox"/>
Yes, between 7 – 14 days of finishing treatment	<input type="checkbox"/>
Yes, it was more than 14 days after finishing treatment	<input type="checkbox"/>
No, my GP's practice did not contact me	<input type="checkbox"/>
No, I was not in hospital for treatment	<input type="checkbox"/>
I have not finished my treatment	<input type="checkbox"/>

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

Please tick one box on each line

	Yes	To some extent	No, not really	Not applicable
GP's practice and hospital	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Hospital and hospital	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

Please write any comment(s) you would like to make here.....

26. Overall, did you have confidence and trust in the doctors and nurses that treated you?

Please tick one box in each column

	Doctor(s)	Nurse(s)
Yes	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
To some extent	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, not really	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
No opinion/not applicable	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄

27. Overall, did the doctors and nurses treat you with respect and dignity?

Please tick one box in each column

	Doctor(s)	Nurse(s)
Yes	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
To some extent	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, not really	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
No opinion/not applicable	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄

28. Overall, please show how good or bad your experience of care was by circling the number on the scale below.



SECTION E

Monitoring (checking) you

1. Were you offered a "key worker" (a person to contact throughout your care)?

Please tick one box

Yes ₁

No ₂ If no, please go to Question 3

Please write here their job title

2. Have you found it useful to have a "key worker"?

Please tick one box

Yes ₁

To some extent ₂

No, not really ₃

3. Do you have regular tests for prostate cancer (e.g. PSA/blood test, DRE/internal examination)?

Please tick one box

Yes ₁

No ₂ If no, please go to Question 13

4. Where do you discuss the results of your tests (eg PSA, DRE)?

At the hospital named at the front of the questionnaire ₁

At another hospital (please write below the details) ₂

Name of the hospital

Town/City

5. 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

I did not want/need an explanation ₄

6. How often are you currently tested for prostate cancer?

Please tick one box

- Every month 1
- Every two months 2
- Every three months 3
- Every four months 4
- Every five months 5
- Every six months 6
- Other (please write below what it was) 7

.....

7. Did the doctor or nurse explain the length of the wait between these 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
- I did not want/need an explanation 4

8. Were you offered a choice of where to have these tests?

Please tick one box

- Yes 1
- No 2

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

Please tick one box

- Yes 1 If yes, please go to Question 11
- No 2

10. Would you have liked a choice of how you wanted to be given your test results?

Please tick one box

- Yes 1
- No 2

11. Did the doctor or nurse explain your test results 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

12. Did the doctor or nurse give you a telephone number to ring if you need any help or advice, or have any questions about your condition (e.g. for talking to a specialist prostate cancer nurse, oncology nurse)?

Please tick one box

- Yes ₁
- No ₂

13. Did the doctor or nurse ask you if you had any of the following needs?

Please tick one box on each line

- | | Yes | No |
|---|---------------------------------------|---------------------------------------|
| Emotional (e.g. patient support group) | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| Spiritual/religious (e.g. someone to talk to) | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| Financial (e.g. benefits available) | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| Day-to-day (e.g. help with housework) | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |

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

Please tick one box on each line

- | | Yes | To some extent | No, not really | Not applicable |
|----------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| GP's practice and hospital | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |
| Hospital and hospital | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

Please write any comment(s) you would like to make here.....
.....
.....

15. Overall, did you have confidence and trust in the doctors and nurses that you saw?

Please tick one box in each column

- | | Doctor(s) | Nurse(s) |
|---------------------------|---------------------------------------|---------------------------------------|
| Yes | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₁ |
| To some extent | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₂ |
| No, not really | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₃ |
| No opinion/not applicable | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₄ |

16. Overall, did the doctors and nurses treat you with respect and dignity?

Please tick one box in each column

	Doctor(s)	Nurse(s)
Yes	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
To some extent	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, not really	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
No opinion/not applicable	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄

17. Overall, please show how good or bad your experience of care was by circling the number on the scale below.

0 1 2 3 4 5 6 7 8 9 10

Worst experience of care  Best experience of care

SECTION F

About you and your health

About your health

1. Please write the month and year when you were last tested for prostate cancer (e.g. PSA/blood test)

Month Year

2. If you have been actively treated for prostate cancer please write the month and year of your last treatment.

Month Year

I have not been treated for prostate cancer (please tick the box)

3. Please show how good or bad your general health is today, in your opinion, by circling a number on the scale below.

0 1 2 3 4 5 6 7 8 9 10
Worst imaginable health state  Best imaginable health state

About you

4. Which age range are you in?

Please tick one box

Up to 54 ₁ 65 – 74 ₃ 85 or more ₅
55 – 64 ₂ 75 – 84 ₄

5. How would you describe your ethnic origin?

Please tick one box

White

₁ White British
₂ White Irish
₃ Any other White background

Mixed

₄ White & Black Caribbean
₅ White & Black African
₆ White & Asian
₇ Any other Mixed background

Asian or Asian British

₈ Indian
₉ Pakistani
₁₀ Bangladeshi
₁₁ Any other Asian background

Black or Black British

₁₂ Caribbean
₁₃ African
₁₄ Any other Black background

Chinese or other ethnic group

₁₅ Chinese
₁₆ Any other ethnic group (please write below the group)
.....

6. Do you have someone to support and/or care for you?
If you have more than one carer can you please just identify who your main carer is by ticking the box.

Please tick one box

- Wife/partner 1
- Other family member/relative 2
- Friend 3
- I do not need someone to support and/or care for me 4
- No 5
- Other (please write below their relationship to you) 6

.....

7. Do you need someone to translate or interpret for you (e.g. sign language) when you see the doctor or nurse?

Please tick one box

- Yes, I need someone to translate 1
- Yes, I need a sign language interpreter 2
- No 3

8. How would you describe your own current situation?

Please tick one box

- Employed 1
- Unemployed 2
- Retired 3
- Unable to work due to ill health or disability 4
- Looking after the family, home dependents 5
- Student 6
- Other (please write below what it is) 7

.....

9. Is the house/flat/other place where you live?

Please tick one box

- Owned by you (with or without a mortgage) 1
- Rented 2
- Residential home or sheltered housing 3
- Other (please write below what it is) 4

.....

10. Including yourself, how many people live in your household who are aged 18 or over?

Please write in the number

11. Do you have a car?

Please tick one box

Yes, one ₁

Yes, two or more ₂

No ₃

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

APPENDIX 7

Prostate Cancer Questionnaire - Patients PCQ-Pv2

YOUR VIEWS ABOUT PRIMARY AND SECONDARY HEALTH CARE (PCQ-P)

Pilot v2 • September 2006

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. You do not need to give your name and your answers will be treated in strict confidence. Please complete all those sections that apply to your experience of care. If there are any questions you do not wish to answer please leave blank.

Please post back the completed questionnaire booklet in the pre-paid envelope provided. Thank you for your help.

If you have any questions regarding the questionnaire, please contact either Paul Sinfield or Shona Agarwal (Researchers) on 0116 258 4874.

This questionnaire booklet is divided into six sections:

Section A: Possible prostate problem.

Section B: Tests for possible prostate cancer.

Section C: Test results.

Section D: Treatment.

Section E: Monitoring.

Section F: About you and your health.



Funded by the NHS Service Delivery
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University of
Leicester

SECTION A

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

A1. Were you taking part in a medical trial?

Please tick one box

Yes ₁

No ₂

A2. Where did you go for the FIRST TIME about your possible prostate problem?

Please tick one box

To the GP's practice ₁

To the local assessment centre/clinic ₂

To the hospital ₃

IF TO THE HOSPITAL, PLEASE GO TO SECTION B

A3. When you went to the GP's practice/local assessment centre who did you see?

Please tick one box

Your GP ₁

Another GP/doctor ₂

A nurse ₃

Other (please write below who it was) ₄

.....

A4. What was your reason(s) for going to the GP's practice/local assessment centre?

Please tick as many boxes as apply

Problems with urinating

Other symptoms e.g. back pain

Part of a general health check

I thought I might be at risk of prostate cancer

Other (please write below what it was)

.....

A5. 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

A6. Did the doctor or nurse explain that prostate cancer might be causing your symptoms?

Please tick one box

- | | |
|--|----------------------------|
| Yes, the explanation was clear | <input type="checkbox"/> 1 |
| Yes, but the explanation could have been clearer | <input type="checkbox"/> 2 |
| No explanation was given | <input type="checkbox"/> 3 |
| I did not have any symptoms | <input type="checkbox"/> 4 |
| I did not want/need an explanation | <input type="checkbox"/> 5 |

The following questions are about your FIRST Prostate Specific Antigen (PSA) blood test and your first Digital Rectal Examination (DRE).

A7. Did you have a PSA blood test and/or a DRE before being referred to hospital?

Please tick one box on each line

- | | Yes | No |
|-----|----------------------------|----------------------------|
| PSA | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| DRE | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |

IF YOU HAVE TICKED NO TO PSA BLOOD TEST AND DRE, PLEASE GO TO QUESTION A16

A8. Did the doctor or nurse explain beforehand what the tests were trying to find out?

Please tick one box in each column

- | | PSA | DRE |
|--|----------------------------|----------------------------|
| Yes, the explanation was clear | <input type="checkbox"/> 1 | <input type="checkbox"/> 1 |
| Yes, but the explanation could have been clearer | <input type="checkbox"/> 2 | <input type="checkbox"/> 2 |
| No explanation was given | <input type="checkbox"/> 3 | <input type="checkbox"/> 3 |
| I did not want/need an explanation | <input type="checkbox"/> 4 | <input type="checkbox"/> 4 |
| I did not have this test | <input type="checkbox"/> 5 | <input type="checkbox"/> 5 |

A9. Did the doctor or nurse explain beforehand how the tests are carried out?

Please tick one box in each column

- | | PSA | DRE |
|--|----------------------------|----------------------------|
| Yes, the explanation was clear | <input type="checkbox"/> 1 | <input type="checkbox"/> 1 |
| Yes, but the explanation could have been clearer | <input type="checkbox"/> 2 | <input type="checkbox"/> 2 |
| No explanation was given | <input type="checkbox"/> 3 | <input type="checkbox"/> 3 |
| I did not want/need an explanation | <input type="checkbox"/> 4 | <input type="checkbox"/> 4 |
| I did not have this test | <input type="checkbox"/> 5 | <input type="checkbox"/> 5 |

A10. Did the doctor or nurse explain beforehand that the tests are not always reliable?

Please tick one box in each column

	PSA	DRE
Yes, the explanation was clear	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
Yes, but the explanation could have been clearer	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No explanation was given	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
I did not want/need an explanation	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄
I did not have this test	<input type="checkbox"/> ₅	<input type="checkbox"/> ₅

A11. Did the doctor or nurse explain beforehand what might happen if the tests were abnormal?

Please tick one box in each column

	PSA	DRE
Yes, the explanation was clear	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
Yes, but the explanation could have been clearer	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No explanation was given	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
I did not want/need an explanation	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄
I did not have this test	<input type="checkbox"/> ₅	<input type="checkbox"/> ₅

A12. Did the doctor or nurse offer you any written information about the tests?

Please tick one box on each line

	Yes	No	I did not have this test
PSA	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
DRE	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃

A13. Did the doctor or nurse involve you as much as you wanted in the decision on whether to have these tests?

Please tick one box in each column

	PSA	DRE
Yes, I was involved as much as I wanted	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
No, I was involved more than I wanted	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, I would have liked to have been more involved	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
No, this test was not offered	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄

A14. Did the doctor or nurse explain the results of your tests?

Please tick one box in each column

	PSA	DRE
Yes, the explanation was clear	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
Yes, but the explanation could have been clearer	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No explanation was given	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
I did not have this test	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄

A15. Did the doctor or nurse give you the results of your tests in a considerate way?

Please tick one box in each column

	PSA	DRE
Yes	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
To some extent	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, not really	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
No explanation was given	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄
I did not have this test	<input type="checkbox"/> ₅	<input type="checkbox"/> ₅

A16. How long was it from your first visit to the GP's practice/local assessment centre until it was decided to refer you to the hospital for tests/further tests?

Please tick one box

Not more than 2 weeks	<input type="checkbox"/> ₁
More than 2 weeks and up to 4 weeks	<input type="checkbox"/> ₂
More than 4 weeks and up to 6 weeks	<input type="checkbox"/> ₃
More than 6 weeks	<input type="checkbox"/> ₄
I was not referred to hospital	<input type="checkbox"/> ₅

IF YOU WERE NOT REFERRED TO HOSPITAL, PLEASE DO NOT ANSWER ANY MORE QUESTIONS AND RETURN THE QUESTIONNAIRE BOOKLET, THANK YOU FOR YOUR TIME.

A17. How did you feel about the time the GP's practice/local assessment took to refer you to the hospital for further tests?

Please tick one box

Too short	<input type="checkbox"/> ₁
About right	<input type="checkbox"/> ₂
Too long	<input type="checkbox"/> ₃

A18. Did the doctor or nurse explain why you were being referred to hospital?

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 did not want/need an explanation ₄

A19. Did the doctor or nurse give you a choice of :

Please tick one box on each line

- | | Yes | No |
|-------------------------------------|---------------------------------------|---------------------------------------|
| Which hospital you wanted to go to? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| The date you wanted to be seen on? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |

A20. Were your needs taken into account when the referral arrangements were made (e.g. transport, time of appointment)?

Please tick one box

- Yes ₁
- No ₂
- I did not have any needs ₃

A21. Did the doctor or nurse explain how soon you would be seen at the hospital?

Please tick one box

- Yes ₁
- No ₂

A22. Overall, did you have confidence and trust in the doctor and nurse that you saw on this occasion?

Please tick one box in each column

- | | Doctor | Nurse |
|---------------------------|---------------------------------------|---------------------------------------|
| Yes, completely | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₁ |
| Yes, to some extent | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₂ |
| No, not very much | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₃ |
| None at all | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₄ |
| No opinion/not applicable | <input type="checkbox"/> ₅ | <input type="checkbox"/> ₅ |

A23. Overall, did the GP practice staff treat you with respect and dignity on this occasion?

Please tick one box in each column

	Doctor	Nurse	Receptionist
Yes, completely	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
Yes, to some extent	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, not very much	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
None at all	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄
No opinion/not applicable	<input type="checkbox"/> ₅	<input type="checkbox"/> ₅	<input type="checkbox"/> ₅

A24. Overall, how would you rate the quality of care provided by your GP/local assessment centre during this stage of finding out what was wrong with you?

Please tick one box

Very good	<input type="checkbox"/> ₁
Good	<input type="checkbox"/> ₂
Fair	<input type="checkbox"/> ₃
Poor	<input type="checkbox"/> ₄
Very poor	<input type="checkbox"/> ₅

Please write any comment(s) you would like to make here

.....

.....

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
- I was taking part in a trial (e.g. PROTECT) ₄
- Other (Please write below who it was) ₅
-

B2. At which hospital did you have your first appointment for tests?

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

B3. Were you an NHS patient or a private patient?

Please tick one box

- NHS patient (treatment was free) ₁
- Private patient (treatment was paid for) ₂

IF PRIVATE PATIENT, PLEASE GO TO SECTION C

B4. Were you told it might be helpful if someone (e.g. wife/partner, relative) could attend the hospital appointment when you went for your tests?

Please tick one box

- Yes ₁
- No ₂

B5. How long did you wait between the date you were referred and the date of your first appointment for tests 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

B6. How did you feel about the length of time you had to wait for your first appointment for tests at the hospital?

Please tick one box

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

IF YOU HAVE MADE MORE THAN ONE VISIT TO THE HOSPITAL FOR TESTS, PLEASE ANSWER THE FOLLOWING QUESTIONS FROM YOUR OVERALL EXPERIENCE.

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

Please tick as many boxes as apply

- Appointment cancelled or postponed
- Getting there (e.g. transport)
- Finding a parking space
- Kept waiting (e.g. more than 30 minutes)
- Getting time off work
- Availability of your medical notes for doctors when required
- Cleanliness
- Other (please write below what it was)

.....

B8. How would you rate the hospital facilities?

Please tick one box on each line

	Very good	Good	Satisfactory	Poor	Not applicable/ Don't know
Waiting area	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Availability of refreshments	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Toilets	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Rooms where the tests were carried out	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

Please write any comment(s) you would like to make here

.....

.....

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

Please tick one box

Yes ₁

I was not examined/tested ₂

No ₃

If no, please write the name(s) of the test(s) here

.....

B10. Did the doctor or nurse explain to you the purpose of these tests?

Please tick one box on each line

	Yes, the explanation was clear	Yes, but the explanation could have been clearer	No explanation was given	I didn't have this test
TRUS/Biopsy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Urine flow	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
PSA* ¹	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
DRE* ²	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Scans (MRI, CT)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

If other, please write the name(s) of the test(s) here

.....

*¹ Prostate Specific Antigen blood test *² Digital Rectal Examination or internal examination

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

Please tick one box on each line

	Yes, the explanation was clear	Yes, but the explanation could have been clearer	No explanation was given	I didn't have this test
TRUS/Biopsy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Urine flow	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
PSA* ¹	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
DRE* ²	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Scans (MRI, CT)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

If other, please write the name(s) of the test(s) here

.....

*¹ Prostate Specific Antigen blood test *² Digital Rectal Examination or internal examination

If you have had more than ONE biopsy, please answer the following questions from the experience of your most recent biopsy.

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, it was not clearly explained ₃
- I did not have a biopsy ₄

**I DID NOT HAVE A BIOPSY,
PLEASE GO TO QUESTION B15**

B13. When you had your biopsy were you offered an anaesthetic?

Please tick one box

- Yes ₁
- No ₂

B14. Did the doctor or nurse explain that you may need medication (e.g. antibiotics) to control any infections caused by the biopsy?

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 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

B17. Did the doctor or nurse explain to you what would happen next?

Please tick one box

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

B18. Overall, did the hospital staff treat you with respect and dignity?

Please tick one box in each column

- | | Doctor(s) | Nurse(s) | Receptionist(s) |
|---------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Yes, all of them | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₁ |
| Yes, some of them | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₂ |
| No, none of them | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₃ |
| No opinion/not applicable | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₄ |

B19. Overall, did you have confidence and trust in the doctor(s) and nurse(s) that you saw?

Please tick one box in each column

- | | Doctor(s) | Nurse(s) |
|---------------------------|---------------------------------------|---------------------------------------|
| Yes, all of them | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₁ |
| Yes, some of them | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₂ |
| No, none of them | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₃ |
| No opinion/not applicable | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₄ |

B20. Overall, how would you rate the quality of care provided by your hospital during this stage of testing?

Please tick one box

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

Please write any comment(s) you would like to make here

.....

.....

SECTION C

Discussing your test results for possible prostate cancer

C1. At which hospital did you discuss your test results?

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

C2. Were you an NHS patient or a private patient?

Please tick one box

NHS patient (treatment was free) ₁

Private patient (treatment was paid for) ₂

IF PRIVATE PATIENT, PLEASE GO TO SECTION D

C3. Which tests did you have at the hospital?

Please tick as many boxes as apply

TRUS/Biopsy

Urine flow

PSA*¹

DRE*²

Scans (e.g. MRI, CT)

If other, please write the name(s) of the test(s) here

.....

.....

*¹ Prostate Specific Antigen blood test *² Digital Rectal Examination or internal examination

The following questions refer to the test(s) that you have ticked

C4. How were you given your test results?

Please tick one box

Face-to-face ₁

Over the telephone ₂

In a letter ₃

If other, please write how you were given your test results here

.....

.....

C5. Would you have liked to have been given your test results in a different way?

Please tick one box

- Yes ₁
No ₂

If yes, please write how would you have liked to have been given your test results here

.....
.....

C6. How long did you have to wait for your test results?

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

C7. How did you feel about the length of the time you had to wait for your test results?

Please tick one box

- Too short ₁
About right ₂
Too long ₃

C8. Were you told that it might be helpful if someone (e.g. wife/partner, relative) could attend the hospital appointment with you to discuss your test results?

Please tick one box

- Yes ₁
No ₂

C9. Did you have enough privacy when you discussed your test results?

Please tick one box

- Yes ₁
No ₂

C10. Did the doctor or nurse explain your test results 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

C11. Did the doctor or nurse explain your test results in a considerate way?

Please tick one box

Yes ₁

To some extent ₂

No, not really ₃

No explanation was given ₄

C12. Did the test results show that you had prostate cancer?

Please tick one box

Yes ₁

IF YES, PLEASE CONTINUE TO THE NEXT QUESTION

No ₂

IF NO, PLEASE DO NOT ANSWER ANY MORE QUESTIONS AND RETURN THE QUESTIONNAIRE, THANK YOU FOR YOUR TIME

C13. Did the doctor or nurse explain your Gleason score to you?*¹

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 did not want/need an explanation ₄

^{*1} A system of grading prostate cancer cells based on how they look under a microscope. Gleason scores range from 2 to 10 and indicate how likely it is that a tumour will spread. A low Gleason score means the cancer cells are similar to normal prostate cells and are less likely to spread; a high Gleason score means the cancer cells are very different from normal and are more likely to spread.

C14. Did the doctor or nurse offer you any written information about your Gleason score?

Please tick one box

Yes ₁

No ₂

C15. After getting your test results, did the doctor or nurse offer you the chance to talk to a specialist prostate cancer nurse?

Please tick one box

Yes ₁

No ₂

C16. How soon after the doctor or nurse gave you your test results did you discuss them with the specialist prostate cancer nurse?

Please tick one box

Straight away ₁

Later that same day ₂

Within a week ₃

Within a month ₄

I did not discuss my test results with the specialist prostate cancer nurse ₅

C17. How did you feel about the length of time you had to wait to discuss your test results with the specialist prostate cancer nurse?

Please tick one box

Too short ₁

About right ₂

Too long ₃

I did not discuss my test results with the specialist prostate cancer nurse ₄

C18. Were you given enough written or printed information by hospital staff?

Please tick one box on each line

	Yes	No	I did not want/need any
About the test results	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
About active treatment	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
About watchful waiting/active monitoring	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃

C19a. Did you have enough time between been given your test results and discussing your treatment options?

Please tick one box

Yes ₁

No ₂

C19b. If no, how much time would you have liked?

Please tick one box

- 15-30 minutes 1
- 31-60 minutes 2
- At a further appointment the next day 3
- At a further appointment another day 4

C20. Which treatment options were you offered after you were given your test results?

Please tick as many boxes as apply

- Prostatectomy*¹
- Radiotherapy
- Hormone therapy*²
- Brachytherapy*³
- Cryotherapy*⁴
- Watchful waiting/active monitoring
- Other (please write below what it was)
-

*¹ Surgery to remove the prostate, including key hole surgery.

*² A series of injections or tablets (e.g. Zoladex).

*³ A type of internal radiation therapy in which radioactive materials are placed in direct contact with the tissue being treated.

*⁴ A technique that uses an extremely cold liquid or instrument to freeze and destroy abnormal cells.

C21. 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
- I did not want/need an explanation 4

C22. Did the doctor or nurse discuss with you 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
- I did not want/need an explanation 4

C23. Were you given an explanation of why the other treatment options were not suitable?

Please tick one box

- Yes ₁
- No, but I would have liked one ₂
- No, I did not want/need one ₃

C24. Did the doctor or nurse offer you any written or printed information about any of the following:

Please tick as many boxes as apply

- The treatment options?
- The side effects or consequences of the treatment options?
- What could be done about the side effects?

C25a. Did you have enough time between been given your treatment options and discussing your treatment decision?

Please tick one box

- Yes ₁
- No ₂

C25b. If no, how much time would you have liked?

Please tick one box

- 15-30 minutes ₁
- 31-60 minutes ₂
- At a further appointment the next day ₃
- At a further appointment another day ₄

C26. 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 (please write below who it was)

.....

* including when they have consulted their team

C27. Did the doctor or nurse involve you as much as you wanted in the decision about which treatment to have?

Please tick one box

No, I was involved more than I wanted ₁

Yes, I was involved as much as I wanted ₂

No, I would have liked to have been more involved ₃

C28. After the treatment decision had been made did the doctor or nurse tell you that you could discuss your treatment decision again?

Please tick one box

Yes ₁ No ₂

C29. 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

C30. Were you satisfied with the way the decision was made about which treatment to have?

Please tick one box

Yes ₁

No ₂

If no, please write here why you were not satisfied.....

.....
.....

C31. Did the doctor or nurse tell you that you could get help from any of the following (e.g. advice, support)?

Please tick as many boxes as apply

Specialist prostate cancer nurse

Another patient to talk to

Patients' support group

Websites (e.g. message boards)

Charities

None of these

I did not want/need any information about help

Other (please write below who/what it was)

.....

C32. Overall, did you have confidence and trust in the doctor and nurse that you saw on this occasion?

Please tick one box in each column

	Doctor	Nurse
Yes, completely	<input type="checkbox"/> 1	<input type="checkbox"/> 1
Yes, to some extent	<input type="checkbox"/> 2	<input type="checkbox"/> 2
No, not very much	<input type="checkbox"/> 3	<input type="checkbox"/> 3
None at all	<input type="checkbox"/> 4	<input type="checkbox"/> 4
No opinion/not applicable	<input type="checkbox"/> 5	<input type="checkbox"/> 5

C33. Overall, how would you rate the quality of care provided by your hospital when you got your test results?

Please tick one box

Very good	<input type="checkbox"/> 1
Good	<input type="checkbox"/> 2
Fair	<input type="checkbox"/> 3
Poor	<input type="checkbox"/> 4
Very poor	<input type="checkbox"/> 5

Please write any comment(s) you would like to make here

.....

.....

SECTION D

Your treatment

D1. Is your current treatment choice watchful waiting/active monitoring?

Please tick one box

Yes ₁ **IF YES, PLEASE GO TO SECTION E**
No ₂

D2. Which treatment have you most recently have?

Please tick as many boxes as apply

Prostatectomy*¹
Radiotherapy (completed/ongoing)
Hormone therapy*² (completed/ongoing)
Brachytherapy*³
Cryotherapy*⁴
Other (please write below what it was)

.....

*¹ Surgery to remove the prostate, including key hole surgery.
*² A series of injections or tablets (e.g. Zoladex).
*³ A type of internal radiation therapy in which radioactive materials are placed in direct contact with the tissue being treated.
*⁴ A technique that uses an extremely cold liquid or instrument to freeze and destroy abnormal cells.

D3. Where did you have your most recent treatment?

Please tick one box

At the hospital named at 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

IF AT THE GP'S PRACTICE, PLEASE GO TO SECTION E

D4. Were you an NHS patient or private patient?

Please tick one box

NHS patient (treatment was free)

 ₁

Private patient (treatment was paid for)

 ₂

IF PRIVATE PATIENT, PLEASE GO TO SECTION E

D5. 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 and up to 8 weeks

 ₄

More than 8 weeks

 ₅

D6. How did you feel about the length of the time you had to wait for your treatment to start?

Please tick one box

Too short

 ₁

About right

 ₂

Too long

 ₃

D7. Before you started your treatment, did a doctor or nurse help you understand the following (e.g. by giving you an explanation, providing written information)?

Please tick one box on each line

Yes

To some extent

No not really

What your treatment would involve

 ₁ ₂ ₃

The possible side effects/consequences of your treatment

 ₁ ₂ ₃

Why your treatment was starting on the date arranged

 ₁ ₂ ₃

Whether you had a choice about where the treatment took place

 ₁ ₂ ₃

What you should do during your treatment

 ₁ ₂ ₃

What you should not do during your treatment

 ₁ ₂ ₃

D8. While you were being treated, could you discuss any concerns about your treatment with the doctor or nurse?

Please tick one box

Yes ₁

No ₂

Don't know ₃

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

Please tick as many boxes as apply

Appointment cancelled or postponed

Getting there (e.g. transport)

Finding a parking space

Kept waiting (e.g. more than 30 minutes)

Getting time off work

Availability of your medical notes for doctors when required

Cleanliness

Ward noise

Other

If other, please write here any other problems experienced

.....

D10. Were you told 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 ₁

D11. While you were being treated, do you think that the hospital staff 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

Yes, some of the time

No, none of the time

I was not in pain/discomfort

D12. Did the doctor or nurse tell you about any of the following sources of help for coping?

Please tick as many boxes as apply

- Specialist prostate cancer nurse
- Another patient to talk to
- Patients' support group
- Websites (e.g. message boards)
- Charities
- None of these
- I did not need/want any information about help for coping
- Other (please write below who/what it was)

.....

D13. Did the doctor or nurse offer you enough information about complementary therapies (e.g. diet/diet supplements/acupuncture/massage/reflexology)?

Please tick one box

- Yes ₁
- No ₂
- I did not want any information ₃

If no, please write here what other information you would have liked

.....

D14. How would you rate the following?

Please tick one box on each line

	Very good	Good	Satisfactory	Poor	Not applicable/ Don't know
Treatment	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Nursing	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Food/drink	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Ward (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

Please write any comment(s) you would like to make here

.....

.....

D15. While you were in the hospital, were your spiritual needs met (e.g. appropriate food, prayer room)?

Please tick one box in each column

	As an inpatient	As an outpatient
Yes	<input type="checkbox"/> 1	<input type="checkbox"/> 1
To some extent	<input type="checkbox"/> 2	<input type="checkbox"/> 2
No, not really	<input type="checkbox"/> 3	<input type="checkbox"/> 3
I did not have any spiritual needs	<input type="checkbox"/> 4	<input type="checkbox"/> 4
Not applicable	<input type="checkbox"/> 5	<input type="checkbox"/> 5

Please write any comment(s) you would like to make here

.....
.....

D16. Did the doctor or nurse explain how well the treatment was going/had gone?

Please tick one box

Yes, the explanation was clear	<input type="checkbox"/> 1
Yes, but the explanation could have been clearer	<input type="checkbox"/> 2
No explanation was given	<input type="checkbox"/> 3

D17. Did the doctor or nurse explain what would happen after your treatment had finished e.g. arrangements for follow-up?

Please tick one box

Yes, the explanation was clear	<input type="checkbox"/> 1
Yes, but the explanation could have been clearer	<input type="checkbox"/> 2
No explanation was given	<input type="checkbox"/> 3
I have not finished my treatment	<input type="checkbox"/> 4

D18. Did the doctor or nurse help you to understand how to care for yourself at home?

Please tick one box

Yes	<input type="checkbox"/> 1
No	<input type="checkbox"/> 2
Not applicable	<input type="checkbox"/> 3

D19. Were you given equipment or supplies (e.g. continence pads) to use at home to help you care for yourself?

Please tick one box

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

If no, I was not given any equipment or supplies. Please write here what you needed

.....

D20. Did a doctor or nurse organise the aftercare services that you needed (e.g. district nurse, health visitor, physiotherapist)?

Please tick one box

- Yes ₁
- No ₂
- I did not need any aftercare services ₃

If no, please write here what aftercare services you needed

.....

D21. Did the doctor or nurse tell you who to contact if you were worried about your treatment or side effects of treatment?

Please tick as many boxes as apply

- Yes, I was told to contact my GP
- Yes, I was told to contact the hospital
- Yes, I was told to contact the prostate cancer specialist nurse
- Yes, I was told to contact a community or district nurse
- Yes, I was told to dial 999
- Yes, I was told to contact someone else
- (please write here who it was).....
- No, I was not told who to contact

D22. Did the doctor or nurse offer you any financial information on welfare or benefits?

Please tick one box

- Yes ₁
- No ₂
- I did not want any financial information on welfare or benefits ₃

D23. At the end of your treatment in hospital were you contacted by your GP's practice?

Please tick as many boxes as apply

- Yes, in less than 7 days of finishing treatment
- Yes, between 7 – 14 days of finishing treatment
- Yes, it was more than 14 days after finishing treatment
- No, my GP's practice did not contact me
- I have not finished my treatment

D24. Have staff in different places worked well together when caring for you for this condition (e.g. information about you passed on, no unnecessary delays)?

Please tick one box on each line

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

Please write any comment(s) you would like to make here

.....

.....

D25. Overall, did you have confidence and trust in the doctor(s) and nurse(s) that treated you?

Please tick one box in each column

- | | Doctor(s) | Nurse(s) |
|---------------------------|---------------------------------------|---------------------------------------|
| Yes, all of them | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₁ |
| Yes, some of them | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₂ |
| No, none of them | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₃ |
| No opinion/not applicable | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₄ |

D26. Overall, did the hospital staff treat you with respect and dignity?

Please tick one box in each column

- | | Doctor(s) | Nurse(s) | Receptionist(s) |
|---------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Yes, all of them | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₁ |
| Yes, some of them | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₂ |
| No, none of them | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₃ |
| No opinion/not applicable | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₄ |

D27. Overall, how would you rate the quality of care provided by your hospital when you were treated?

Please tick one box

Very good 1

Good 2

Fair 3

Poor 4

Very poor 5

Please write any comment(s) you would like to make here

.....
.....

SECTION E

Monitoring (checking) you

E1. Were you offered a "key worker" (the same person to contact throughout your care)?

Please tick one box

Yes ₁

No ₂

IF NO, PLEASE GO TO QUESTION E3

Please write here their job title

E2. Have you found it useful to have a "key worker"?

Please tick one box

Yes ₁

To some extent ₂

No, not really ₃

E3. Do you have regular tests for prostate cancer (e.g. PSA blood test, DRE/internal examination)?

Please tick one box

Yes ₁

No ₂

IF NO, PLEASE GO TO QUESTION E14

E4. Have you experienced any problems with the regular tests you have for prostate cancer.

Please tick one box

Yes ₁

No ₂

If yes, please write here what problems they were

E5. Where do you discuss the results of your tests (e.g. PSA blood test, DRE)?

Please tick one box

At the hospital named at the front of the questionnaire ₁

At another hospital (please write below the details) ₂

Name of the hospital

Town/City

GP's practice ₃

E6. 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
- I did not want/need an explanation ₄

E7. How often are you currently tested for prostate cancer?

Please tick one box

- Every month ₁
 - Every two months ₂
 - Every three months ₃
 - Every four months ₄
 - Every five months ₅
 - Every six months ₆
 - Other (please write below what it was) ₇
-

E8. Did the doctor or nurse reassure you that the length of the wait between the tests for prostate cancer was appropriate for you?

Please tick one box

- Yes ₁ No ₂

E9a. Were you offered a choice of where to have these tests (e.g. GP's practice, hospital)?

Please tick one box

- Yes ₁ No ₂

E9b. If no, would you have liked a choice of where to have these tests?

Please tick one box

- Yes ₁ No ₂

E10. How were you given your test results?

Please tick one box

- Face to face ₁
- Over the telephone ₂
- In a letter ₃

If other, please write how you were given your test results.....
.....

E11. Would you have liked to have been given your test results in a different way?

Please tick one box

- Yes ₁ No ₂
-

If yes, how would you have liked to have been given your test results

.....

E12. Did the doctor or nurse explain your test results 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

E13. Did the doctor or nurse give you a telephone number to ring if you need any help or advice, or have any questions about your condition (e.g. for talking to a specialist prostate cancer nurse, oncology nurse)?

Please tick one box

Yes ₁ No ₂

E14. Did a doctor or nurse discuss with you the possible side effects of your treatment (e.g. incontinence, impotence)?

Please tick one box

Yes ₁

No ₂

I did not have any side effects ₃

E15. Did the doctor or nurse ask you if you had any of the following needs?

Please tick one box on each line

	Yes	No
Emotional (e.g. patient support group)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
Spiritual/religious (e.g. someone to talk to)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
Financial (e.g. benefits available)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
Day-to-day (e.g. help with housework)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂

E16. Have staff in different places worked well together when caring for you for this condition (e.g. information about you passed on, no unnecessary delays)?

Please tick one box on each line

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

Please write any comment(s) you would like to make here.....

.....

E17. Overall, did you have confidence and trust in the doctor(s) and nurse(s) that you saw?

Please tick one box in each column

	Doctor(s)	Nurse(s)
Yes, all of them	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
Yes, some of them	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, none of them	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
No opinion/not applicable	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄

E18. Overall, did the doctor(s)/nurse(s)/receptionist(s) treat you with respect and dignity?

Please tick one box in each column

	Doctor(s)	Nurse(s)	Receptionist(s)
Yes, all of them	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
Yes, some of them	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, none of them	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
No opinion/not applicable	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄

E19. Overall, how would you rate the quality of care provided by your GP's practice and/or hospital while you are being monitored?

Please tick one box

Very good	<input type="checkbox"/> ₁
Good	<input type="checkbox"/> ₂
Fair	<input type="checkbox"/> ₃
Poor	<input type="checkbox"/> ₄
Very poor	<input type="checkbox"/> ₅

Please write any comment(s) you would like to make here

.....

.....

SECTION F

About you and your health

It will help us put your answers in context, so that the NHS know if different groups of people have different requirements.

About your health

F1. Please write the month and year when you were last tested for prostate cancer (e.g. PSA blood test)

Month Year

F2. If you have been actively treated for prostate cancer please write the month and year of your last treatment.

Month Year

I have not been treated for prostate cancer (please tick the box)

F3. Overall, please show how good or bad your general health is today, in your opinion by ticking one box below.

Please tick one box

Very good	<input type="checkbox"/>	1
Good	<input type="checkbox"/>	2
Fair	<input type="checkbox"/>	3
Poor	<input type="checkbox"/>	4
Very poor	<input type="checkbox"/>	5

About you

F4. Which age range are you in?

Please tick one box

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

F5. How would you describe your ethnic origin?

Please tick one box

White

- ₁ White British
- ₂ White Irish
- ₃ Any other White background

Mixed

- ₄ White & Black Caribbean
- ₅ White & Black African
- ₆ White & Asian
- ₇ Any other Mixed background

Asian or Asian British

- ₈ Indian
- ₉ Pakistani
- ₁₀ Bangladeshi
- ₁₁ Any other Asian background

Black or Black British

- ₁₂ Caribbean
- ₁₃ African
- ₁₄ Any other Black background

Chinese or other ethnic group

- ₁₅ Chinese
- ₁₆ Any other ethnic group (please write below the group)

F6. Do you have someone to support and/or care for you?

If you have more than one carer can you please just identify who your main carer is by ticking one box below.

Please tick one box

- Wife/partner ₁
- Other family member/relative ₂
- Friend ₃
- No, I do not need someone to support and/or care for me ₄
- No, but I would like someone to support and/or care for me ₅
- Other (please write below their relationship to you)

.....

F7. Do you need someone to translate or interpret for you (e.g. sign language) when you see the doctor or nurse?

Please tick one box

- Yes, I need someone to translate ₁
- Yes, I need a sign language interpreter ₂
- No ₃

F8. How would you describe your own current situation?

Please tick one box

- Employed (full-time, part-time, self-employed) ₁
- Unemployed ₂
- Retired ₃
- Unable to work due to ill health or disability ₄

Looking after the family, home dependents 5
Student 6
Other (please write below what it is)

.....

F9. Is the house/flat/other place where you live?

Please tick one box

Owned by you (with or without a mortgage) 1
Rented 2
Residential home or sheltered housing 3
Other (please write below what it is) 4

.....

F10. Including yourself, how many people live in your household who are aged 18 or over?

Please write in the number

F11. How many cars are there in your household?

Please tick one box

Yes, one 1 Yes, two or more 2 No 3

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

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

APPENDIX 8

Prostate Cancer Questionnaire - Patients PCQ-Pv3

PROSTATE QUESTIONNAIRE YOUR VIEWS ABOUT YOUR HEALTH CARE (PCQ-P)

Pilot v3.1 • November 2006

You have been 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.

Please note we have selected patients from your hospital who have been tested for prostate cancer. While every effort is made to ensure this questionnaire is not sent to anyone who has not been tested for prostate cancer, as with any system errors may occur. If you have been sent this questionnaire by mistake, please accept our apologies and return it to us indicating this.

Please complete all those sections that apply to your experience of care. If there are any questions you do not wish to answer please leave blank. You do not need to give your name and your answers will be treated in strict confidence.

Please post back the completed questionnaire booklet in the pre-paid envelope provided. Thank you for your help.

If you have any questions regarding the questionnaire, please contact either Paul Sinfield or Shona Agarwal (Researchers) on 0116 258 4874.



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University of
Leicester

SECTION A

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

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

Please tick one box

To the GP's practice ₁

To the local assessment centre/clinic ₂

To the hospital ₃

IF TO THE HOSPITAL, PLEASE GO TO SECTION B

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 (eg. problems with urinating, blood in urine, back pain)

Part of a general health check

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

Other (please write below what it was)

.....

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. Did you have a PSA blood test and/or a DRE (digital rectal examination) at the GP's practice/local assessment centre before being referred to hospital?

Please tick one box on each line

PSA Yes ₁ No ₂

DRE Yes ₁ No ₂

IF YOU HAVE TICKED NO TO PSA BLOOD TEST AND DRE, PLEASE GO TO QUESTION A12

A5. 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

A6. Did the doctor or nurse explain:

Please tick one box on each line

	Yes	No	I did not have this test
How the DRE test would be carried out?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
That the PSA test is not always reliable?	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂

A7. Did the doctor or nurse explain what would happen if the results were abnormal?

Please tick one box

Yes ₁ No ₂

A8. Did the doctor or nurse offer you any written information about the test(s)?

Please tick one box

Yes ₁ No ₂

A9. Were you given a choice about whether you wanted to be tested for prostate cancer?

Please tick one box

Yes	<input type="checkbox"/> ₁
To some extent	<input type="checkbox"/> ₂
No, not really	<input type="checkbox"/> ₃

A10. Did the doctor or nurse clearly explain your test results?

Please tick one box

Yes, the explanation was clear	<input type="checkbox"/> ₁
Yes, but the explanation could have been clearer	<input type="checkbox"/> ₂
No explanation was given	<input type="checkbox"/> ₃

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

Please tick one box

Yes	<input type="checkbox"/> ₁
To some extent	<input type="checkbox"/> ₂
No, not really	<input type="checkbox"/> ₃

A12. How long was it from your first visit to the GP's practice/local assessment centre until it was 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 SECTION F

A13. How did you feel about the time the GP's practice/local assessment centre took 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
- I did not want/need an explanation 4

A15. Did the doctor or nurse give you a choice of :

Please tick one box on each line

- | | Yes | No |
|-------------------------------------|----------------------------|----------------------------|
| Which hospital you wanted to go to? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| The date you wanted to be seen on? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |

A16. Were you asked if you had any needs when the referral arrangements were made (e.g. transport needs, time of appointment)?

Please tick one box

- Yes 1
- No 2

A17. Did the doctor or nurse tell you how soon you would be seen at the hospital?

Please tick one box

Yes ₁
No ₂

A18. Overall, did you have confidence in the doctor or nurse that you saw at the GP's practice/local assessment centre?

Please tick one box in each column

	Doctor	Nurse
Yes, completely	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
Yes, to some extent	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, not very much	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
No, none at all	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄
Not applicable	<input type="checkbox"/> ₅	<input type="checkbox"/> ₅

A19. Overall, were you treated with respect and dignity by the staff at the GP's practice/local assessment centre?

Please tick one box in each column

	Doctor(s)	Nurse(s)	Receptionist(s)
Yes, by all of them	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
Yes, by some of them	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, by none of them	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
Not applicable	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄

A20. Overall, how would you rate the quality of care provided by your GP/local assessment centre during this stage of finding out what was wrong with you?

Please circle one of the numbers

0 1 2 3 4 5 6 7 8 9 10

Worst experience  Best experience

Please write any comment(s) you would like to make here

.....
.....

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 (Please write below who it was) ₄
-

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

Please tick as many boxes as apply

- TRUS/Biopsy
- Urine flow
- PSA*¹
- DRE*²
- Scans (e.g. MRI, CT)
- I did not have any tests at this hospital

If other, please write the name(s) of the test(s) here

.....

.....

*¹ Prostate Specific Antigen blood test *² Digital Rectal Examination or internal examination

IF YOU DID NOT HAVE ANY TESTS AT THIS HOSPITAL, PLEASE GO TO SECTION C

B3. Were you advised that it might be helpful if someone (e.g. wife/partner, relative) could attend the hospital appointment when you went for your tests?

Please tick one box

- Yes ₁ No ₂

B4. How long did you wait between the date you were referred and the date of your first appointment for tests 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

B5. How did you feel about the length of time you had to wait for your first appointment for tests at the hospital?

Please tick one box

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

B6. Did you experience any problems with your hospital visit(s)?

Please tick as many boxes as apply

- Appointment cancelled or postponed
 - Getting there (e.g. transport)
 - Finding a parking space
 - Kept waiting (e.g. more than 30 minutes)
 - Inconvenient appointment time
 - Availability of your medical notes for doctors when required
 - Cleanliness
 - Other (please write below what it was)
-

B7. How would you rate the hospital facilities?

Please tick one box on each line

	Very good	Good	Satisfactory	Poor	Not applicable/ Don't know
Waiting area	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Availability of refreshments	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Toilets	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
Rooms where the tests were carried out	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

Please write any comment(s) you would like to make here

.....

.....

B8. Did you have enough privacy while the doctor or nurse was examining/testing you?

Please tick one box

- Yes ₁
- No ₂

If no, please write the name(s) of the examination/test(s) here

.....

.....

B9. 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

B10. Did the doctor or nurse explain to you what each test would involve?

Please tick one box on each line

	Yes, the explanation was clear	Yes, but the explanation could have been clearer	No explanation was given	I didn't have this test
TRUS/Biopsy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Urine flow	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
PSA* ¹	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
DRE* ²	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Scans (MRI, CT)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

*¹ Prostate Specific Antigen blood test *² Digital Rectal Examination or internal examination

IF YOU HAVE HAD MORE THAN ONE BIOPSY, PLEASE ANSWER THE FOLLOWING QUESTIONS FROM THE EXPERIENCE OF YOUR MOST RECENT BIOPSY.

B11. 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 B14

B12. When you had your biopsy were you offered a local anaesthetic?

Please tick one box

Yes ₁

No ₂

B13. Did the doctor or nurse clearly explain that you may need medication (e.g. antibiotics) to control any infections caused by the biopsy?

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 clearly 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

B15. 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

B16. Did the doctor or nurse clearly explain to you what would happen next?

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. Overall, were you treated with respect and dignity by the staff at the hospital?

Please tick one box in each column

	Doctor(s)	Nurse(s)	Receptionist(s)
Yes, by all of them	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁	<input type="checkbox"/> ₁
Yes, by some of them	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂	<input type="checkbox"/> ₂
No, by none of them	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃	<input type="checkbox"/> ₃
Not applicable	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄	<input type="checkbox"/> ₄

SECTION C

Getting the diagnosis

C1. Were you given your diagnosis at the hospital named on the front of the questionnaire?

Please tick one box

Yes ₁

No ₂

IF NO, PLEASE GO TO SECTION D

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 the 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. Did the doctor or nurse clearly explain your diagnosis?

Please tick one box

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

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. Were you diagnosed with prostate cancer?

Please tick one box

- Yes ₁
- No ₂

IF NO, PLEASE GO TO SECTION F

C9. Did the doctor or nurse clearly 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
- I did not want/need an explanation ₄

C10. Did the doctor or nurse clearly 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
- I did not want/need an explanation ₄

C11. 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

C12. 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 test results with the specialist nurse ₄

C13. Were you given any written information about your diagnosis?

Please tick one box

- Yes ₁
- No ₂

C14. Which treatment options were discussed with you after you were given your diagnosis?

Please tick as many boxes as apply

- Prostatectomy*¹
- Radiotherapy
- Hormone therapy*²
- Brachytherapy*³
- Cryotherapy*⁴
- Watchful waiting/active monitoring
- Other (please write below what it was)

.....

*¹ Surgery to remove the prostate, including key hole surgery.

*² A series of injections or tablets (e.g. Zoladex).

*³ A type of internal radiation therapy in which radioactive materials are placed in direct contact with the tissue being treated.

*⁴ A technique that uses an extremely cold liquid or instrument to freeze and destroy abnormal cells.

C15. 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

C16. Did the doctor or nurse clearly 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 clearly 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 clearly explain what could be done about the 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
- I did not want/need an explanation ₄

C19. Did the doctor or nurse clearly explain why the other treatment options were not suitable for 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
- I did not want/need an explanation ₄

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

Please tick one box on each line

- | | Yes | No |
|---|---------------------------------------|---------------------------------------|
| The treatment options? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| The possible side effects or consequences of the treatment options? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |

C21. How do you feel about the length of time between being given your treatment options and discussing your treatment decision?

Please tick one box

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

C22. Did the doctor or nurse encourage you to take your time before making a decision about which treatment to have?

Please tick one box

- Yes ₁
- No ₂
- The treatment decision was made by the doctor ₃

C23. 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 (please write below who it was)
-

* including when they have consulted their team

C24. 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

C25. Were you confident that the treatment decision was the best one for your partner/relative/friend?

Please tick one box

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

SECTION D

Your treatment

D1. Which treatment have you most recently had?

Please tick as many boxes as apply

- Prostatectomy*¹
 - Radiotherapy (completed/ongoing)
 - Hormone therapy*² (completed/ongoing)
 - Brachytherapy*³
 - Cryotherapy*⁴
 - No active treatment (eg. active monitoring)
 - Other (please write below what it was)
-

**IF NO ACTIVE TREATMENT,
PLEASE GO TO SECTION E**

*¹ Surgery to remove the prostate, including key hole surgery.
*² A series of injections or tablets (e.g. Zoladex).
*³ A type of internal radiation therapy in which radioactive materials are placed in direct contact with the tissue being treated.
*⁴ A technique that uses an extremely cold liquid or instrument to freeze and destroy abnormal cells.

D2. Where did you have your most recent treatment?

Please tick as many boxes as apply

- At the hospital named at the front of the questionnaire
- At another hospital (please write below the details)
- Name of the hospital
- Town/City
- At the GP's practice

D3. Were you an NHS patient or private patient?

Please tick one box

- NHS patient (treatment was free) ₁
- Private patient (treatment was paid for) ₂

IF PRIVATE PATIENT, PLEASE GO TO SECTION E

D4. 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 and up to 8 weeks 4
- More than 8 weeks 5

D5. How did you feel about the length of the time you had to wait for your treatment to start?

Please tick one box

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

D6. Before you started your treatment, did a doctor or nurse give you information about the treatment to help you feel prepared (eg. 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

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. While you were receiving treatment were you able to discuss any concerns about your treatment with the doctor or nurse?

Please tick one box

- Yes 1
- No 2
- I did not have any concerns 3

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

Please tick as many boxes as apply

- Appointment cancelled or postponed
- Getting there (e.g. transport)
- Finding a parking space
- Kept waiting (e.g. more than 30 minutes)
- Inconvenient appointment time
- Availability of your medical notes for doctors when required
- Cleanliness
- Ward noise
- Other

If other, please write here any other problems experienced

.....

D10. How would you rate the following?

Please tick one box on each line

- | | Very good | Good | Satisfactory | Poor | Not applicable/
Don't know |
|---|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Treatment | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| Nursing | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| Food/drink | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| Ward (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 |

D11. At the hospital, were your spiritual needs met (e.g. appropriate food, prayer room)?

Please tick one box

- Yes ₁
- To some extent ₂
- No, not really ₃
- Not applicable ₄

D12. While you were being treated, do you think that the hospital staff 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

D13. Did the doctor or nurse give you any information about complementary therapies (e.g. diet/diet supplements/acupuncture/massage/reflexology)?

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

D14. 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

D15. 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
- He has not finished his treatment 4

D16. Did 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

D17. Did a doctor or nurse discuss with you how to manage any potential side effects of the treatment (eg. continence, problems with sex, pain)

Please tick one box

- Yes 1
- To some extent 2
- No, not really 3
- Not applicable 4

D18. Were you given equipment or supplies (e.g. continence pads) to use at home to help you care for yourself?

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

D19. Did a doctor or nurse discuss whether you might need any extra day to day help (eg. help with housework)?

Please tick one box

- Yes ₁
- No ₂

D20. Did a doctor or nurse organise the aftercare services that you needed (e.g. district nurse, physiotherapist)?

Please tick one box

- Yes ₁
- No ₂
- I did not need any aftercare services ₃

D21. Did the doctor or nurse offer you any financial information on welfare or benefits?

Please tick one box

- Yes ₁
- No ₂

D22. 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 (eg. 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, DRE/internal examination)?

Please tick one box

Yes ₁

No ₂

IF NO, PLEASE GO TO SECTION F

E2. Where do you usually discuss the results of your tests (e.g. PSA blood test, DRE)?

Please tick one box

At the hospital named at the front of the questionnaire ₁

At another hospital (please write below the details) ₂

Name of the hospital

Town/City

GP's practice ₃

E3. Did the doctor or nurse clearly 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

I did not want/need an explanation ₄

E4. How often are you currently tested for prostate cancer?

Please tick one box

Every three months ₁

Every six months ₂

Every year ₃

Other (please write below what it is) ₄

.....

E5. Has a 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

E6. 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

E7. Were you offered a choice of how to be given your test results (eg. face to face, by telephone)?

Please tick one box

Yes ₁ No ₂

E8. Has the doctor or nurse clearly explained what can affect your PSA levels (eg. exercise, ejaculation)?

Please tick one box

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

E9. Does the doctor clearly explain what the test results mean?

Please tick one box

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

E10. Has the doctor or nurse given you a telephone number to ring if you need any help or advice, or have any questions about your condition (e.g. for talking to a specialist nurse)?

Please tick one box

Yes ₁ No ₂

E11. Do you know how to get advice and help in managing symptoms or side effects of treatment (eg. continence, problems with sex, pain)?

Please tick one box

Yes ₁
No ₂
I do not have any side effects ₃

E12. Are staff in different places working well together when monitoring you for this condition (e.g. information about you passed on, no unnecessary delays)?

Please tick one box on each line

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

SECTION F

About you and your health

This information will help us put your answers in context, and show whether different groups of people have different requirements.

About your health

F1. Have you been actively treated for prostate cancer in the past year?

Please tick one box

Yes ₁ No ₂

F2. Have you been tested for prostate cancer in the past year?

Please tick one box

Yes ₁ No ₂

F3. Overall, please show how good or bad your general health is today, in your opinion by ticking one box below.

Please tick one box

Very good ₁

Good ₂

Fair ₃

Poor ₄

Very poor ₅

About you

F4. Which age range are you in?

Please tick one box

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

F5. Do you have someone to support and/or care for you (eg. wife/relative)?

Please tick one box

Yes ₁ No ₂

F6. How would you describe your ethnic origin?

Please tick one box

White

- ₁ White British
- ₂ White Irish
- ₃ Any other White background

Mixed

- ₄ White & Black Caribbean
- ₅ White & Black African
- ₆ White & Asian
- ₇ Any other Mixed background

Asian or Asian British

- ₈ Indian
- ₉ Pakistani
- ₁₀ Bangladeshi
- ₁₁ Any other Asian background

Black or Black British

- ₁₂ Caribbean
- ₁₃ African
- ₁₄ Any other Black background

Chinese or other ethnic group

- ₁₅ Chinese
- ₁₆ Any other ethnic group (please write below the group)

F7. Do you need someone to translate or interpret for you (e.g. sign language) when you see the doctor or nurse?

Please tick one box

- Yes, I need someone to translate ₁
- Yes, I need a sign language interpreter ₂
- No ₃

F8. How would you describe your own current situation?

Please tick one box

- Employed (full-time, part-time, self-employed) ₁
- Unemployed ₂
- Retired ₃
- Unable to work due to ill health or disability ₄
- Looking after the family, home dependents ₅
- Student ₆
- Other (please write below what it is)

.....

The following questions refer to your current main job, or (if you are not working now) to your last main job. Please tick one box only per question.

F9. Do (did) you work as an employee or are (were) you self-employed?

- Employee ₁
- Self-employed with employees ₂
- Self-employed / freelance without employees (go to question F12) ₃

F10. For employees: indicate below how many people work (worked) for your employer at the place where you work (worked).

For self-employed: indicate below how many people you employ (employed). Go to question F12 when you have completed this question.

1 to 24 ₁

25 or more ₂

F11. Do (did) you supervise any other employees?

A supervisor or foreman is responsible for overseeing the work of other employees on a day-to-day basis

Yes ₁ No ₂

F12. Please tick one box to show which best describes the sort of work you do.

(If you are not working now, please tick a box to show what you did in your last job).

Please tick one box

Modern professional occupations ₁

such as: teacher - nurse - physiotherapist - social worker - welfare officer - artist - musician - police officer (sergeant or above) - software designer

Clerical and intermediate occupations ₂

such as: secretary - personal assistant - clerical worker - office clerk - call centre agent - nursing auxiliary - nursery nurse

Senior managers or administrators ₃

(usually responsible for planning, organising and co-ordinating work and for finance) such as: finance manager - chief executive

Technical and craft occupations ₄

such as: motor mechanic - fitter - inspector - plumber - printer - tool maker - electrician - gardener - train driver

Semi-routine manual and service occupations ₅

such as: postal worker - machine operative - security guard - caretaker - farm worker - catering assistant - receptionist - sales assistant

Routine manual and service occupations ₆

such as: HGV driver - van driver - cleaner - porter - packer - sewing machinist - messenger - labourer - waiter / waitress - bar staff

Middle or junior managers ₇

such as: office manager - retail manager - bank manager - restaurant manager - warehouse manager - publican

Traditional professional occupations ₈

such as: accountant - solicitor - medical practitioner - scientist - civil / mechanical engineer

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

APPENDIX 9

Structured evaluation
form: criterion validity

Structured evaluation form: criterion validity

A. About the questionnaire	
A1. What is the title of the questionnaire?	
A2. Which organisation(s) developed the questionnaire	
A3. When was it developed (year)?	
A4. Where is it from? (circle one of the options)	<i>UK</i> <i>US</i> <i>Other</i>
A5. Is it a local initiative (e.g. just one hospital), or national?	<i>Local</i> <i>National/international</i>
B. Appropriateness/relevance	
B1. Is the questionnaire specific to prostate cancer	<i>specific to prostate cancer</i> <i>generic cancer</i> <i>general patient population</i> <i>other (give details):</i>
B2. What stages of care does the questionnaire cover?	<i>specific stage e.g. inpatient</i> <i>several stages e.g. outpatient, inpatient</i> <i>general overview of care</i> <i>other (give details):</i>
B3. What does the questionnaire measure?	<i>patient experience</i> <i>patient satisfaction</i> <i>other (give details):</i>
B4. What type of questions?	<i>report</i> <i>rating</i> <i>mix of both</i> <i>other (give details):</i>

C. Reliability / validity	
C1. Evidence of reliability (cronbach's alpha / test-retest reliability)	Yes No <i>Details:</i>
C2. Evidence of validity (Content e.g. patient involvement/assessment of measure; Construct e.g. relationships between patterns of score such as age and satisfaction; Criterion e.g. comparison with other standard questionnaires)	Yes No <i>Details:</i>
C3. Evidence for responsiveness (sensitivity to change)	Yes No <i>Details:</i>
C4. Respondent burden (high = more than about 5 mins to complete)	<i>High Low</i> <i>Details (e.g. how many questions, how long does it take to complete?):</i>
C5. Are there dimensions / themes i.e. clusters of questions on the same issue?	Yes, statistically validated (e.g. factor analysis) Yes, not statistically validated No <i>Details:</i>
D. Any other comments about questionnaire	

APPENDIX 10

The National Survey of NHS Patients Short Questionnaire (NCSR v3.2 and v3.3)

The National Survey of NHS Patients Short Questionnaire

NCSR Version 3.2

This questionnaire is similar to the other questionnaire that you have been asked to fill in (the PCQ-P questionnaire). We have asked you to fill in these two questionnaires to find out if people report their experiences in similar or different ways. Please complete all the questions that apply to you.

Please think about your hospital visits for treatment and/or monitoring of prostate cancer when you fill in this questionnaire

Part A: Your most recent hospital visit

A1. These questions are about your most recent visit to the hospital named on the front of the questionnaire.

Please write in below the date of your most recent visit to this hospital:

Day Month Year

A2. During this visit, in your opinion, were there enough **doctors** on duty to care for you in hospital?

Tick ONE only

There were **always** or **nearly always** enough doctors on duty ₁

There were **sometimes** enough doctors on duty ₂

There were **rarely** or **never** enough doctors on duty ₃

A3. During this visit, in your opinion, were there enough **nurses** on duty to care for you in hospital?

Tick ONE only

There were **always** or **nearly always** enough nurses on duty ₁

There were **sometimes** enough nurses on duty ₂

There were **rarely** or **never** enough nurses on duty ₃

Part B Outpatient appointments

Thinking about visits to be TESTED for prostate cancer

B1. Have you had an **out-patient** appointment to be tested for this condition, at the hospital named on the front of the questionnaire, **in the last 2 years**?

Tick ONE only

Yes ₁ **Go to B2**

No ₂ **Go to C1**

B2. When was your **most** recent out-patient appointment to be tested for this condition?

Please write in the month and year. If you are not sure, please give your best guess.

Month Year

B3. Was this **most** recent out-patient appointment ever cancelled or postponed by the hospital? *Tick ONE only*

- Yes the appointment was cancelled or postponed **once** 1
- Yes the appointment was cancelled or postponed **more than once** 2
- No, the appointment was **not** cancelled or postponed by the hospital 3
- Can't remember 8

B4. How long did you **wait, after your appointment time**, before seeing a doctor at the out-patient clinic on this occasion? *Tick ONE only*

- Less than 10 minutes 01 **Go to B5**
- 10 minutes or more, but less than 20 minutes 02 **Go to B5**
- 20 minutes or more, but less than 30 minutes 03 **Go to B5**
- 30 minutes or more, but less than 1 hour 04 **Go to B5**
- 1 hour or more 05 **Go to B5**
- Can't remember 06 **Go to B5**
- Did not see a doctor 08 **Go to B8**

B5. **How much time** did the doctor spend with you during this out-patient appointment? *Tick ONE only*

- Less than 10 minutes 1
- 10 minutes or more, but less than 20 minutes 2
- 20 minutes or more, but less than 30 minutes 3
- 30 minutes or more, but less than 1 hour 4
- 1 hour or more 5
- Can't remember 8

B6. Do you feel that the time that the doctor spent with you on this occasion was too long, too short, or about right?

Tick ONE only

- Too long 1
Too short 2
About right 3
Can't remember 4
-

B7. Did you have **confidence and trust** in the hospital doctor who saw you as an outpatient on this occasion?

Tick ONE only

- Yes, a lot 1
Yes, a fair amount 2
Not very much 3
None at all 4
Can't say 8
-

B8. Did you have enough privacy when discussing your condition or treatment with the doctors or nurses as an outpatient on this occasion?

Tick ONE only

- Yes 1
No 2
There were no discussions 3
-

B9. Were you treated with respect and dignity by the **doctors or nurses** as an out-patient on this occasion?

Tick ONE only

- Yes 1
No 2
-

Part C: Finding out what was wrong with you

C1. When did you **first** notice signs or symptoms of this condition?

Please write in the month and year. If you are not sure, please give your best guess.

Month Year

C2. Had you visited a General Practitioner (GP) about this condition at any point **before** you attended hospital?

Yes ₁ **Go to C3**

No ₂ **Go to C4**

C3. After visiting your GP about this condition, how long did you have to wait before you had your **first** appointment with a **hospital doctor**?

Tick ONE only

Was seen by hospital doctor/consultant the same day or next day ₀₁

More than 2 days, but within 1 week ₀₂

More than 1 week, but within 2 weeks ₀₃

More than 2 weeks, but within 1 month ₀₄

More than 1 month, but within 3 months ₀₅

More than 3 months, but within 6 months ₀₆

More than 6 months, but within 1 year ₀₇

More than 1 year ₀₈

Can't remember ₉₈

C4. Were you told what was wrong with you **during** this first hospital appointment, or **before** or **after** this first hospital appointment?

Tick ONE only

Told **during** this first hospital appointment ₀₁ **Go to C5**

Told **before** this first hospital appointment ₀₂ **Go to C5**

Told **after** this first hospital appointment:

1 day to 2 weeks **after** ₀₃ **Go to C5**

More than 2 weeks, up to 1 month **after** ₀₄ **Go to C5**

More than 1 month, up to 3 months **after** ₀₅ **Go to C5**

More than 3 months, up to 6 months **after** ₀₆ **Go to C5**

More than 6 months **after** ₀₇ **Go to C5**

Have not been told what is wrong with me ₀₈

If you have not been told what is wrong with you, please do not answer any more questions, and return the questionnaire

C5. Were you told what was wrong with you in person, over the telephone, or in a letter?

Tick ONE only

In person ₁

Over the telephone ₂

In a letter ₃

C6. How much time was spent telling you what was wrong with you?

Tick ONE only

Less than 10 minutes ₁

10 minutes or more, but less than 30 minutes ₂

30 minutes or more, but less than 1 hour ₃

1 hour or more ₄

Can't remember ₈

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

Please return this questionnaire, along with the other questionnaires, in the envelope provided

The National Survey of NHS Patients Short Questionnaire

NCSR Version 3.3

This questionnaire is similar to the other questionnaire that you have been asked to fill in (the PCQ questionnaire). We have asked you to fill in these two questionnaires to find out if people report their experiences in similar or different ways. Please complete all the questions that apply to you.

Please think about your hospital visits for treatment and/or monitoring of prostate cancer when you fill in this questionnaire

Part A: Your most recent hospital visit

A1. These questions are about your most recent visit to the hospital named on the front of the questionnaire.

Please write in below the date of your most recent visit to this hospital:

Day Month Year

A2. During this visit, in your opinion, were there enough **doctors** on duty to care for you in hospital?

Tick ONE only

There were **always** or **nearly always** enough doctors on duty 1

There were **sometimes** enough doctors on duty 2

There were **rarely** or **never** enough doctors on duty 3

A3. During this visit, in your opinion, were there enough **nurses** on duty to care for you in hospital?

Tick ONE only

There were **always** or **nearly always** enough nurses on duty 1

There were **sometimes** enough nurses on duty 2

There were **rarely** or **never** enough nurses on duty 3

Part B: Your first hospital treatment

Thinking about the **FIRST** hospital visit which involved being **TREATED** for prostate cancer

B1. Was the date of this **first** hospital visit ever cancelled or postponed **by the hospital**?

Tick ONE only

Yes, the appointment was cancelled or postponed **once** 1

Yes, the appointment was cancelled or postponed **more than once** 2

No, the appointment was **not** cancelled or postponed by the hospital 3

Can't remember 4

B2. During this visit, did you have confidence and trust in the **hospital doctors** who treated you? *Tick ONE only*

Yes, in all of them 1

Yes, in some of them 2

No, in none of them 3

B3. During this visit, did you have confidence and trust in the **nurses** who were caring for you? *Tick ONE only*

Yes, in all of them 1

Yes, in some of them 2

No, in none of them 3

B4. How much of the time were you treated with respect and dignity by the **doctors and nurses and other hospital staff**? *Tick ONE only*

Always 1

Most of the time 2

Only some of the time 3

Never 4

B5. During this visit, did the hospital doctors or nurses discuss **the purpose** of your operation or treatment? *Tick ONE only*

Yes, and I **completely** understood what was said 1

Yes, and I understood **some** of what was said 2

Yes, but I **did not understand** what was said 3

No, the purpose was **not discussed** at all 4

I did not want to discuss it 5

Can't remember 8

B6. During this visit, were you asked to sign a consent form for your treatment?

Yes 1

No 2

Can't remember 8

B7. Were you ever in any pain or discomfort during this visit?

Yes 1

No 2

Part C: Leaving hospital

Still thinking about the **FIRST** hospital visit which involved being **TREATED** for prostate cancer

C1. Before you left hospital on that occasion, did the hospital doctors or nurses spend enough time telling you what would happen after you left hospital?

Tick ONE only

Yes, they spent enough time 1

No, they spent some time, but not enough 2

No, they spent no time at all 3

C2. Before you left hospital, were you given any **written** or **printed** information about what you should or should not do after leaving hospital?

Tick ONE only

Yes 1

No 2

Can't remember 3

Part D: Outpatient appointments

Thinking about being treated or monitored for prostate cancer

D1. Have you had an **out-patient** appointment for this condition, at **any** hospital, **in the last 2 years**?

Tick ONE only

Yes 1 **Go to D2**

No 2

If No, please do not answer any more questions, and return the questionnaire

D2. When was your **most** recent out-patient appointment for this condition?

Please write in the month and year. If you are not sure, please give your best guess.

Month

Year

D3. Was this **most** recent out-patient appointment ever cancelled or postponed by the hospital? *Tick ONE only*

- Yes the appointment was cancelled or postponed **once** 1
- Yes the appointment was cancelled or postponed **more than once** 2
- No, the appointment was **not** cancelled or postponed by the hospital 3
- Can't remember 8

D4. How long did you **wait, after your appointment time**, before seeing a doctor at the out-patient clinic on this occasion? *Tick ONE only*

- Less than 10 minutes 01 **Go to D5**
- 10 minutes or more, but less than 20 minutes 02 **Go to D5**
- 20 minutes or more, but less than 30 minutes 03 **Go to D5**
- 30 minutes or more, but less than 1 hour 04 **Go to D5**
- 1 hour or more 05 **Go to D5**
- Can't remember 06 **Go to D5**
- Did not see a doctor 08 **Go to D8**

D5. **How much time** did the doctor spend with you during this most recent out-patient appointment? *Tick ONE only*

- Less than 10 minutes 1
- 10 minutes or more, but less than 20 minutes 2
- 20 minutes or more, but less than 30 minutes 3
- 30 minutes or more, but less than 1 hour 4
- 1 hour or more 5
- Can't remember 8
-

D6. Do you feel that the time that the doctor spent with you on this occasion was too long, too short, or about right?

Tick ONE only

- Too long 1
Too short 2
About right 3
Can't remember 4
-

D7. Did you have **confidence and trust** in the hospital doctor who saw you as an outpatient on this occasion?

Tick ONE only

- Yes, a lot 1
Yes, a fair amount 2
Not very much 3
None at all 4
Can't say 8
-

D8. Did you have enough privacy when discussing your condition or treatment with the doctors or nurses as an outpatient on this occasion?

Tick ONE only

- Yes 1
No 2
There were no discussions 3
-

D9. Were you treated with respect and dignity by the **doctors or nurses** as an out-patient on this occasion?

Tick ONE only

- Yes 1
No 2
-

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

Please return this questionnaire, along with the other questionnaires, in the envelope provided

APPENDIX 11

Prostate Care Questionnaire - Patients PCQ-Pv4

MEASURING PROSTATE CANCER EXPERIENCE YOUR VIEWS ABOUT YOUR HEALTH CARE (PCQ-P)

Pilot v4.0 • May 2007
Patient

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 sent to anyone who has not been tested for prostate cancer, as with any system errors may occur. If you have been given/sent this questionnaire by mistake, please accept our apologies and return it to us indicating this.

Please complete all those sections that apply to your experience of care. If there are any questions you do not wish to answer please leave blank. You do not need to give your name and your answers will be treated in strict confidence.

Please return the completed questionnaire booklet. Thank you for your help.

If you have any questions regarding the questionnaire, please contact the person named on the information sheet.



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

This questionnaire was designed by



SECTION A

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

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

Please tick one box

To the GP's practice ₁

To the local assessment centre/clinic ₂

To the hospital ₃

IF TO THE HOSPITAL, PLEASE GO TO SECTION B

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. 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 being referred to hospital?

Please tick one box on each line

	Yes	No
PSA blood test	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂

Digital Rectal Examination (where a doctor or nurse feels your prostate using their finger)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
---	---------------------------------------	---------------------------------------

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

A5. 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

A6. Were you given information about being tested for prostate cancer (e.g. what the tests would involve)?

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

A7. Did the doctor or nurse explain what would happen if the results were abnormal?

Please tick one box

- Yes ₁ No ₂

A8. Did the doctor or nurse offer you any WRITTEN information about being tested for prostate cancer?

Please tick one box

- Yes ₁ No ₂

A9. 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

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 SECTION F

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
- I did not want/need an explanation ₄

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

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

- TRUS/Biopsy
- 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 SECTION F

Please answer the following questions from your experience of being tested at the hospital named on the front of the questionnaire

B3. Were you advised that it might be helpful if someone (e.g. wife/partner, relative) could attend the hospital appointment when you went for your tests?

Please tick one box

- Yes ₁ No ₂

B4. How long did you wait between the date you were referred and the date of your first appointment for tests 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

B5. How did you feel about the length of time you had to wait for your first appointment for tests at the hospital?

Please tick one box

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

B6. Before you were tested at the hospital, were you given written information about the tests to help you feel prepared (e.g. what your test 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, cost)
- Kept waiting (e.g. more than 30 minutes)
- Inconvenient appointment time
- Availability of your medical notes for doctors when required
- Cleanliness
- I did not have any of these problems

B8. How would you rate the hospital facilities?

Please tick one box on each line

- | | Very good | Good | Satisfactory | Poor | Not applicable/
Don't know |
|--|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Waiting area | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| Availability of refreshments | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| Toilets | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| 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 on each line

	Yes, the explanation was clear	Yes, but the explanation could have been clearer	No explanation was given	I didn't have this test
TRUS/Biopsy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Urine flow	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
PSA blood test	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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
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 etc)?

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 offer you any support while you were waiting for your diagnosis (e.g. someone to talk to about any concerns that you had)?

Please tick one box

Yes ₁ No ₂

B17. Did the doctor or nurse explain to you what would happen next?

Please tick one box

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

B18. Overall, were you treated considerably by the staff at the hospital?

Please tick one box in each column

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

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 at 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

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 the 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 SECTION F

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
- I did not want/need an explanation ₄

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
- I did not want/need an explanation ₄

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 test results with the specialist nurse ₄

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

Please tick one box

- Yes ₁ No ₂

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

Please tick one box

- At the hospital named at 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

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
- I did not want/need an explanation 4

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 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
- I did not want/need an explanation ₄

C19. Did the doctor or nurse explain why the 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
- I did not want/need an explanation ₄

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

Please tick one box on each line

- | | Yes | No |
|---|---------------------------------------|---------------------------------------|
| The treatment options? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| The possible side effects or consequences of the treatment options? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| What could be done about the side effects | <input type="checkbox"/> ₁ | <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 hospital 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)
- 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.
- No active treatment (eg. active monitoring)
- HIFU (High Intensity Frequency Ultrasound)
- Other

IF NO ACTIVE TREATMENT, PLEASE GO TO SECTION E

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 at 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

D3. Were you an NHS patient or private patient?

Please tick one box

- NHS patient (treatment was free) ₁
- Private patient (treatment was paid for) ₂

IF PRIVATE PATIENT, PLEASE GO TO SECTION E

D4. 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 and up to 8 weeks 4
- More than 8 weeks 5

D5. How did you feel about the length of the time you had to wait for your treatment to start?

Please tick one box

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

D6. 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

D7. 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

D8. 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

D9. 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

D10. 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, cost)
- Kept waiting (e.g. more than 30 minutes)
- Inconvenient appointment time
- Availability of your medical notes for doctors when required
- Cleanliness
- I did not have any of these problems

D11. How would you rate the following?

Please tick one box on each line

- | | Very good | Good | Satisfactory | Poor | Not applicable/
Don't know |
|---|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Treatment | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| Nursing | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| Food/drink | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| Room 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 |
| Ward (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 |

D12. At the hospital, were your spiritual needs met (e.g. appropriate food, prayer room)?

Please tick one box

- Yes ₁
- To some extent ₂
- No, not really ₃
- Not applicable (e.g. I was not treated in hospital) ₄

D13. 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

D14. 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

D15. Before you left the hospital or finished your treatment did the doctor or nurse explain to you what would happen next in your care (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

D16. 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

D17. 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
- Not applicable 4

D18. When you left hospital or finished your treatment were you given equipment or supplies to help you care for yourself (e.g. continence pads, pain killers)?

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

D19. When you left hospital or finished your treatment were you told how to get further equipment or supplies (e.g. continence pads, painkillers) you needed to help you care for yourself?

Please tick one box

- Yes 1 No 2

D20. 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 1
- Yes, but not as soon as I needed them 1
- No, I did not get the aftercare service I needed 2
- I did not need any aftercare services 3

D21. Did 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

D22. Did the doctor or nurse offer you any financial information on welfare or benefits?

Please tick one box

- Yes 1 No 2

D23. 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

D24. Have staff in different places worked well together when treating you for prostate cancer (e.g. information about you passed on, no unnecessary delays)?

Please tick one box on each line

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

D25. 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 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 SECTION F

- E2. Where do you usually have these tests?

Please tick one box

At the hospital named at the front of the questionnaire ₁

At another hospital (please write below the details) ₂

Name of the hospital

Town/City

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

I did not want/need an explanation ₄

- 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 the results of your tests?

Please tick one box

At the hospital named at the front of the questionnaire ₁

At another hospital (please write below the details) ₂

Name of the hospital

Town/City

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 what can affect your PSA levels (e.g. exercise, ejaculation)?

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 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

E11. Has the doctor or nurse given you a telephone number to ring if you need any help or advice, or have any questions about your condition (e.g. for talking to a specialist nurse)?

Please tick one box

Yes ₁ No ₂

SECTION F

About you and your health

This information will help us put your answers in context, and show whether different groups of people have different requirements.

F1. Overall, how good or bad is your general health is 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. How would you describe your ethnic origin?

Please tick one box

White

- ₁ White British
- ₂ White Irish
- ₃ Any other White background

Mixed

- ₄ White & Black Caribbean
- ₅ White & Black African
- ₆ White & Asian
- ₇ Any other Mixed background

Asian or Asian British

- ₈ Indian
- ₉ Pakistani
- ₁₀ Bangladeshi
- ₁₁ Any other Asian background

Black or Black British

- ₁₂ Caribbean
- ₁₃ African
- ₁₄ Any other Black background

Chinese or other ethnic group

- ₁₅ Chinese
- ₁₆ Any other ethnic group (please write below the group)

.....

F5. Do you need someone to translate or interpret for you (e.g. sign language) when you see the doctor or nurse?

Please tick one box

- Yes, I need someone to translate 1
- Yes, I need a sign language interpreter 2
- No 3

F6. How would you describe your own current situation?

Please tick one box

- Employed (full-time, part-time, self-employed) 1
- Unemployed 2
- Fully retired 3
- Unable to work due to ill health or disability 4
- Looking after the family, home dependents 5
- Student 6
- Other 7

The following questions refer to your current main job, or (if you are not working now) to your last main job. Please tick one box only per question.

F7. Do (did) you work as an employee or are (were) you self-employed?

- Employee 1
- Self-employed with employees 2
- Self-employed / freelance without employees (go to question F10) 3

F8. For employees: indicate below how many people work (worked) for your employer at the place where you work (worked).

For self-employed: indicate below how many people you employ (employed). Go to question F10 when you have completed this question.

- 1 to 24 1
- 25 or more 2

F9. Do (did) you supervise any other employees?

A supervisor or foreman is responsible for overseeing the work of other employees on a day-to-day basis

- Yes 1 No 2

F10. Please tick one box to show which best describes the sort of work you do.

(If you are not working now, please tick a box to show what you did in your last job).

Please tick one box

Modern professional occupations

such as: teacher - nurse - physiotherapist - social worker - welfare officer - artist - musician - police officer (sergeant or above) - software designer

 1

Clerical and intermediate occupations

such as: secretary - personal assistant - clerical worker - office clerk - call centre agent - nursing auxiliary - nursery nurse

 2

Senior managers or administrators

(usually responsible for planning, organising and co-ordinating work and for finance) such as: finance manager - chief executive

 3

Technical and craft occupations

such as: motor mechanic - fitter - inspector - plumber - printer - tool maker - electrician - gardener - train driver

 4

Semi-routine manual and service occupations

such as: postal worker - machine operative - security guard - caretaker - farm worker - catering assistant - receptionist - sales assistant

 5

Routine manual and service occupations

such as: HGV driver - van driver - cleaner - porter - packer - sewing machinist - messenger - labourer - waiter / waitress - bar staff

 6

Middle or junior managers

such as: office manager - retail manager - bank manager - restaurant manager - warehouse manager - publican

 7

Traditional professional occupations

such as: accountant - solicitor - medical practitioner - scientist - civil / mechanical engineer

 8

**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.**

APPENDIX 12

Prostate Care Questionnaire - Patients PCQ-P

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.**

APPENDIX 13

Scoring the questionnaires

Scoring the questionnaire

In terms of reporting the results of the questionnaire for quality improvement purposes, it is recommended that overall summary scores are produced as well as detailed frequency counts for each individual question. For the patient questionnaire, it is recommended that overall section scores are produced as well as scores for each the sub-factors identified for each section. These summary scores, accompanied by the detailed frequency data should make it easy to identify specific problem areas.

There are three main steps involved in producing section and factor scores for the final version of the questionnaire:

First raw scores must first be transformed into a 0 to 1 scale where 0 indicates a negative experience, and 1 indicates a positive experience. Hence questions with two responses (e.g. yes/no) are recoded with yes = 1 and no = 0; questions with three responses (e.g. yes, to some extent, no) are recoded with yes = 1, to some extent = 0.5 and no = 0 etc.

Second, to avoid questions with multiple sub-questions being overly weighted in the section score, a single score for each relevant question must then be produced by calculating the mean score across the sub-questions

Third, for each respondent a mean score for each section or factor can be produced by summing the recoded scores on the relevant questions and dividing this by the number of questions completed in the section or factor, then multiplying this figure by 100 to produce a score for the section or factor on a 0-100 scale:

$$\frac{\text{Sum of scores}}{\text{Number of questions completed}} \times 100$$

Scores are only calculated for respondents who have completed at least 50% of the questions in the respective section or factor.

This is relatively simple scoring system. The availability of a large data set from the questionnaire in the future would enable a more complex scoring system to be developed, to best represent the underlying factor structure of each questionnaire.

Instructions are given below for all sections of the questionnaire. Please refer to the instructions relevant to the data collected (e.g. if only sections D and E of the questionnaire have been used, ignore the references to Sections A, B and C).

1. Step 1: recode into standard scores

a. Recode all relevant questions, creating new variables (e.g. rA3, rA4 etc) Where 'missing' is indicated this refers to the standard coding for missing values (in most cases this will be 88)

	Original score	Recoded score
SECTION A: GP VISITS & REFERRAL		
A3. <i>Did the doctor or nurse take your concerns seriously?</i>	1 2 3 4	1 0.5 0 missing
A4. <i>Were you given information about being tested for prostate cancer</i>	1 2 3	1 0.5 0
A5. <i>Did the doctor or nurse explain what would happen if the results were abnormal?</i>	1 2	1 0
A6. <i>Did the doctor or nurse offer you any written information about being tested for prostate cancer?</i>	1 2	1 0
A7. <i>Were you given a choice about whether you wanted to be tested for prostate cancer?</i>	1 2 3	1 0.5 0
A9. <i>Did the doctor or nurse explain that the tests were trying to find out whether you might have prostate cancer?</i>	1 2 3	1 0.5 0
A10. <i>Did the doctor or nurse explain your test results?</i>	1 2 3	1 0.5 0
A11. <i>Did the doctor or nurse give you your test results in a considerate way?</i>	1 2 3	1 0.5 0
A13. <i>How did you feel about the time the GP's practice/local assessment centre took to refer you to hospital?</i>	1 2 3	0 1 0
A14. <i>Did the doctor or nurse explain that you were being referred to hospital to find out if you had prostate cancer?</i>	1 2 3	1 0.5 0
A15. <i>Were you told at the GP's practice how soon you would be seen at the hospital?</i>	1 2	1 0
A16a. <i>Did the doctor or nurse give you a choice of which hospital you wanted to go to / the date you wanted to be seen on?</i>	1 2	1 0
A16b. <i>Were you asked if you had any needs when the referral arrangements were made (e.g. transport needs, time of appointment)?</i>	1 2	1 0

SECTION B: TESTS AT THE HOSPITAL		
<i>B4. How did you feel about the length of time you had to wait for your first appointment at the hospital?</i>	1	0
	2	1
	3	0
<i>B5. Were you advised that it might be helpful if someone (e.g. wife/partner, relative) could attend the hospital appointment when you went for your tests?</i>	1	1
	2	0
<i>B6. Before you were tested at the hospital were you given written information about the tests to help you feel prepared?</i>	1	1
	2	0
<i>B7a. Did you experience any problems with your hospital visit(s)? appointment cancelled or postponed</i>	1 missing	0 1
<i>B7b. Did you experience any problems with your hospital visit(s)? getting there</i>	1 missing	0 1
<i>B7c. Did you experience any problems with your hospital visit(s)? parking</i>	1 missing	0 1
<i>B7d. Did you experience any problems with your hospital visit(s)? kept waiting</i>	1 missing	0 1
<i>B7e. Did you experience any problems with your hospital visit(s)? inconvenient appointment time</i>	1 missing	0 1
<i>B7f. Did you experience any problems with your hospital visit(s)? medical notes not available</i>	1 missing	0 1
<i>B7g. Did you experience any problems with your hospital visit(s)? cleanliness</i>	1 missing	0 1
<i>B8a. How would you rate: Waiting area?</i>	1	1
	2	0.67
	3	0.33
	4	0
	5	missing
<i>B8b. How would you rate: Availability of refreshments?</i>	1	1
	2	0.67
	3	0.33
	4	0
	5	missing
<i>B8c. How would you rate: Toilets?</i>	1	1
	2	0.67
	3	0.33
	4	0
	5	missing
<i>B8d. How would you rate: Rooms where the tests were carried out?</i>	1	1
	2	0.67
	3	0.33
	4	0
	5	missing
<i>B9. Did you have enough privacy while the doctor or nurse was examining/testing you?</i>	1	1
	2	0

<i>B10. Did the doctor or nurse explain that these test results were to find out if you had prostate cancer?</i>	1 2 3	1 0.5 0
<i>B11a. Explanation of what test would involve: TRUS/biopsy?</i>	1 2 3 4	1 0.5 0 missing
<i>B11b. Explanation of what test would involve: urine flow?</i>	1 2 3 4	1 0.5 0 missing
<i>B11c. Explanation of what test would involve: PSA?</i>	1 2 3 4	1 0.5 0 missing
<i>B11d. Explanation of what test would involve: DRE?</i>	1 2 3 4	1 0.5 0 missing
<i>B11e. Explanation of what test would involve: Scans (MRI, CT)?</i>	1 2 3 4	1 0.5 0 missing
<i>B12. Did the doctor or nurse explain to you that the biopsy might be painful?</i>	1 2 3 4	1 0.5 0 missing
<i>B13. When you had your most recent biopsy were you offered a local anaesthetic?</i>	1 2	1 0
<i>B14. Did the doctor or nurse explain that the biopsy may cause after-effects?</i>	1 2 3	1 0.5 0
<i>B15. Did the doctor or nurse explain to you how long you would have to wait for your test results?</i>	1 2 3	1 0.5 0
<i>B16. Did the doctor or nurse explain to you what would happen next?</i>	1 2 3	1 0.5 0
<i>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)?</i>	1 2	1 0
<i>B18a. Overall were you treated considerately by the staff at the hospital: Doctors</i>	1 2 3	1 0.5 0
<i>B18b. Overall were you treated considerately by the staff at the hospital: Nurses</i>	1 2 3	1 0.5 0

<i>B18c. Overall were you treated considerately by the staff at the hospital: Receptionists</i>	1 2 3	1 0.5 0
<i>B19a. Have staff in different places worked well together when testing you for prostate cancer: between GP's practice and hospital?</i>	1 2 3 4	1 0.5 0 missing
<i>B19b. Have staff in different places worked well together when testing you for prostate cancer: between hospitals?</i>	1 2 3 4	1 0.5 0 missing
<i>B19c. Have staff in different places worked well together when testing you for prostate cancer: between different departments (e.g. Urology and Oncology)?</i>	1 2 3 4	1 0.5 0 missing
SECTION C: DIAGNOSIS AND TREATMENT DECISION		
<i>C3. How did you feel about the length of the time you had to wait to get your diagnosis?</i>	1 2	1 0
<i>C4. Were you advised that it might be helpful if someone (e.g. partner, relative) could attend the hospital appointment with you to get your diagnosis?</i>	1 2	1 0
<i>C5. Did you have enough privacy when you discussed your diagnosis?</i>	1 2	1 0
<i>C7. Were you given your diagnosis in a considerate way?</i>	1 2 3	1 0.5 0
<i>C8. Did the doctor or nurse clearly explain how aggressive the cancer was likely to be?</i>	1 2 3	1 0.5 0
<i>C11. How did you feel about the length of time you had to wait to discuss your diagnosis with the specialist nurse?</i>	1 2 3 4	1 0.5 0 missing
<i>C12. Were you given any written information about your diagnosis?</i>	1 2	1 0
<i>C14. How did you feel about the length of time between being given your diagnosis and discussing your treatment options?</i>	1 2 3	0 1 0
<i>C15. Did the doctor or nurse explain which treatment options were open to you?</i>	1 2 3	1 0.5 0
<i>C16. Did the doctor or nurse explain what these treatment options would involve?</i>	1 2 3	1 0.5 0

<i>C17. Did the doctor or nurse explain the possible side effects or consequences of these treatment options?</i>	1 2 3	1 0.5 0
<i>C18. Did the doctor or nurse explain what could be done about the possible side effects?</i>	1 2 3	1 0.5 0
<i>C19. Did the doctor or nurse clearly explain why other treatment options were not open to you?</i>	1 2 3	1 0.5 0
<i>C20a. Did the doctor or nurse give you any written information about the treatment options?</i>	1 2	1 0
<i>C20b. Did the doctor or nurse give you any written information about the possible side effects or consequences of the treatment options?</i>	1 2	1 0
<i>C20c. Did the doctor or nurse give you any written information about what could be done about the side effects of the treatment options?</i>	1 2	1 0
<i>C21. Did the doctor or nurse make you feel that you could ask any questions you wanted to?</i>	1 2 3	1 0.5 0
<i>C22. How do you feel about the length of time you had to consider your treatment options before the treatment decision was made?</i>	1 2 3	0 1 0
<i>C23. Did the doctor or nurse involve you as much as you wanted in the decision about which treatment to have?</i>	1 2 3	1 0 0
<i>C24. Did the doctor or nurse give you the help you wanted to make the treatment decision?</i>	1 2 3	1 0 missing
<i>C26. Were you confident that the treatment decision was the best one for you?</i>	1 2 3	1 0.5 0
<i>C27. Did the doctor or nurse tell you that you could change your mind about which treatment to have?</i>	1 2	1 0
<i>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)?</i>	1 2 3	1 0.5 0
<i>C29. Have hospital staff worked well together in giving your diagnosis and deciding which treatment to have?</i>	1 2 3	1 0.5 0

SECTION D: TREATMENT AND DISCHARGE		
<i>D4. How did you feel about the length of time you had to wait for your treatment to start?</i>	1 2 3	0 1 0
<i>D5. Before you started your treatment, did a 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)?</i>	1 2 3	1 0.5 0
<i>D6. Did the doctor or nurse give you any information about what you could do that might help at this stage (e.g. diet, exercises)?</i>	1 2	1 0
<i>D7. Were you advised that it might be helpful if someone (e.g. partner, relative) could go with you when you went for treatment?</i>	1 2	1 0
<i>D8. During the course of your treatment were you able to discuss any concerns about your treatment with the doctor or nurse?</i>	1 2 3	1 0 missing
<i>D9a. Did you experience any of the following problems with your hospital visit(s)? appointment cancelled or postponed</i>	1 missing	0 1
<i>D9b. Did you experience any of the following problems with your hospital visit(s)? getting there</i>	1 missing	0 1
<i>D9c. Did you experience any of the following problems with your hospital visit(s)? parking</i>	1 missing	0 1
<i>D9d. Did you experience any of the following problems with your hospital visit(s)? kept waiting</i>	1 missing	0 1
<i>D9e. Did you experience any of the following problems with your hospital visit(s)? inconvenient appointment time</i>	1 missing	0 1
<i>D9f. Did you experience any of the following problems with your hospital visit(s)? medical notes not available</i>	1 missing	0 1
<i>D9g. Did you experience any of the following problems with your hospital visit(s)? cleanliness</i>	1 missing	0 1
<i>D10a. How would you rate: the treatment?</i>	1 2 3 4 5	1 0.67 0.33 0 missing
<i>D10b. How would you rate: the nursing?</i>	1 2 3 4 5	1 0.67 0.33 0 missing

<i>D10c. How would you rate: the food/drink?</i>	1	1
	2	0.67
	3	0.33
	4	0
	5	missing
<i>D10d. How would you rate: the ward (e.g. privacy, noise, cleanliness)?</i>	1	1
	2	0.67
	3	0.33
	4	0
	5	missing
<i>D11. While you were being treated, do you think that the hospital staff did everything they could to help with your pain or discomfort (e.g. give you enough medication)?</i>	1	1
	2	0.5
	3	0
	4	missing
<i>D12. Did the doctor or nurse explain how well the treatment was going/had gone?</i>	1	1
	2	0.5
	3	0
<i>D13. Before you left hospital or finished your treatment did the doctor or nurse explain to you what would happen next (e.g. arrangements for follow-up)?</i>	1	1
	2	0.5
	3	0
	4	missing
<i>D14. Before you left hospital or finished your treatment were you given an explanation about what to expect (e.g. potential side effects and how long they might last, recovery time)?</i>	1	1
	2	0.5
	3	0
	4	missing
<i>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)?</i>	1	1
	2	0.5
	3	0
<i>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, pain killers)?</i>	1	1
	2	0.5
	3	0
	4	missing
<i>D17. When you left hospital or finished your treatment were you told how to get further equipment or supplies (e.g. continence pads) you needed to help you care for yourself?</i>	1	1
	2	0
	3	missing
<i>D18. Did a doctor or nurse organise the aftercare services that you needed (e.g. district nurse, physiotherapist, home help)?</i>	1	1
	2	0.5
	3	0
	4	missing
<i>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)?</i>	1	1
	2	0.5
	3	0
<i>D20. Did the doctor or nurse offer you any financial information on welfare or benefits?</i>	1	1
	2	0
<i>D22a. Overall were you treated considerately by the staff at the hospital: Doctors</i>	1	1
	2	0.5
	3	0

<i>D22b. Overall were you treated considerately by the staff at the hospital: Nurses</i>	1 2 3	1 0.5 0
<i>D22c. Overall were you treated considerately by the staff at the hospital: Receptionists</i>	1 2 3	1 0.5 0
<i>D23a. Have staff in different places worked well together when treating you for prostate cancer: between GP's practice and hospital?</i>	1 2 3 4	1 0.5 0 missing
<i>D23b. Have staff in different places worked well together when treating you for prostate cancer: between hospitals?</i>	1 2 3 4	1 0.5 0 missing
<i>D23c. Have staff in different places worked well together when treating you for prostate cancer: between different departments (e.g. Urology and Oncology)?</i>	1 2 3 4	1 0.5 0 missing
SECTION E: MONITORING		
<i>E3. Have you been offered a choice of where to have these tests (e.g. GP's practice, hospital)?</i>	1 2	1 0
<i>E4. Did the doctor or nurse explain why you have these regular tests?</i>	1 2 3	1 0.5 0
<i>E6. Has a doctor or nurse reassured you that the length of the wait between these tests for prostate cancer is appropriate for you?</i>	1 2	1 0
<i>E8. Were you offered a choice of how to be given your test results (e.g. face-to-face, by telephone)?</i>	1 2	1 0
<i>E9. Has the doctor or nurse explained your test results (e.g. what the PSA score means, how reliable the PSA score is)?</i>	1 2 3	1 0.5 0
<i>E10. Has the doctor or nurse given you any information about who to contact for advice or support (e.g. specialist nurse, patient support group)?</i>	1 2 3	1 0.5 0
<i>E11. Has the doctor or nurse offered you information about what you could do that might help at this stage (e.g. diet, exercises)?</i>	1 2	1 0
<i>E12. Has the doctor or nurse told you how to get advice and help in managing symptoms or side effects of treatment (e.g. continence, problems with sex, pain)?</i>	1 2 3	1 0 missing
<i>E13a. Have staff in different places worked well together when monitoring you for this condition: between GP's practice and hospital?</i>	1 2 3 4	1 0.5 0 missing

<i>E13b. Have staff in different places worked well together when monitoring you for this condition: between hospitals?</i>	1	1
	2	0.5
	3	0
	4	missing
<i>E13c. Have staff in different places worked well together when monitoring you for this condition: between different departments (e.g. Urology and Oncology)?</i>	1	1
	2	0.5
	3	0
	4	missing

2. Step 2: Calculate mean scores for all questions with multiple sub-sections

The following scores should be calculated, to ensure that questions with multiple sub-questions are not overly weighted in the final score. The variables shown in the calculation are the recoded scores for individual questions (e.g. rA16a refers to the recoded score on Section A question 16a etc). The mean should be calculated for all respondents who have completed at least one of the sub-questions.

	Calculated by taking the mean of:
SECTION A	
meanA16	rA16a, rA16b
SECTION B	
meanB7	rB7a, rB7b, rB7c, rB7d, rB7e, rB7f, rB7g
meanB8	rB8a, rB8b, rB8c, rB8d
meanB11	rB11a, rB11b, rB11c, rB11d, rB11e
meanB18	rB18a, rB18b, rB18c
mean B19	rB19a, rB19b, rB19c
SECTION C	
meanC20	rC20a, rC20b, rC20c
SECTION D	
meanD9	rD9a, rD9b, rD9c, rD9d, rD9e, rD9f, rD9g
meanD10	rD10a, rD10b, rD10c, rD10d, rD10e
meanD22	rD22a, rD22b, rD22c
meanD23	rD23a, rD23b, rD23c
SECTION E	
meanE13	rE13a, rE13b, rE13c

3. Step 3: Calculate overall scores for each section and factors within sections

The calculation for overall scores for each respondent on the sections and factors within sections is given in the table below. It is shown how this can be calculated by hand and SPSS syntax is also given. It should be noted that overall scores should only be calculated for respondents who have completed at least 50% of the questions in the relevant section or factor. The variables shown in the calculation are the recoded scores for individual questions (e.g. rA3 refers to the recoded score on Section A question 3 etc), or the means calculated in step 2 above (e.g. meanA16). As well as some of the questions being reworded slightly, a small number of questions were added to the questionnaire following the testing reported in Chapter 5.

New questions have been included in the calculation of overall section scores for each section in the table below. Where it is clear that the new questions relate to factors then these have been added into the calculation of factor scores. However, in cases where it is not clear whether the new question is addressing the same issue as any of the factors in a section, the question is not included in any of the factor scores.

	Number of questions	Calculation	In SPSS syntax
Section A: GP VISITS & REFERRAL	12	$((rA3 + rA4 + rA5 + rA6 + rA7 + rA9 + rA10 + rA11 + rA13 + rA14 + rA15 + meanA16) / \text{number of questions completed}) * 100$	<code>(MEAN.6 (rA3,rA4,rA5,rA6, rA7, rA9, rA10, rA11, rA13, rA14, rA15, meanA16))*100</code>
Factor 1: Explanation	7	$((rA4 + rA5 + rA7 + rA9 + rA10 + rA11 + rA14) / \text{number of questions completed}) * 100$	<code>(MEAN.3 (rA4,rA5, rA7, rA9, rA10, rA11, rA14))*100</code>
Factor 2: Referral	3	$((rA6 + rA15 + meanA16) / \text{number of questions completed}) * 100$	<code>(MEAN.1 (rA6,rA15, meanA16))*100</code>
Factor 3: Taking the problem seriously	2	$((rA3 + rA13) / \text{number of questions completed}) * 100$	<code>(MEAN.1 (rA3, rA13))*100</code>

Section B: TESTS AT THE HOSPITAL	16	$(rB4 + rB5 + rB6 + \text{mean}B7 + \text{mean}B8 + rB9 + rB10 + \text{mean}B11 + rB12 + rB13 + rB14 + rB15 + rB16 + rB17 + \text{mean}B18 + \text{mean}B19) / \text{number of questions completed}) * 100$	$(\text{MEAN}.8 (rB4, rB5, rB6, \text{mean}B7, \text{mean}B8, rB9, rB10, \text{mean}B11, rB12, rB13, rB14, rB15, rB16, rB17, \text{mean}B18, \text{mean}B19)) * 100$
Factor 1: Explanation & support	6	$(rB6 + rB10 + rB14 + rB15 + rB16 + rB17) / \text{number of questions completed}) * 100$	$(\text{MEAN}.3 (rB6, rB10, rB14, rB15, rB16, rB17)) * 100$
Factor 2: Quality of care	4	$(\text{mean}B7 + \text{mean}B8 + \text{mean}B11 + rB12) / \text{number of questions completed}) * 100$	$(\text{MEAN}.2 (\text{mean}B7, \text{mean}B8, \text{mean}B11, rB12)) * 100$
Factor 3: Appointment	2	$(rB4 + rB9) / \text{number of questions completed}) * 100$	$(\text{MEAN}.1 (rB4, rB9)) * 100$
Section C: DIAGNOSIS AND TREATMENT DECISION	21	$(rC3 + rC4 + rC5 + rC7 + rC8 + rC11 + rC12 + rC14 + rC15 + rC16 + rC17 + rC18 + rC19 + \text{mean}C20 + rC21 + rC22 + rC23 + rC24 + rC26 + rC27 + rC28 + rC29) / \text{number of questions completed}) * 100$	$(\text{MEAN}.10 (rC3, rC4, rC5, rC7, rC8, rC11, rC12, rC14, rC15, rC16, rC17, rC18, rC19, \text{mean}C20, rC21, rC22, rC23, rC24, rC26, rC27, rC28, rC29)) * 100$
Factor 1: Explanation & support	11	$(rC15 + rC16 + rC17 + rC18 + rC19 + \text{mean}C20 + rC21 + rC23 + rC24 + rC26 + rC28) / \text{number of questions completed}) * 100$	$(\text{MEAN}.6 (rC15, rC16, rC17, rC18, rC19, \text{mean}C20, rC21, rC23, rC24, rC26, rC28)) * 100$

Factor 2: Making treatment decision	4	$(rC4 + rC8 + rC12 + rC27) / \text{number of questions completed} * 100$	$(\text{MEAN.2 } (rC4, rC8, rC12, rC27)) * 100$
Factor 3: Getting diagnosis	3	$(rC3 + rC5 + rC7) / \text{number of questions completed} * 100$	$(\text{MEAN.1 } (rC3, rC5, rC7)) * 100$
Factor 4: Length of wait	3	$(rC11 + rC14 + rC22) / \text{number of questions completed} * 100$	$(\text{MEAN.1 } (rC11, rC14, rC22)) * 100$
Section D: TREATMENT AND DISCHARGE	18	$(rD4 + rD5 + rD6 + rD7 + rD8 + \text{meanD9} + \text{meanD10} + rD11 + rD12 + rD13 + rD14 + rD15 + rD16 + rD17 + rD18 + rD19 + rD20 + \text{meanD22} + \text{meanD23}) / \text{number of questions completed} * 100$	$(\text{MEAN.9 } (rD4, rD5, rD6, rD7, rD8, \text{meanD9}, \text{meanD10}, rD11, rD12, rD13, rD14, rD15, rD16, rD17, rD18, rD19, rD20, \text{meanD22}, \text{meanD23})) * 100$
Factor 1: Preparation for discharge	8	$(rD12 + rD13 + rD14 + rD15 + rD16 + rD17 + rD18 + rD19) / \text{number of questions completed} * 100$	$(\text{MEAN.4 } (rD12, rD13, rD14, rD15, rD16, rD17, rD18, rD19,)) * 100$
Factor 2: Treatment	6	$(rD4 + rD5 + rD8 + \text{meanD10} + rD11 + \text{meanD23}) / \text{number of questions completed} * 100$	$(\text{MEAN.3 } (rD4, rD5, rD8, \text{meanD10}, rD11, \text{meanD23})) * 100$
Factor 3: Information	3	$(rD6 + rD7 + rD20) / \text{number of questions completed} * 100$	$(\text{MEAN.1 } (rD6, rD7, rD20)) * 100$

Section E: MONITORING	9	$(rE3 + rE4 + rE6 + rE8 + rE9 + rE10 + rE11 + rE12 + \text{mean}E13) / \text{number of questions completed} * 100$	$(\text{MEAN}.4 (rE3, rE4, rE6, rE8, rE9, rE10, rE11, rE12, \text{mean}E13)) * 100$
Factor 1: Explanation & reassurance	3	$(rE4 + rE6 + rE9) / \text{number of questions completed} * 100$	$(\text{MEAN}.1 (rE4, rE6, rE9)) * 100$
Factor 2: Advice	4	$(rE10 + rE11 + rE12 + \text{mean}E13) / \text{number of questions completed} * 100$	$(\text{MEAN}.2 (rE10, rE11, rE12, \text{mean}E13)) * 100$
Factor 3: Choice	2	$(rE3 + rE8) / \text{number of questions completed} * 100$	$(\text{MEAN}.1 (rE3, rE8)) * 100$

APPENDIX 14

Papers published in peer reviewed journals

Is seeing a specialist nurse associated with positive experiences of care? The role and value of specialist nurses in prostate cancer care. Carolyn Tarrant, **Paul Sinfield**, Shona Agarwal and Richard Baker. BMC Health Services Research 2008, 8:65 (27 Mar 2008). <http://www.biomedcentral.com/1472-6963/8/65>

Patient-centred care? Patients' and carers' experience of prostate cancer care. **Paul Sinfield**, Richard Baker, Shona Agarwal, Carolyn Tarrant. Patient Education and Counseling 2008, Volume 73, Issue 1, Pages 91-96

Men's and carers' experiences of care for prostate cancer: a narrative literature review. **Paul Sinfield** Richard Baker, Janette Cammosso-Stefinovic, Shona Agarwal, Carolyn Tarrant, Killian Mellon, Roger Kockelbergh, Will Steward, Andrew M Colman. Health Expectations 2009, 12 (3): 301-312.

The Prostate Care Questionnaire for Patients (PCQ-P): Reliability, validity and acceptability. Carolyn Tarrant, Richard Baker, Andrew M Colman, **Paul Sinfield**, Shona Agarwal, John K Mellon, Will Steward, Roger Kockelbergh. BMC Health Services Research 2009, 9:199 (4 November 2009) <http://www.biomedcentral.com/1472-6963/9/199/>

Research article

Open Access

Is seeing a specialist nurse associated with positive experiences of care? The role and value of specialist nurses in prostate cancer care

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Abstract

Background: Specialist nurses may play an important role in helping to improve the experiences of patients with prostate cancer, however there is concern that the specialist nurse role is under threat in the UK due to financial pressures in the NHS. This study explored the role and value of specialist nurses in prostate cancer care via a survey and patient interviews.

Methods: This paper reports findings from two studies. A survey of patients from three hospitals across the UK (289/481, 60%), investigated whether patients who saw a specialist nurse had different experiences of information provision and involvement in decision-making, to those who did not. Qualitative interviews were also carried out with 35 men recently tested or treated for prostate cancer, recruited from two hospitals in the UK. Interviews explored patients' views on the role and value of the specialist nurse.

Results: Survey findings indicated that patients who saw a specialist nurse had more positive experiences of receiving written information about tests and treatment, and about sources of advice and support, and were more likely to say they made the treatment decision themselves. In interviews, patients described specialist nurse input in their care in terms of providing information and support immediately post-diagnosis, as well as being involved in ongoing care. Two key aspects of the specialist nurse role were seen as unique: their availability to the patient, and their ability to liaise between the patient and the medical system.

Conclusion: This study indicates the unique role that specialist nurses play in the experience of patients with prostate cancer, and highlights the importance of maintaining specialist nurse roles in prostate cancer care.

Background

The care that cancer patients in the UK receive has been under scrutiny, and patients with prostate cancer have been found to report less positive experiences of care than patients with other types of cancer. Patients with prostate cancer are less likely to have the opportunity to discuss

side effects of treatment, to understand how well their treatment has gone, or to get information about support and self help groups, than patients with other types of cancer [1].

The role of the specialist nurse in prostate cancer care can be varied, but is primarily focused on the provision of information and support to patients [2]. Specialist nurse involvement may help to improve the experiences of patients with prostate cancer, and may be associated with positive outcomes [3-5]. The NICE Improving Outcomes Guidance on urological cancers emphasised the importance of specialist nurses in prostate cancer care [6], however, prostate cancer patients have lower levels of access to specialist nurses than do patients with other types of cancer [1]. Individuals and organizations involved in prostate cancer care have pointed to the availability of specialist nurses as a key priority for government action [7].

Set against this, current financial pressures in the NHS are threatening specialist nurse posts, with specialist nurses expressing concern that they may face losing their jobs, or may have to give up some or all of their time in their specialist role to work as generalist nurses on hospital wards in order to cover staffing shortages [8-10]. The role of specialist nurses in dealing with information, advice and emotional support, may appear to be "less tangible and a relative 'luxury' when compared with ward-based nurses" [11], leading to their roles being reviewed when resources are constrained. However, Richardson [12] has identified that patients with prostate cancer are more likely to report unmet needs if they do not see a specialist nurse.

There is a need for further research into the role and value of specialist nurses in prostate cancer care, to support decisions about the importance of maintaining and increasing the availability of specialist nurses to patients with prostate cancer.

This paper reports findings from two linked studies carried out as part of a larger study to develop a measure of patient experience of prostate cancer care [13]. A questionnaire survey of patients' experiences of prostate cancer care provided an opportunity to investigate whether patients who saw a specialist nurse had more positive experiences of care than those who did not. Qualitative interviews with patients and carers further explored patient perceptions of the role and value of the specialist nurse in prostate cancer care.

Methods

Two methodological approaches were used: a quantitative patient survey and a qualitative investigation of patients' experiences.

A questionnaire on experiences of prostate cancer care was mailed to a sample of 481 patients who had been tested or treated for prostate cancer during the previous two years at one of three hospitals in different regions of the UK. Patients were randomly selected from clinic lists for

several clinics at each hospital, including patients who were undergoing different types of treatment, and were at different stages in their care. There were no age restrictions put on the sample. Clinic staff were asked to check the lists and exclude any patients who had not been diagnosed, or who were not aware of their diagnosis.

The questionnaire was developed as part of the larger study, and was based on themes identified through interviews of patients with prostate cancer and health professionals [13]. The questionnaire included a question about whether the patient had seen a specialist nurse following their diagnosis. It also included a number of questions relating to the provision of information about treatment options, patient involvement in the treatment decision, and the provision of information about sources of advice and support. Univariate analysis (ANOVA) was used to identify whether patients who saw a specialist nurse had different experiences of these issues to patients who did not see a specialist nurse.

In order to further explore the role of the specialist nurse in prostate cancer care, an analysis of patient interviews undertaken as part of the larger study [13] was also carried out. Interviews were with prostate cancer patients from two hospitals in the East Midlands, UK, recruited using a quota sampling frame to ensure that patients at different stages of disease and treatment, and in different age and ethnicity groups, were included. Patients were identified from attendees at Urology Clinics and from hospitals' patient registers. In addition, two cancer charities were asked to contact patients from ethnic minority groups to ensure that both South Asians and Afro-Caribbeans were represented in the sample.

The interviews were semi-structured and aimed to explore patients' experiences over the course of their care, including initial GP visit(s), further testing, diagnosis, treatment, and ongoing monitoring (where relevant). The interviews did not specifically aim to explore the role of the specialist nurse, although the role and value of the specialist nurse emerged as a theme. Interviews were carried out in patients' own homes; in some cases, the patient's wife or partner was present and also participated in the interview. The interviews were audiotaped and transcribed verbatim, then transferred into the software package NUD*IST 6, and analysed using the Framework approach [14]. Analysis was undertaken to specifically explore the role and value of the specialist nurse in patients' experiences of prostate cancer care. All quotes used have been anonymised, and a patient identification number is given in brackets at the end of each quote.

Results

Participants

The questionnaire was completed by 289 patients (60%). Of these, 252 (87.2%) had seen a specialist nurse, and 37 (12.8%) had not. The characteristics of survey responders are given in Table 1. Patients who did not see a specialist nurse were more likely to be in the 75+ age group than patients who did see a specialist nurse ($F = 8.20$; $p < 0.001$), but did not differ significantly in terms of ethnicity, health status, treatment type, or time since most recent treatment.

Qualitative interviews were carried out with 35 patients; in 10 of the interviews the wife/partner was also present. The characteristics of the patients interviewed are given in Table 2.

Findings – questionnaire survey

Results from the questionnaire survey were analysed to explore whether patients who saw a specialist nurse had different experiences of care to patients who did not see a specialist nurse. Table 3 shows the odds ratios for questions on patient experience of care, comparing patients who did see a specialist nurse with those who did not, adjusted to take patient age into account. An odds ratio greater than one indicates that a positive response to the question was more likely in the first group (who did see a specialist nurse) than in the second group (who did not see a specialist nurse).

Patients who saw a specialist nurse were significantly more likely to say that they were given enough written or printed information about their test results and treatment options (Table 3, questions 1, 2, 3, 7 and 8). They were also more likely to feel that their treatment options were clearly explained (Table 3, question 4). Patients who saw

a specialist nurse were much more likely to report that they had been given enough information about sources of help (Table 3, question 13). There were no significant differences in terms of whether side effects of treatment were clearly discussed, or whether the doctor or nurse discussed with them why other treatment options were not suitable (Table 3, questions 5 and 6).

Patients who saw a specialist nurse were more likely to say that they made the treatment decision themselves (Table 3, question 9), although there was no significant difference between the groups in the extent to which they felt involved in the treatment decision. Patients who saw a specialist nurse were more likely to have been told that they could discuss the treatment decision again, and could change their mind about treatment (Table 3, questions 11 and 12).

Findings – qualitative interviews

The analysis of the qualitative interviews explored the role of the specialist nurse in prostate cancer care, with the aim of understanding the differences in experiences of patients who did and did not see a specialist nurse, and the perceived value of the specialist nurse role.

Role of the specialist nurse in patients' experiences of prostate cancer care

Most patients first saw the specialist nurse after being given their diagnosis by a consultant. At this stage patients often had to contemplate their diagnosis, consider a range of treatment options, and make a treatment decision. Here the role of the specialist nurse involved providing time for the patient to talk about the diagnosis and ask questions, and providing information about the diagnosis, treatment options, and support services.

Table 1: Characteristics of questionnaire survey responders (n = 289)

		Saw specialist nurse number (%)	Did not see specialist nurse number (%)	Total number (%)
Age	up to 54	6 (2.4)	0	6 (2.1)
	55–64	83 (32.9)	7 (18.9)	90 (31.1)
	65–74	121 (48.0)	14 (37.8)	135 (46.7)
	75 or over	29 (11.5)	16 (43.2)	45 (15.6)
Ethnicity	White	211 (83.7)	35 (94.9)	246 (85.1)
	South Asian	5 (2.0)	2 (5.4)	7 (2.4)
	African/Caribbean	21 (8.3)	0	21 (7.3)
	Other	1 (0.4)	0	1 (0.3)
Stage of disease/ treatment	Newly diagnosed (not yet treated)	0	0	0
	Being actively monitored without treatment	38 (15.1)	10 (27.0)	48 (16.6)
	Had curative treatment (e.g. prostatectomy, radiotherapy)	147 (58.3)	14 (37.8)	161 (55.7)
	Having hormone therapy	52 (20.6)	11 (29.7)	63 (21.8)

Table 2: Characteristics of interviewed patients (n = 35)

		Total number (%)
Age	up to 54	5 (14.3)
	55–70	13 (37.1)
	70 or over	17 (48.6)
Ethnicity	White	26 (74.3)
	South Asian	4 (11.4)
	African/Caribbean	5 (14.3)
Stage of disease/treatment	Newly diagnosed (not yet treated)	3 (8.6)
	Being actively monitored without treatment	7 (20.0)
	Had curative treatment (e.g. prostatectomy, radiotherapy)	17 (48.6)
	Having hormone therapy	8 (22.9)

[Consultant] said to go with the nurse and she'll explain everything to me, which she did, and made a good job of it ... I was with her about 20 minutes, half an hour...to have things explained and you had the opportunity to ask questions (38)

She was able to talk about the support services that were available in the event of having different options (43)

As well as playing an important role for patients immediately post-diagnosis, specialist nurses provided ongoing support for many patients during the course of treatment and follow-up, through their availability for consultation either by telephone or in person, and in some cases, through arranging patient support groups:

I will go back and be checked from time to time and honestly, my nurse specialist is always there and I will require that service for some time to come (49)

The oncology nurse does run once a month in one of the local pubs in the town a sort of a prostate get together and has done for three or four years probably (15)

Unique features of the specialist nurse role

Analysis of patient interviews highlighted the unique nature of the specialist nurse role, and the value of this role to patients. Two key features of the specialist nurse role distinguished it from the roles of other health professionals involved in prostate cancer care. These features were: the availability of the specialist nurse to the patient, and the ability of the specialist nurse to liaise between the medical system and the patient.

The availability of the specialist nurse to the patient

Patients described the availability of the specialist nurse firstly in terms of the amount of time the specialist nurse was able to spend with them, and secondly in terms of the

specialist nurse's availability for contact throughout their care.

Firstly, patients felt that the specialist nurse was able to spend as much time with them as was needed, and that their time with the nurse was not constrained. This was in direct contrast with the consultant, who was seen as having a limited consultation time. Having this time to talk things over was particularly important for patients after being given their diagnosis. The fact that specialist nurses were available for as much time as the patient needed was highly valued.

I had two, possibly, at least two meetings of hour and a half, two hours ...discussing in detail all the possibilities, all the options, my fears ...She did say herself, take as long as you want, you know, I haven't booked you down for a specific period of time and the first few meetings did take an hour and a half, two hours. Because I had so much to discuss with her (47)

Patients who did not see a specialist nurse after getting their diagnosis highlighted the lack of unconstrained time to talk things over, which had a negative emotional impact on them.

So there I am ... fairly confirmed I would think at that stage that I'm going to need cancer treatment, but none really to turn to. That was the thing, that in the whole experience of this, that was the worst moment. I needed somebody ...you know, in a ten minute appointment [consultant]'d really stretched his appointment time I'm sure to give me the benefit of his knowledge ... But that's what I felt I needed, someone to talk to, talk it through (14)

The timing of the consultation with the specialist nurse was important: one patient described seeing the specialist nurse immediately after being given the diagnosis, and felt that this was too soon as he was still in shock following the diagnosis.

Table 3: Odds ratios for questions on patient experience of care: comparison of responses from patients who did, and did not, see a specialist nurse

Question	Saw specialist nurse Frequency of positive responses/total responses (%)	Did not see specialist nurse Frequency of positive responses/total responses (%)	Age-adjusted odds ratio ratio, (95% confidence interval) <i>p</i> value
1. Given enough written or printed information about the test results	175/225 (77.8)	14/32 (43.8)	4.58 (2.01; 10.43) <i>p</i> < 0.001
2. Given enough written or printed information about active treatment	163/195 (83.6)	14/25 (56.0)	3.73 (1.46; 9.56) <i>p</i> = 0.01
3. Given enough written or printed information about watchful waiting/ active monitoring	127/160 (79.4)	8/22 (36.4)	6.69 (2.45; 18.25) <i>p</i> < 0.001
4. Doctor or nurse clearly explained what treatment options would involve	210/239 (87.9)	22/36 (61.1)	3.51 (1.54; 8.01) <i>p</i> = 0.003
5. Doctor or nurse discussed clearly the possible side effects or consequences of treatment options	195/239 (81.6)	26/36 (72.2)	1.47 (0.63; 3.45) <i>p</i> = 0.37
6. Doctor or nurse gave an explanation of why the other treatment options were not suitable	136/202 (67.3)	15/30 (50)	2.05 (0.92; 4.60) <i>p</i> = 0.08
7. Doctor or nurse offered written or printed information about the treatment options	170/250 (68.0)	11/37 (29.7)	3.90 (1.76; 8.63) <i>p</i> = 0.001
8. Doctor or nurse offered written or printed information about the side effects or consequences of the treatment options	158/252 (62.7)	10/37 (27.0)	3.81 (1.71; 8.49) <i>p</i> = 0.001
9. Patient made decision about which type of treatment to have (alone or in partnership with a health professional)	157/251 (62.5)	11/37 (29.7)	2.69 (1.18; 6.12) <i>p</i> = 0.02
10. Doctor or nurse involved patient as much as wanted in the decision about which treatment to have	192/237 (81.0)	23/34 (67.6)	1.69 (0.73; 3.88) <i>p</i> = 0.22
11. After the treatment decision had been made, doctor or nurse told patient they could discuss their treatment decision again	152/235 (64.7)	10/34 (29.4)	3.78 (1.68; 8.53) <i>p</i> = 0.001
12. Doctor or nurse told patient that they could change their mind about which treatment to have	132/230 (57.4)	6/33 (18.2)	4.71 (1.82; 12.22) <i>p</i> = 0.001
13. Doctor or nurse gave patient enough information about sources of help (e.g. support group/charities)	226/252 (89.7)	16/37 (43.2)	9.36 (4.11; 21.34) <i>p</i> < 0.001

No you can't absorb it and that's in a way was one little criticism of [specialist] nurse ... 'you've got prostate cancer' ... and she carts you off into a tiny little cubicle of a room ...and I don't know what the hell she said because ...that was too soon ...I was in a, in a state of numbness anyway at that point and so I don't really know what it was she was trying to achieve (19)

In contrast, one patient described how the specialist nurse had been sensitive to his shock and given him time to come to terms with the diagnosis.

She said to me 'well whatever you are told today you're not gonna take it all in' so they gave me a booklet on

prostate cancer and treatments, what is involved and whatever and I was told to go away and read it, and then if I'd got any questions or you know things like that... (54)

A second key aspect of availability that patients valued was the possibility of contact with the specialist nurse for advice and support throughout their care.

Patients were often given the specialist nurse's phone number as a point of contact if they had any concerns or questions. This meant that contact with the specialist nurse was easy, and could be patient-initiated, so patients

could have access to support or information as and when they needed it.

It worried me to death ...my mind were in like a whirl. I felt, I had to ring... [specialist nurse], 'cause I ask, I was asking myself questions I couldn't answer, you know 'Why this? And why that?'...after I spoke to her I felt a lot better ...Oh I can ring [specialist nurse] up any time I want to (27)

Just having the contact number was seen as a source of reassurance, whether or not the patient actually needed to use it.

[You can] contact her any time you want to...That's important that you can do that. What does it do, give you sort of reassurance that if you've got a problem or a concern that you can ring, that you know who to ring (38)

Patients who did not have access to this relatively quick and responsive source of support and information had to wait until they had an opportunity, in a scheduled consultation, to discuss issues of concern.

Interviewer: Would you find [contact number for specialist nurse] useful?

Patient: Yes, I would really because if um, odd times I've passed a bit of blood from the bowel and I could ring up and say, 'is that natural?'... You've sort of, you've got to wait till the next appointment, which is three months apart, and that's if they don't cancel it again or nowt (31)

The ability of the specialist nurse to liaise between the medical system and the patient

The second unique aspect of the specialist nurse role was that specialist nurses were seen as being in a position to liaise between the medical system and the patient. This involved firstly providing or restating information about diagnosis and treatment in terms which were clearly understandable to the patient, and secondly, acting as an advocate for the patient to facilitate the care process.

Firstly, patients described specialist nurses as helping them to understand and come to terms with their diagnosis and treatment through translating medical information in order to present it in an understandable way. This involved communicating in a patient-centred way and using non-medical language. Specialist nurses were also seen as more likely to address wider issues than simply the diagnosis and treatment, such as the impact of treatments on patients' lifestyles.

Patient: She did explain what the effects of the treatments are, the hormone therapy and so on...

Wife: She was down to earth, she didn't come up with any, you know so many medical terms...and she came up with a lot of practical things that perhaps the consultant wouldn't think to say... the fact that it's affecting your lifestyle (48)

Secondly, patients described this liaison role in terms of specialist nurses acting on their behalf to short-cut delays in care, to gain more information for them, and even to access particular medical services.

She can fiddle about and bang heads in the administration and get things happening (48)

There is two specialist nurses there, I've got their numbers, I speak to them and if there's anything else they will speak to the consultant and then they'll get back to me (54)

I said 'I want... [test]'...My surgeon said ' [patient name] does not require [test]'...But she got it, she got it through another um, consultant (49)

Where specialist nurses were involved in patient support groups, this helped to facilitate this informal liaison role.

When we go to our [patient support] meetings if I say to the oncology nurse ... 'well I've been a little bit worried because...' so she says 'ok don't worry about it I'll see Mr. so and so in the morning I'll give you a ring' (1)

Discussion

Results from the questionnaire survey indicate that patients who saw a specialist nurse were more likely to have received written information and clear explanations about their tests and treatment options, and about sources of help and support. Patients who saw a specialist nurse were more likely to say that they had made the treatment decision themselves.

The qualitative findings elaborate on and help to explain these differences. In interviews, patients described the contribution of the specialist nurse to their experiences of care immediately post-diagnosis, as well as over the longer term of their treatment and monitoring for prostate cancer. The specialist nurse was primarily seen as providing patients with time to talk and reflect on the diagnosis, providing advice, information and support (including information which could support the patient in making a treatment decision), and in some cases helping to facilitate the course of the patient's care. When patients did not

see a specialist nurse, they experienced gaps in their care, in particular, a lack of time to talk things over post-diagnosis, and a lack of immediate access to advice and support over the course of their care.

Importantly, patients' accounts highlight the unique features of the specialist nurse role, which make it possible for specialist nurses to contribute to patients' positive experiences of care. Firstly, patients described the availability of the specialist nurse, in terms of the amount of time the specialist nurse was able to spend with them in contrast with other medical staff such as consultants, and the possibility of patient-initiated contact with the specialist nurse. This concurs with Boxhall and Dougherty's study [15] in which patients valued the extra time available to them with specialist nurses compared to doctors. The second unique aspect of the specialist nurse role was that specialist nurses were seen as being in a position to liaise between the medical system and the patient. This included providing or restating information about diagnosis and treatment in terms which were clearly understandable to the patient, and acting as an advocate for the patient to facilitate the care process. These two key aspects of care have been advocated as important to the specialist nurse role [16], and this study indicates that these aspects of the role are recognised and valued by patients

The unique nature of the specialist nurse role, with their level of availability to the patient and their position at the interface between the patient and the health system, was seen as enabling specialist nurses to address specific patient needs. Some of these needs could not be met by professionals in different roles, as other roles do not share the unique characteristics of the specialist nurse role (for example, consultants are not able to offer patients their time for unlimited periods). Taken together, the findings of the questionnaire survey and the qualitative interviews suggest that specialist nurses make a unique and valuable contribution to patient experience of prostate cancer care.

There are several limitations to the work reported here which should be noted. Firstly, the questionnaire survey was not a randomised controlled study of an intervention, and there is a risk of selection bias. It is possible that patients who did and did not see a specialist nurse differed on factors which were not measured as part of the study. For example, patients who did not see a specialist nurse may have felt less need for nurse input, or may have had more or less advanced disease. This may have had an impact on the study findings, given that only 12.8% of participants had not seen a specialist nurse. However it is notable that the groups did not differ in terms of treatment type or health status. Those who did not see a specialist nurse were older than those who did, and it is possible that some of the participants who did not see a

specialist nurse may have been given their diagnosis prior to the widespread input of specialist nurses in care. The survey involved a relatively small number of patients in three hospitals, and responders to the survey were predominantly White British. In addition there were considerable numbers of missing responses on some questions. Although the response rate to the survey was relatively high, the 40% of invited patients who did not respond to the survey may differ systematically to those who did respond, for example, they may be older, or have more advanced disease. Hence the generalisability of the survey results may be limited. The interviews reported here did not systematically explore the role of the specialist nurse; rather this was an issue raised spontaneously by patients, and the analysis is limited to the issues raised by patients. Also, the sampling frame for interviews did not aim specifically to sample those who did and did not see a specialist nurse. The studies do not make a distinction between different types of specialist nurse (e.g. urology specialist nurse and prostate cancer specialist nurse). Nevertheless, the quantitative and qualitative components of the study present complementary findings that together demonstrate the benefits reported by patients of specialist nurses.

Conclusion

In conclusion, this study indicates that specialist nurses play an important and unique role in prostate cancer care, and have a positive impact on patient experience. It is essential that specialist nurses are supported in their unique role, and that their input is not threatened by financial and organisational pressures.

Competing interests

The author(s) declare that they have no competing interests.

Authors' contributions

The authors contributed to the article as follows: CT, PS and RB designed the study. CT, PS and SA collected the data. CT analysed the data with input from PS, SA and RB. CT drew up the draft manuscript and PS, SA and RB contributed to producing the final version.

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Men's and carers' experiences of care for prostate cancer: a narrative literature review. **Paul Sinfield** Richard Baker, Janette Cammosso-Stefinovic, Shona Agarwal, Carolyn Tarrant, Killian Mellon, Roger Kockelbergh, Will Steward, Andrew M Colman. *Health Expectations* 2009, 12 (3): 301-312

Research article

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The Prostate Care Questionnaire for Patients (PCQ-P): Reliability, validity and acceptability

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Abstract

Background: In England, prostate cancer patients report worse experience of care than patients with other cancers. However, no standard measure of patient experience of prostate cancer care is currently available. This paper describes an evaluation of the reliability, validity and acceptability of the PCQ-P, a newly developed instrument designed to measure patient experience of prostate cancer care.

Methods: The reliability, acceptability and validity of the PCQ-P were tested through a postal survey and interviews with patients. The PCQ-P was posted to 1087 prostate cancer patients varying in age, occupation, and overall health status, sampled from five hospitals in England. Nonresponders received one reminder. To assess criterion validity, 935 patients were also sent sections of the National Centre for Social Research Shortened Questionnaire; and to assess test-retest reliability, 296 patients who responded to the questionnaire were resent it a second time three weeks later. A subsample of 20 prostate cancer patients from one hospital took part in qualitative interviews to assess validity and acceptability of the PCQ-P. Acceptability to service providers was evaluated based on four hospitals' experiences of running a survey using the PCQ-P.

Results: Questionnaires were returned by 865 patients (69.2%). Missing data was low across the sections, with the proportion of patients completing less than 50% of each section ranging from 4.5% to 6.9%. Across the sections of the questionnaire, internal consistency was moderate to high (Cronbach's alpha ranging from 0.63 to 0.80), and test-retest stability was acceptable (intraclass correlation coefficients ranging from 0.57 to 0.73). Findings on criterion validity were significant. Patient interviews indicated that the PCQ-P had high face validity and acceptability. Feedback from hospitals indicated that they found the questionnaire useful, and highlighted important considerations for its future use as part of quality improvement initiatives.

Conclusion: The PCQ-P has been found to be acceptable to patients and service providers, and is ready for use for the measurement of patient experience in routine practice, service improvement programmes, and research.

Background

In this paper we report the reliability and validity of a questionnaire to measure the experience of prostate cancer care. We also report the acceptability of the questionnaire to patients and to hospitals providing care for patients with prostate cancer.

In England, patients with prostate cancer report worse experience of care than patients with other cancers [1,2], and the provision of readily usable measures was one element of a wider initiative designed to improve services [3,4]. While care outcomes can be assessed through standard measures of health-related quality of life [5], which include reports of general health and impact on functioning, no standard measures of patient experience of the process and delivery of prostate cancer care are available [6]. In recent years, patient surveys have tended to focus on patient experience of care rather than on satisfaction with care. Satisfaction is a complex concept incorporating patients' expectations, their experience of what happened in care, their feelings about the care they received, and the importance to the patient of the aspect of care concerned. Measures of patients' experience - which comprise patients' reports of what happened in specific aspects of the delivery of care - are simpler to interpret and act upon than measures of satisfaction [7]. Surveys of experience are now generally preferred by providers, and considered helpful in evaluating and improving services.

In the wake of the NHS next stage review, all NHS organisations will be required to gather and publish information about patient experience of care, as part of a process of working towards high quality of care for all [8]. The availability of valid and acceptable measures of patient experience is crucial to ensuring that meaningful data are collected. To be suitable for wide use, measures of experience need to be developed systematically to address the issues that are important to patients, to be readily understood and acceptable by patients, and to meet standards of reliability and validity. They should also be acceptable to providers, enabling them to assess specific stages of care, depending on the provider's focus for quality improvement. Our aim was to develop a robust and acceptable measure suitable for use in routine practice and research. This paper describes such a measure of patient experience of prostate cancer care - the Prostate Care Questionnaire for Patients (PCQ-P) - and reports on the formal evaluation of the measure's reliability, validity and acceptability to patients and service providers. A companion measure for use with carers of men with prostate cancer has also been developed [9].

Methods

Development and characteristics of the PCQ-P

The PCQ-P is a measure developed from preliminary research designed to determine the issues most important

to prostate cancer patients, including a literature review of the experiences of patients of prostate cancer care, and interviews with patients and service providers [10-12]. Key issues included: information and explanations, involvement in decision making, provision of advice and support, delays in care, choice, coordination of care, and practical issues (such as travel, and facilities at the hospital). Questions on these issues were developed, phrased in the words used by patients. Thorough piloting was undertaken [10]. The measure, along with a user guide, is available online for download and use [13]. The questionnaire is divided into five sections: GP visits and referral (Section A, 17 questions); tests at the hospital (Section B, 19 questions); diagnosis and treatment decision (Section C, 30 questions); treatment and discharge (Section D, 25 questions); and monitoring (Section E, 15 questions). There is a sixth section to collect health and sociodemographic information (Section F, 10 questions). Sections can be administered separately, or in appropriate combinations (e.g. it may be useful to give sections A, B, and C in combination to patients who have recently received a diagnosis of prostate cancer). A short version of the questionnaire, comprising 24 questions chosen to include the most important issues to patients, is also available [10,13].

Sampling

Five hospitals in England were selected to participate in the study to test reliability, validity and acceptability to patients. Hospitals represented a range in terms of urban and rural locality, teaching and non-teaching hospitals, and foundation trust status (Table 1). Each hospital drew a consecutive sample of all patients who had been diagnosed with, or treated for, prostate cancer within the past two years, excluding patients who had died or were too ill to participate; this produced a list of between 152 and 253 patients per hospital depending on the numbers of patients with prostate cancer under their care. The sample included patients at different stages of care (e.g. undergoing treatment, undergoing post-treatment monitoring). A total of 1087 patients were identified. Hospital staff mailed sections of the PCQ-P to patients, and non-responders were sent one reminder. Sections A, B, C, and F in combination were sent to 431 patients (in hospitals 1 and 3), and Sections D, E and F to 504 patients (in hospitals 2 and 4). One hundred and fifty two patients (in hospital 5) received all 5 sections in combination.

Measures of reliability, validity and acceptability to patients

To assess criterion validity, 935 patients (in hospitals 1 to 4) were also sent sections of the National Centre for Social Research Shortened Questionnaire (NCSRSQ), a questionnaire designed to measure patients' experience of care for several different forms of cancer [14]. To assess test-retest reliability, 296 patients from two hospital sites

Table 1: Features of hospitals: testing the questionnaire for reliability, validity, and acceptability to patients

	Hospital 1	Hospital 2	Hospital 3	Hospital 4	Hospital 5
Foundation Trust	No	No	No	Yes	Yes
Teaching Hospital	No	No	Yes	Yes	Yes
Population served	Urban	Rural	Urban	Urban	Rural
Location in England	South	South West	South West	London	East Anglia

(hospitals 1 and 2) were posted the PCQ-P questionnaire again three weeks later.

In addition, 20 patients from hospital 5, who had completed all sections of the PCQ-P, took part in semi-structured interviews to explore acceptability and face validity. Eleven face-to-face and nine telephone interviews were carried out. Interviews were not transcribed, but notes were taken by the interviewer during the interview.

Key properties of the questionnaire sections, including aspects of validity, reliability, and acceptability to patients were analysed. For the purpose of testing the properties of the questionnaire, overall scores were calculated for each section of the questionnaire, by summing scores across questions and converting to a score out of 100, with higher scores indicating more positive experiences of care [10]. All statistical analyses were conducted using SPSS version 16.0.

Acceptability to patients

Acceptability was evaluated by examining completion rates for individual questions and questionnaire sections, and by analysing distributions of responses for individual questions. Acceptability was also assessed in patient interviews, by asking patients how they felt about the experience of completing the questionnaire.

Validity

Criterion validity was assessed by examining Pearson correlations between scores on sections B to E of the PCQ-P and the NCSRSQ. The NCSRSQ did not contain comparable questions for section A of the PCQ-P. The NCSRSQ is a measure of problems in care, where in contrast to the PCQ-P a higher score indicates a less positive experience of care, therefore a negative correlation between the scores on the two questionnaires was expected. The NCSRSQ is a generic questionnaire rather than being specific to prostate cancer, and a medium-sized correlation co-efficient (-0.3 to -0.5) was expected as an indicator of validity [15,16]. Face validity was investigated through patient interviews, in which patients were asked to describe their experiences of care in conjunction with inspection of their

responses to the questionnaire, as well as being asked directly whether there were any important aspects of care that were not included in the questionnaire. Content validity was assessed through comparing the results of exploratory principal components analysis (PCA) with themes identified through the preliminary research [11,12].

Reliability

Internal consistency reliability for each section was measured using Cronbach's alpha [17]. Stability reliability was assessed using intraclass correlation coefficients (ICCs) between scores on the first and second completion of the questionnaire. Stability was also assessed by calculating the percentages of patients answering each question the same way on the first and second completion of the questionnaire.

Usability and acceptability to service providers

The usability and acceptability of the questionnaire to service providers was assessed through inviting a separate sample of hospitals to coordinate and run a patient experience survey using the PCQ-P, then seeking feedback on their experiences of this process. Hospitals were recruited via Service Improvement Leads (SILs) at the Cancer Networks, who identified hospitals within their network that would be willing to take part in this stage of the study. Four hospitals in England were selected from the list of identified hospitals, selected to ensure a range in terms of urban and rural locality, teaching and non-teaching hospitals, and foundation trust status. The characteristics of the four hospitals which took part in this separate stage of acceptability testing are given in Table 2. Hospitals were provided with questionnaires, a user guide developed as part of the study [13], and software to enable them to enter their data and produce basic summary results. Three hospitals each used a different selection of sections of the full measure, and one hospital used the short version of the questionnaire covering the whole patient journey. Hospitals were asked to survey around 100 patients, and feedback on their experiences was gained through semi-structured interviews with one or two key persons who had administered the survey in each hospital (total of 5

Table 2: Features of hospitals: testing the questionnaire for usability and acceptability to service providers

	Hospital A	Hospital B	Hospital C	Hospital D
Foundation Trust	Yes	Yes	No	No
Teaching Hospital	Yes	No	No	Yes
Population served	Urban	Rural	Rural	Urban
Location in England	London	South West	Midlands	Midlands

interviews), along with informal discussion with other members of hospital staff. Interviews were not transcribed, but notes were taken by the interviewer during the interview.

Results

Acceptability to patients

Questionnaires were returned by 865 patients (69.2%); 355 completed Sections A, B, C and F (response rate: 61%), and 510 completed Sections D, E and F (response rate: 77.7%). This response rate is similar to that achieved for prostate cancer patients in the National Survey of NHS Cancer Patients in 1999/2000 [18]. The demographic characteristics and health status of responders are summarised in Table 3.

The proportion of patients completing fewer than 50% of the questions in each section was low: 16 patients (4.5%) for Section A, 20 (5.6%) for Section B, 18 (5.1%) for Section C, 30 (5.9%) for Section D, and 35 (6.9%) for Section E. Missing data were usually due to patients omitting whole sections, sometimes appropriately (e.g. no medical tests at the named hospital) but without making the reasons clear. For patients who completed more than 50% of the questionnaire, missing data for individual questions ranged from 0% to 15.4%, the majority showing less than 10% missing data. Responses to most questions were well distributed across response options. Overall, patients more often reported positive experiences, with mean overall scores ranging from 65.9 to 86.4 across the sections. Descriptive statistics of section scores are shown in Table 4.

In the patient interviews, patients described the questions as easy to understand, and the majority did not report any problems with filling in the questionnaire. One patient commented that his case did not fit well with the sequence of sections as they were presented in the full questionnaire (compiled from all five subsections), and two patients felt that the full questionnaire was too long. Three patients emphasised that each section should be administered as soon as possible after the relevant phase of treatment or care, as they found it difficult to remember in detail events from several months previously. Patients

suggested that the sections should be divided and used as separate questionnaires, or with just two to three sections in combination, with appropriate sections being administered as soon as possible after the relevant stage of care.

Criterion validity

Out of 935 patients, 592 (63.3%) completed both a PCQ-P and a NCSR questionnaire. Response rates were 224/431 (52%) for Sections A, B, C, and F, and 368/504 (73%) for Sections D, E, and F. Pearson's correlation coefficient between Sections B and C and the first half NCSRSQ was -0.23 ($p = 0.002$, $N = 175$), and between Sections D and E and the second half NCSRSQ was -0.46 ($p < 0.001$, $N = 201$). These correlations are in the expected direction, the first is small and the second is medium [15,16], and both are significant at $p < 0.005$.

Face and content validity

All interview participants indicated that the questionnaires covered important aspects of care. However, several patients highlighted gaps in the section on discharge. The particular issues identified as important were: knowing what to expect in terms of recovery time and side effects; and knowing how to obtain appropriate supplies after discharge (such as continence pads). This led to two questions on these issues being added to the questionnaire.

Content validity was assessed through exploratory principal components analysis. Analysis identified three to four components for each section of the questionnaire (see additional file 1: exploratory PCA). For example in section A (GP visits and referral), three components emerged, and inspection of questions within each component suggested that the components related to: 'explanation', 'taking the problem seriously' and 'experience of referral'. Comparison of these components with themes from the initial patient interviews and literature review [11,12] confirmed that the key aspects of care identified in the preliminary research were satisfactorily incorporated in the PCQ-P.

Internal consistency reliability

Cronbach's alpha coefficients ranged from 0.63 to 0.80, indicating moderate to high internal consistency for all sections of the PCQ-P (Table 5).

Table 3: Demographic characteristics and overall health status of patient sample: reliability and validity testing

Age (years)	N (%) ⁱ
< 54	18 (2.1)
55-64	215 (24.9)
65-74	350 (40.5)
75+	262 (30.3)
Overall health	
Very good	253 (29.2)
Good	385 (44.5)
Fair	166 (19.2)
Poor	28 (3.2)
Very poor	10 (1.2)
Ethnicity	
White British/Irish	803 (92.8)
South Asian	10 (1.2)
African/Caribbean	17 (2.0)
Other	2 (0.2)
Current situation	
Employed	185 (21.3)
Retired	624 (72.1)
Other	24 (2.8)
Current or most recent occupation	
Professional	239 (27.6)
Managerial	178 (20.6)
Clerical	35 (4.0)
Technical/craft	148 (17.1)
Manual/service	136 (15.7)

ⁱMay not add to 100 due to missing data

Test-retest reliability

Out of 296 patients, 148 (50%) completed the retest questionnaire; 79/125 (63.2%) completed Sections A, B, C,

and F, and 69/171 (40.4%) completed Sections D, E, and F. Patients completing retest questionnaires did not differ significantly from other patients in terms of age, health status, ethnic group, or employment status ($p > 0.05$ in each case). The test-retest ICCs for the five sections were between 0.57 and 0.73, and all were significant at $p < 0.001$ (Table 5), indicating acceptable reliability [19]. The consistency of responses to individual questions was high, between 52.6% and 100% of patients answering identically on the first and second mailing. Most questions (94, 88.7%), were answered perfectly consistently by over 70% of responders. The questions where responses were less consistent were those with a higher number of response options, and for these questions the difference between responses on the first and second completion of the questionnaire tended to be a shift to the neighbouring response option, for example, from 'good' to 'very good'.

Acceptability to service providers

Three of the four participating hospitals chose to administer the questionnaire by post, and one used a combination of postal administration and face-to-face administration in urology clinics. None of the hospitals reported major difficulties with running the survey. However, the administration of the survey was seen as time consuming, and hospitals found this problematic; one hospital in particular had difficulty finding staff with time available to run the survey. Hospitals felt that the provision of support to run the survey would be helpful, and one hospital suggested that administering the survey prospectively to patients over a longer period of time would be more manageable and would produce valuable data.

Agreement to conduct the survey had initially been obtained from a consultant in each hospital, and some staff felt that an essential first stage would be a meeting involving all staff who would have a role in the administration of the survey. This would promote ownership of the survey, ensure local support, and provide a setting where input of time could be negotiated. There were mixed feelings about the involvement of an external organisation to coordinate the survey, possibly on a national basis; staff described a preference for using surveys as part of their own internal quality improvement process, and were resistant to the idea of surveys being used as an "external stick" (Hospital B) to raise performance, or being linked to financial incentives.

Hospital staff feedback indicated that they found the questionnaire relevant and would value it as a tool for their own use, particularly if benchmarks or comparative data were available from other hospitals. Staff were particularly keen to have access to comparative data for local hospitals, as they felt this would have the greatest impact on efforts to improve quality - they "like to do better than others locally!" (Hospital A). It is possible to present com-

Table 4: Descriptive statistics of overall scores from the five sections of the questionnaire

Section ⁱ	N	Mean score	SD	Minimum	Maximum	% with lowest possible score	% with highest possible score
Section A	307	65.9	21.1	.00	100.0	0.7	5.1
Section B	328	82.3	14.0	28.5	100.0	0.0	3.9
Section C	292	86.4	13.4	27.8	100.0	0.0	17.5
Section D	304	71.0	16.2	16.2	100.0	0.0	1.2
Section E	459	71.3	20.8	.00	100.0	0.4	12.0

ⁱSection A = GP visits and referral, Section B = tests at the hospital, Section C = diagnosis and treatment decision, Section D = treatment and discharge, Section E = monitoring

parative data on the PCQ-P at the level of whole sections, components within sections, and individual questions, using bar charts (Figure 1 illustrates this with data from three of the hospitals involved in reliability and validity testing). Although further work is required to establish the components within each section, the PCQ-P shows potential to produce data across a range of levels of detail that may be useful in interpreting their results. For example, inspecting results at the level of section and component scores allows a hospital to identify areas where they may be performing less well than other hospitals, then inspecting specific question results within a component can help pinpoint specific areas of care which may be problematic.

Discussion

The evaluation of the PCQ-P demonstrates that the instrument incorporates issues that are important to prostate cancer patients, has good reliability and validity, and is acceptable to patients and service providers. The PCQ-P can be used flexibly - single sections can be used independently or in combination with other relevant sections, and a short version [10] covering the whole patient journey is also available.

Some limitations should be noted. The evaluation of criterion validity was hampered by the absence of any satisfactory criterion. No other suitable measure of patient experience of prostate cancer care was available, hence a

Table 5: Reliability: Internal consistency and stability of the five sections of the PCQ-P

Section ⁱ	Internal consistency	Stability: Test-retest reliability		
	Cronbach's α	1st mailing mean score SD, min-max (N)	2nd mailing mean score SD, min-max (N)	Intraclass Correlation Coefficient (ICC)
Section A	0.80	69.1 19.6, 11.5-100 (60)	68.5 18.7, 16.7-100 (62)	0.68
Section B	0.63	84.4 15.3, 28.5-100 (73)	81.3 10.6, 39.7-99.4 (72)	0.57
Section C	0.77	88.4 12.0, 55.0-100 (62)	87.6 13.1, 31.3-100 (63)	0.61
Section D	0.80	73.2 17.1, 27.7-99.23 (48)	74.8 14.5, 41.4-100 (49)	0.73
Section E	0.68	74.3 21.9, 16.7-100 (61)	74.9 19.7, 18.8-100 (60)	0.70

ⁱSection A = GP visits and referral, Section B = tests at the hospital, Section C = diagnosis and treatment decision, Section D = treatment and discharge, Section E = monitoring

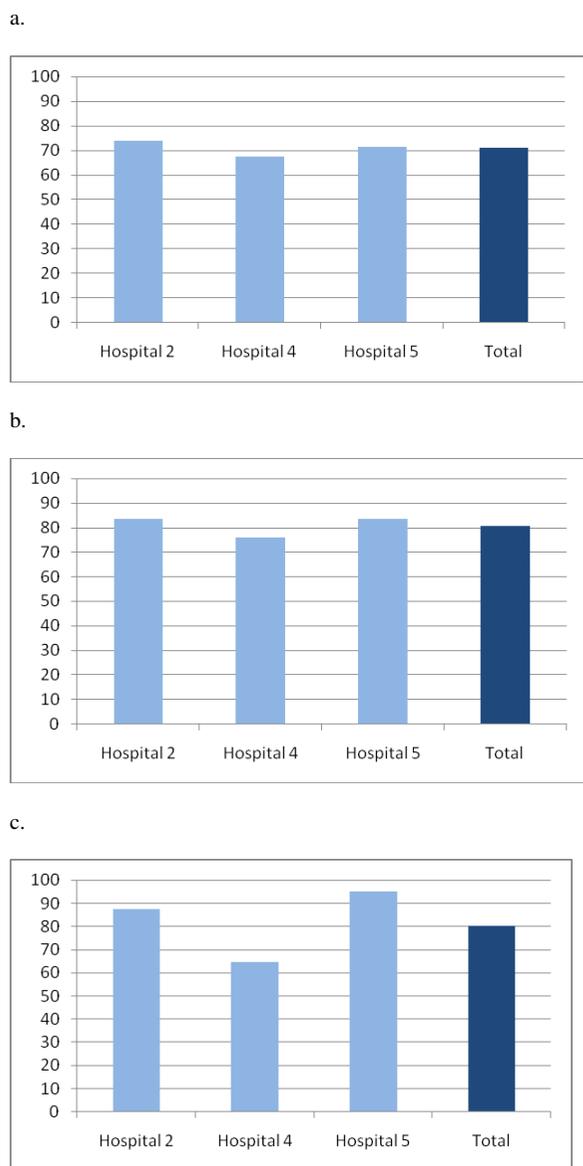


Figure 1
Comparative data from three hospitals. a. Overall scores for section D. b. Scores for component 'discharge'. c. Percentage of patients responding positively to 'discharge' question: 'Did the doctor or nurse give you any information about who to contact for advice or support (e.g. specialist nurse, patient support group)?'

generic patient experience questionnaire (NCSRSQ) was used as an indicative criterion. Nevertheless, the findings of the criterion validity check show small to medium sized, but significant, correlations between scores on the PCQ-P and the NCSRSQ. Taken in conjunction with other tests of the PCQ-P's properties, this provides support for the validity of the PCQ-P as a measure of patient experi-

ence of prostate cancer care. The findings of this study confirm that the PCQ-P is suitable for use in service improvement programmes. The study also highlights the approach to using the questionnaire preferred by patients (sections of the questionnaire administered separately, as soon as possible after the corresponding care stage), and indicates important considerations for hospitals planning to use the questionnaire, including ensuring that staff time is made available to administer the questionnaire. The development of a version of the questionnaire that could be self-administered via computer would be valuable in addressing this problem.

Attempts to develop and improve services should include assessment of patient experience when evaluating the impact of changes. In the UK, the greater involvement of commissioners in the future will present an additional opportunity to monitor and improve patient experience, and patient experience surveys should play a role in this [20]. The PCQ-P could be used in future national patient surveys. The use of a robust and acceptable questionnaire, specifically designed to collect experiences of prostate cancer care, would allow GPs and hospitals to evaluate their performance on the aspects of care that are most important to prostate cancer patients, and to compare their performance to other, similar GP practices and hospitals. The establishment of benchmark scores for the questionnaire would be of value in this context, and could be established via a national survey.

Conclusion

This study has demonstrated how a sophisticated patient experience questionnaire can be developed and evaluated systematically. Although the development process is prolonged, thoroughness in development and testing provides confidence in the data produced by the measure, and increases the value of the data for use in service evaluation and research. The PCQ-P could provide a starting point for the development of instruments for other cancer groups, as many of the issues that it covers are relevant to other cancers. For example, the need for information and support throughout care is pertinent to the other common cancers, including lung, colorectal, and breast cancer. New measures would require careful testing before use. Nonetheless, the detailed process undertaken to develop the prostate care questionnaire provides a springboard for developing instruments for other cancers.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

CT participated in the design of the study, carried out the research and data analysis, and prepared the first draft of this paper; RB was lead of the complete project, and

participated in the design of the study reported in this paper; AMC participated in the design of the study and in data analysis. PS participated in the design of the study and carried out the research. SA carried out the research. JKM, WS, and RK participated in the design of the study and advised on study conduct. All authors were involved in revising and approving the final manuscript.

Additional material

Additional file 1

Exploratory Principal Components Analysis with Varimax rotation for each section of the PCQ-P. Table showing results of an exploratory PCA for all sections of the PCQ-P.

Click here for file

[<http://www.biomedcentral.com/content/supplementary/1472-6963-9-199-S1.docx>]

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APPENDIX 15

Conference presentations

Society for Academic Primary Care: Annual scientific conference

- 2005: Patients' and partners' experience of prostate cancer care: a systematic review of the literature
- 2006: Prostate cancer care: what is important to patients and their carers?

Prostate cancer care: patient involvement in decision making (poster presentation)

- 2007: From primary care to secondary care: the experiences of prostate cancer patients (poster presentation)

Society for Academic Primary Care: Regional conference

- 2008: Prostate cancer care: improving measures of the patient experience

Patients' and partners' experience of prostate cancer care: a systematic review of the literature

Funded by SDO

Study team

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Presentation outline

- Background
- Search
- Findings

testing

referral and diagnosis

treatment decisions

treatment

post treatment

experiences throughout many stages of care

- Conclusions
- Limitations

Background

- Prostate cancer most common cancer in men in the UK (1 in 5 of all new male cancers)
- Huge increases in incidence in last 20 years but mortality has remained fairly stable
- Treatment options: active monitoring, prostatectomy, radiotherapy, brachytherapy, cryotherapy, and hormone therapy (for advanced disease)

Search

- What are the experiences of care of men and their carers at different stages of prostate cancer?
- Databases: Medline, Embase, Cinahl, Psycinfo, Sigle
- 1263 articles identified, 108 and 36 follow up references reviewed, 80 relevant and obtained

Reviewing the literature

- Possible themes and stages of care identified
- Studies: questionnaires, interviews, focus groups and RCTs
- Framework approach was used
 - findings were coded in NUD*IST
 - themes were summarised under each of the stages of care

Coding of studies

Themes	Information Knowledge	Decision-making	Support Care	Needs, problems, concerns	Pain, side-effects	Experience, views	Satisfaction, quality
Stages of care							
Screening	2	4				3	
Referral and diagnosis	3		1	2	1	3	
Treatment decisions	12	12				5	
Treatment	3	1	2	3	4	6	1
Post treatment	2		10	1	1	2	
Relapse							
Palliative care							
Terminal care							
Through many stages	4		3	2		2	



Testing for prostate cancer

- Patients favour testing
- Testing prompted by: media publicity, GP recommendation, symptoms, and influence of male friends
- Lack of pre-test information and discussion with GP

Referral and diagnosis

- Biopsy: anxiety, embarrassment and pain
- Shock of diagnosis and on-going anxiety
- Patients and partners gathered information
- Support welcomed

Treatment decisions (1)

- Information needs similar to other cancer patients
- Specialists' input of critical importance
- Patients' knowledge often incomplete
- Patients want involvement in decision-making process

Treatment decisions (2)

- Treatment decision follows diagnosis
- Doctors take leading role
- Treatment choice: range of influences
- Patients may trade off life expectancy to avoid side effects

Treatment

Patients have:

- information and knowledge deficits
- substantial stress and seek support
- anxiety while waiting for treatment
- benefited from complementary therapies

Post treatment

- Patients unaware of self-help resources
- Patients and partners wanted information about treatment effects and how to manage them
- Improvements in knowledge, reduction in depression and increasing self-efficacy

Experiences throughout care

Patients:

- had unmet information needs
- valued specialist nurses and support groups
- reported a fragmented approach to their care and treatment (radiotherapy)
- and partners reported shock at diagnosis, the need to be involved in all discussions, and for more self-care information

Conclusions

Part of a study to develop a measure of patient experience

- Patients have information needs through many stages of care
- Patients and partners have knowledge deficits
- Patients want involvement in decisions
- Partners want involvement in discussions

Limitations

- Studies are from: USA, Canada, UK, Australia, Sweden and Finland
- Studies involved small numbers of patients and partners
- Limited research on testing, and referral and diagnosis
- No studies found on relapse, palliative care and terminal care

Prostate cancer care: what is important to patients and their carers?

Funded by SDO

Study team

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Presentation outline

- Background
- Methods
- Findings
- Conclusions

Background

Prostate cancer

- most common cancer in men in the UK (1 in 5 of all new male cancers)
- huge increases in incidence in last 20 years but mortality has remained fairly stable
- treatment options: active monitoring, prostatectomy, radiotherapy, brachytherapy, cryotherapy, and hormone therapy and chemotherapy (for advanced disease)

Methods

- Recruitment at 2 hospitals and 2 charities
- Interviews with 30 patients and 10 carers
- Interviews were audio-taped and transcribed
- Interviews were coded in NUD*IST and analysed using the Framework approach

Findings

1. Testing and referral

Patients and their carers want explanations of:

- the tests and outcomes
- reasons for referral and speed of referral

Findings

2. Tests at the hospital

Patients want:

- inconvenience to be kept to a minimum
- to be prepared for possible pain of biopsy
- clear and considerate communication

Carers want:

- to be kept informed

Findings

3. Diagnosis and treatment decision

Patients and their carers want:

- the diagnosis to be communicated appropriately
- to understand the treatment options and the potential side-effects
- to have the role they want in the treatment decision

Findings

4. Discharge and monitoring

Patients and carers want:

- information on discharge
- contact information about support groups, patients and websites
- to have a contact number/access to a specialist nurse
- monitoring

Conclusions

- Timely information
- Clear and sensitive communication
- Preferred decision-making role
- Help with coping
- On-going support

Findings from literature review

- Patients have information needs through many stages of care
- Patients and partners have knowledge deficits
- Patients want involvement in decisions
- Partners want involvement in discussions

Prostate cancer care: patient involvement in decision making

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Background

- Prostate cancer is the second most common cancer in men in England and Wales¹. Yet, there is no national screening programme in the UK, no clear agreement about whether patients should be routinely tested for it and no clear evidence as to what is the most effective treatment.
- Patients may expect to be involved in such decisions, particularly given the cultural shift in medicine towards shared decision-making.

Aim

- To report patients' experiences of their involvement in decisions about being tested for prostate cancer and about which treatment to have.

Methods

- Face-to-face interviews were carried out with 30 patients with prostate cancer. Patients were recruited from two hospitals (Leicester General Hospital and Kettering General Hospital) and from two charities (Coping with Cancer and Cancer Black Care).
- Patients were recruited from each of the following groups:
 - Age under 55; 56-70 and over 70
 - Ethnic origins; white; South Asian and Afro-Caribbean
 - Referred from: primary care; and another hospital department
- The interviews were recorded on audio-tape, transcribed and coded using NUD*IST.
- Data was analysed using the Framework analysis technique.

Results

Testing (Primary Care)

- The majority of patients presented with urinary symptoms and were tested by their GP using the PSA (Prostate Specific Antigen) test and sometimes the DRE (Digital Rectal Examination) in addition.
- Symptomatic patients were not routinely involved in the decision about whether to be tested for prostate cancer.
- Most patients did not receive an explanation of the purpose of the tests or their reliability.

Diagnosis and Treatment decision (Secondary Care)

- Patients were usually shocked by the diagnosis of prostate cancer when it was delivered by the clinician.
- In most cases, the clinician explained the treatment option(s) in the same consultations, and patients reported having difficulty concentrating on the information provided. One patient said that "you hear that word [cancer] and sort of everything gets blocked out".

The decision making process tended to take one of two forms:

- In many cases, patients were directed to the specialist prostate cancer nurse for further information (including information packs for patients) and were told to return several weeks later to inform the clinician of their treatment decision.
- Other patients, including those with advanced disease, reported that the clinician tended to make the treatment decision for them and then informed them of their choice. Several patients stated that "the decision was made, the alternative treatment option(s) were not explained to them and that they just went along with it as they did not know enough to question the clinician".
- Many patients wanted more information about the potential side-effects of the different treatment options.

Conclusions

- Many patients with prostate cancer want a shared approach to decision making. Yet, the majority are not experiencing this. Clinicians need to provide patients with timely information and the opportunity to enable them to play a shared role in decisions about their care.

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From primary care to secondary care: the experiences of prostate cancer patients

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Introduction

- Prostate cancer is the most common cancer in men in the UK and patients commonly present to primary care with symptoms. Patients are usually tested (PSA blood test and a digital rectal examination) and, depending on the results, referred to secondary care for further investigations.
- Our study is developing measures of patient experience through different phases of the care pathway from initial presentation onwards and here we report on the experiences of men in primary care.

Methods

1. Interviews

- Men with prostate cancer were recruited at two hospitals and via two charities (to ensure South Asian and Afro-Caribbean patients were included).
- Semi structured interviews of 35 patients were conducted, audio taped and transcribed verbatim. Data were coded using NUD*IST and analysis carried out using the Framework approach.

2. Questionnaires

- Questionnaires were developed and piloted at three hospitals.
- 289/481 (60%) questionnaires were completed and returned. Responses were recoded (0=positive response; 1=negative response).
e.g. Before the test did the doctor or nurse give you an explanation of what the PSA test was trying to find out?

Yes, the explanation was clear	0
Yes, but the explanation could have been clearer	1
No explanation was given	1
I did not want/need an explanation	0

Prescott, A. (2004) National Survey of NHS patients. Cancer: analysis of themes. Department of Health

- Frequencies were run using SPSS to establish scores for different aspects of care

Results

1. Symptoms

Interviews: GPs took the symptoms of patients seriously but it was not routinely explained that they may indicate prostate cancer

Interviewer: *You were having difficulty passing water?"*

Patient: *"Yes. He did an examination as far as he could. Said something wasn't right, so I went to the [hospital name]"*
(patient #15)

Questionnaire question: Did the [primary care] doctor or nurse give you an explanation of what might be causing your symptoms?

Negative responses by patients attending 3 hospitals reporting on primary care:

n = 68/258 (26%)

2. Purpose of PSA test

Interviews: Patients were tested for prostate cancer but some were not made aware beforehand of the purpose of the tests

"at the time I didn't know what a PSA blood test meant until he asked me if he could do a rectal examination"
(patient#10)

"when I went back to my GP....I thought it was going to be because my cholesterol level was high so I was quite surprised and he then explained that it was a PSA level of 11 or 12 whatever it was, and he explained that it was a measure of a possibility of cancer"
(patient #11)

Questionnaire question: Before the test, did the [primary care] doctor or nurse give you an explanation of what the PSA test was trying to find out?

Negative responses by patients attending 3 hospitals reporting on primary care:

n = 32/169 (19%)

3. Explanation of the PSA test results

Interviews: Where test results were given, this was done considerably but some patients were not clear about the results of their tests

"the doctor reassured me and said that, as I now know is the case, that just because my PSA reading was high and needed checking it didn't necessarily mean I had cancer"
(patient#14)

"Well I knew what it [PSA test] was but they didn't really tell me and explain to me what was high and what was low, but I don't know if 50 might have been high or if 50 might have been low. I don't really know."
(patient #7)

Questionnaire question: Did the [primary care] doctor or nurse give you an explanation of the results of your PSA test?

Negative responses by patients attending 3 hospitals reporting on primary care:

n = 48/180 (27%)

4. Explanation of referral to hospital

Interviews: Patients were referred to secondary care for further tests, but some did not understand why they were referred

"So at that stage she [the GP] hadn't talked about cancer or anything like that. In fact she never did. All she did was refer me to the hospital"
(patient #45).

Questionnaire question: Did the [primary care] doctor or nurse give you an explanation of why you were referred to hospital?

Negative responses by patients attending 3 hospitals reporting on primary care:

n = 44/255 (17%)

Conclusions

Our research showed that some patients move from primary care to secondary care with little or no understanding that they have been referred to find out if they have prostate cancer. This may cause problems for both patients and clinicians in secondary care.

Main project title: Prostate cancer care: Improving measures of the patient experience
<http://www.sdo.lshtm.ac.uk/sdo772004.html>

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Prostate cancer care: improving measures of the patient experience

Funded by SDO

Study team

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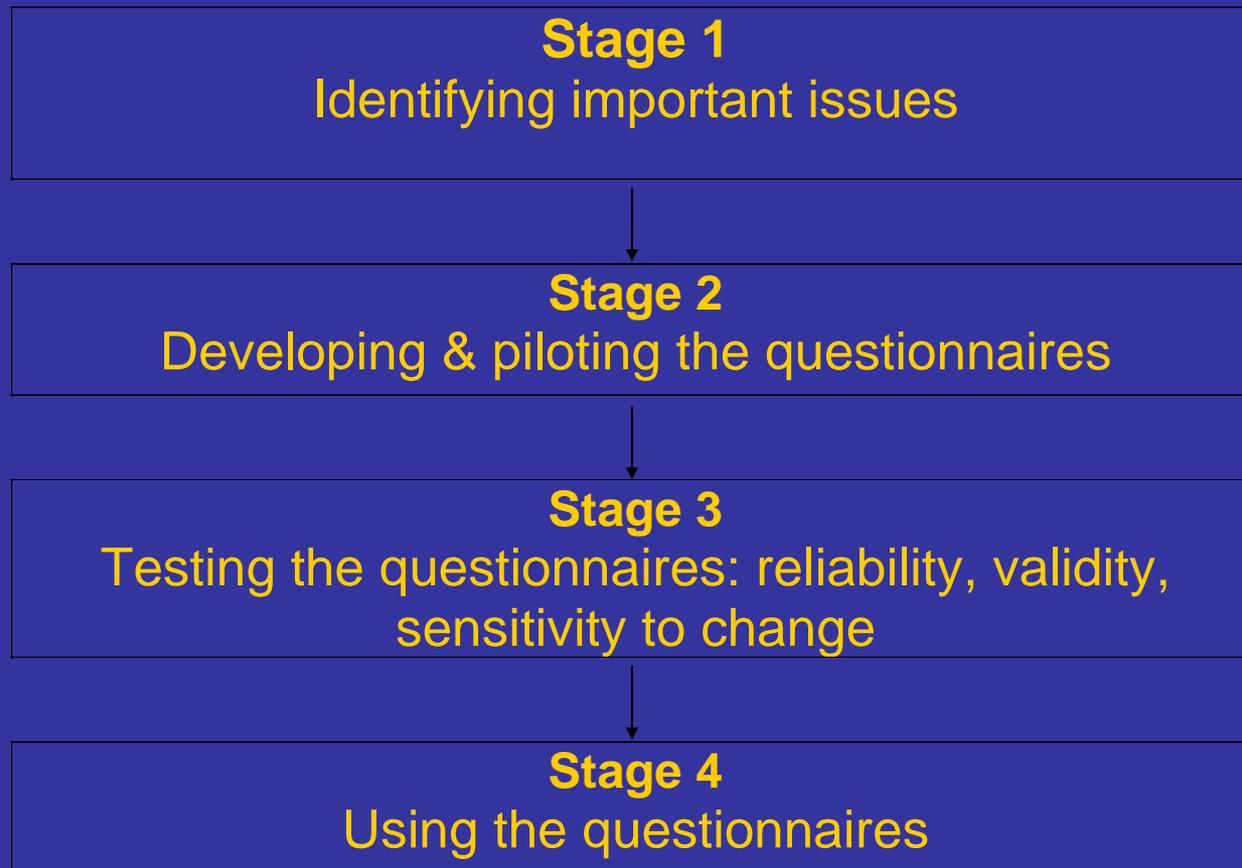
Outline of presentation

- Background
- Developing the measure
- Implications for primary care
- Conclusions

Background

- Prostate cancer is second most common cancer in men (nearly 35,000 men are diagnosed in the UK each year; 24% of new male cancer diagnoses)
- Range of treatments, and significant side-effects
- National patient surveys show prostate cancer care less satisfactory than other cancer care
- Patient experience v patient satisfaction

Developing the measure



Stage 1: identifying important issues

Methods

- Literature review
- Questionnaire survey of Cancer Networks
- Interviews with:
 - patients and carers
 - health care professionals
 - CSC Leads
 - Cancer Network staff
 - voluntary sector workers

Findings

- Format: a questionnaire, easy to understand and complete
- Content: cover all phases of care, involve carers and include issues on:
 - provision of information
 - opportunity for involvement in discussions
 - decision-making
 - service delivery (testing, treatment, monitoring)

Findings from patient and carer interviews (1)

Primary care:

- pre-test information and discussion lacking
- clear explanation of test results and reason for referral not routinely given
- contact after end of treatment/discharge valued
- on-going support valued e.g. nursing services

Secondary:

- generally positive about facilities, some issues re parking/waiting/re-arranged appointments
- shock of diagnosis, some poor communication

Stage 2: developing and piloting the questionnaires

Initial version of the questionnaires drafted:

- based on issues identified at stage 1
 - five sections covering the whole patient journey
 - separate carer questionnaire created
- Reviewed by research team, panel and patients and carers (PCQ-Pv1 and PCQ-Cv1)
 - Revised questionnaires piloted: in 2 hospitals (150 patients, and 100 carers each time) leading to (PCQ-Pv2 and PCQ-Cv2). Piloting repeated leading to (PCQ-Pv3 and PCQ-Cv3).

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

Please tick one box

- | | | |
|-----------------------------|--------------------------|---|
| Yes | <input type="checkbox"/> | 1 |
| To some extent | <input type="checkbox"/> | 2 |
| No, not really | <input type="checkbox"/> | 3 |
| I did not have any concerns | <input type="checkbox"/> | 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 | <input type="checkbox"/> | 1 |
| Yes, but I would have liked more information | <input type="checkbox"/> | 2 |
| No, I was not given any information | <input type="checkbox"/> | 3 |

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

Please tick one box

- Yes 1 No 2

Stage 3: testing the questionnaires

- Face validity: interviews of patients and carers
- Postal testing in 5 hospitals involving 865 patients, 595 carers
 - test retest reliability (Pearson correlations)
 - internal consistency (Cronbach's alpha)
 - sensitivity to change (ANOVA)
 - content validity (Principal Components Analysis)
- Lead to PCQ-Pv4 and PCQ-Cv4

Stage 4: using the questionnaires

4 hospitals administered the different sections of the questionnaires:

- Positive feedback about questionnaires and software
- Response rates reasonable: mean 60%, range 49%-67%
- Recommend postal administration
 - hospitals may need support to carry out surveys
 - face-to-face for hard to reach groups
- Attitudes to patient experience surveys vary: positive, indifferent, sceptical
 - surveys should not be “external stick” but “useful internal tool”
 - need all staff to be informed and involved throughout

Individual questions: discharge

% of patients giving a positive response, excluding 'not applicable' (n)

	Hospital 5	Hospital 2	Hospital 4	Total
<i>D15. Before you left hospital or finished treatment did the doctor or nurse explain to you what would happen next (e.g. arrangements for follow-up)?</i>	91% (53)	96% (103)	90% (100)	92%
<i>D16. Did the doctor or nurse give you any information about who to contact for advice or support (e.g. specialist nurse, patient support group)?</i>	95% (63)	87% (127)	65% (116)	80%
<i>D17. 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)?</i>	51% (59)	62% (115)	51% (102)	55%
<i>D18. Were you given equipment or supplies (e.g. continence pads) to use at home to help you care for yourself?</i>	46% (26)	61% (54)	44% (27)	53%



Implications for primary care

- Surveys (national, regional) would provide results of:
 - patients' and carers' experience of primary care
 - patients' and carers' experience of secondary care
- PCTs, large practices, assessment centres and polyclinics may be able to administer sections of the questionnaires themselves

Conclusions

Methods

- willingness to be involved: patients and carers*; health service staff; vol. sector staff
- difficulties: ethics, R&D, hospital admin., health service staff

Outcomes

- tested and usable tools to help service improvement
- lessons learnt for developing similar tools for other conditions

Findings from literature review

- Patients have information needs through many stages of care
- Patients and partners have knowledge deficits
- Patients want involvement in decisions
- Partners want involvement in discussions

Findings from cancer network survey

- Format: questionnaires (easy to complete for all)
- Administration: audit departments, patient groups may be able to help
- Frequency: regularly repeated
- Feedback: to patients and staff
- Problems: resources, response rate, acting on findings
- Content: cover all of the patient journey and include carers

Findings from patient and carer interviews 1

Primary care:

- pre-test information and discussion lacking
- clear explanation of test results and reason for referral not routinely given
- contact after end of treatment/discharge valued
- on-going support valued e.g. nursing services

Secondary:

- generally positive about facilities, some issues re parking/waiting/re-arranged appointments
- shock of diagnosis, some poor communication

Findings from patient and carer interviews (2)

Secondary:

- information needs and decision making role of patients needs to be established
- specialist nurse role valued
- anxious to start treatment and want information about it and the effects
- need information at end of treatment/discharge re outcome of treatment and support
- monitoring re-assures patients and carers
- carers want to be included in discussions
- carers need access to support

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