Developing a measure of patient experience of prostate cancer care

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Abstract

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Paul Sinfield

Background
In England, improvement of cancer services is a policy priority and improvement of patient experience of cancer care is an element of this policy. National surveys identified that patients with prostate cancer (the most common cancer in men) experienced worse care than patients with other cancers.

Aim
To develop a valid, reliable and acceptable measure of patient experience of prostate cancer care suitable for use in routine practice.

Methods
1. Review of the literature to establish the existence of any measures of prostate cancer care, and patients' and carers' experiences of prostate cancer care
2. Survey of Cancer Networks to investigate their experiences of administering measures of patient experience and suggestions for developing a new measure
3. Interviews of healthcare professionals, voluntary sector staff, patients and carers to establish their views on the format and content of a new measure
4. Piloting the questionnaire to review its comprehensibility and reduce the number of questions to a minimum
5. Testing the questionnaire for validity, reliability and acceptability in hospital settings

Findings
The questionnaire, PCQ-P (Prostate Care Questionnaire – Patients), has been developed through a detailed and systematic process. It has acceptable validity and reliability and has been used successfully in hospitals. PCQ-P is divided into sections related to different phases of care that can be used individually or in combinations as preferred. Questionnaire findings can be presented by individual question and as scores for sections, so individual aspects of patients' experiences of care can be examined, as well as comparisons made between different hospitals.

Conclusions
PCQ-P has been systematically developed and may be used at local, regional and national levels.

The methods used to develop this questionnaire may be adopted to develop measures of patient experience of other cancers.

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I would like to thank the following people for their invaluable help:

1. PhD supervisors: Professors Richard Baker and Keith Stevenson who provided me with the advice and encouragement I needed to complete this thesis.
2. Research team: my colleagues on the research team whose contributions were vital to the successful conduct and completion of the research.
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5. Staff in the NHS and charities: who work hard to improve and deliver prostate cancer care also made time for interviews and the piloting of the questionnaire.
6. Research funders: NHS Service Delivery and Organisation who funded the research study *Prostate cancer care: improving measures of the patient experience* which provided the opportunity to carry out the research for this thesis.
7. My colleague Carolyn Tarrant for her advice and encouragement.
8. My partner, Marj., for her encouragement to complete the thesis.

This thesis was based on my involvement in the NHS SDO commissioned research study, *Prostate cancer care: improving measures of the patient experience*. To demonstrate that the thesis was based on my contribution to this study, I have outlined below the work I was responsible for.

I was a co-applicant on the research proposal and identified as the lead researcher. This role ran for the full length of the project and included applying for ethical and R&D approvals for the study to start. I led the research throughout the study, convening meetings to discuss and plan the

research as well as co-ordinating the research team. I was fully involved in all aspects of the study.

In the literature review reported in Chapter 2 I drafted the search strategy, reviewed papers and helped compile the table summarising the relevant papers. I was the lead author on the narrative literature review published in 2009 (see below for details).

During the research to inform the measure reported in Chapter 3, I conducted the survey of Cancer Networks and was responsible for interviews of Cancer Network staff, clinicians, voluntary sector staff, and patients and carers. I was the lead author for the paper that reported on patients' and carers' experiences of prostate cancer care published in 2008 (see below for details).

The process of drafting the measure of patient experience is reported in Chapter 4. I was responsible for the first draft of the questionnaire, along with managing the review process and making revisions to produce a version ready to be piloted.

The two rounds of piloting of the questionnaire reported in Chapter 5 involved me in both the administration of the questionnaire and the analysis of the data. I was also part of the team that reviewed the questionnaire, and was responsible for making the revisions to produce the next version, ready for testing.

The testing of the questionnaire for validity and reliability is reported in Chapter 6. I conducted interviews to ascertain face validity and entered some of the data from questionnaire responses into a database ready for analysis. The statistical tests applied to the data were conducted by Carolyn Tarrant using SPSS, who produced the charts of the results. I was involved in the interpretation of the results for content and criterion validity, and reliability. I was co-author of the paper reporting the reliability, validity and acceptability of the questionnaire for patients, published in 2009 (see below for details).

The revision of the questionnaire and piloting are described in Chapter 7. I was part of the team that reviewed the questionnaire, and was responsible for producing the next version with the revisions ready for piloting. I also conducted the final pilot in two of the hospitals and was responsible for the final revisions made to the questionnaire.

Papers published (for copies see Appendix 14)

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/

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Chapter 1: Introduction

In this chapter I will state the aim of the thesis before describing the nature of prostate cancer and the current UK policies to address this disease. In the final section I will discuss measures of patient experience.

1.1 Aim of the thesis

The aim of this thesis is to develop a measure of patients' experience of prostate cancer care. It is intended that the measure should be suitable for routine use by health care professionals in the evaluation of the health care services people with prostate cancer receive at different phases of their care. It should also be acceptable to patients, deal with issues important to patients and health service staff, be convenient to administer and analyse, be sensitive to changes in patient experience and services, and provide reliable and valid findings. The phases of care to be covered by such a measure will be determined from the research conducted. These aims arise from the goals of a study commissioned by the NIHR SDO R&D Programme (National Institute Health Research Service Delivery and Organisation Research and Development), in association with the NHS Cancer Plan 2000.

Rationale

Prostate cancer is the most common cancer in men in the UK (Office for National Statistics, 2005), and two national surveys of cancer patients have revealed that men with prostate cancer report a poorer experience of care (Department of Health, 2002; National Audit Office, 2004). A rigorously developed measure of patient experience would allow health care

professionals to capture the experiences of care of patients with prostate cancer so that services can be reviewed and modified to meet their needs better. This should lead to improvements in prostate patients' experience of care and may bring them more into line with the experiences of care of other cancer patients.

The following sections of this Chapter presents epidemiological and clinical information about prostate cancer, and sets out the policy background that led to the study described in this thesis.

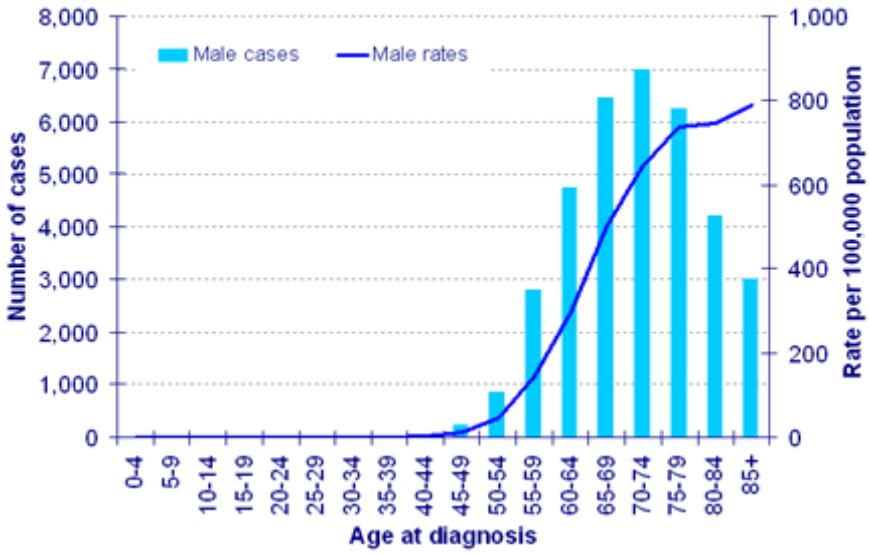
1.2 Prostate cancer

1.2.1 Epidemiology

Incidence and mortality

Prostate cancer incidence rates are strongly related to age. There are few cases in the under 50s and there are steep rises in subsequent age groups with the largest number in the 70-74 age group.

Figure 1.1: Numbers of new cases and age specific incidence rates, prostate cancer, UK 2006

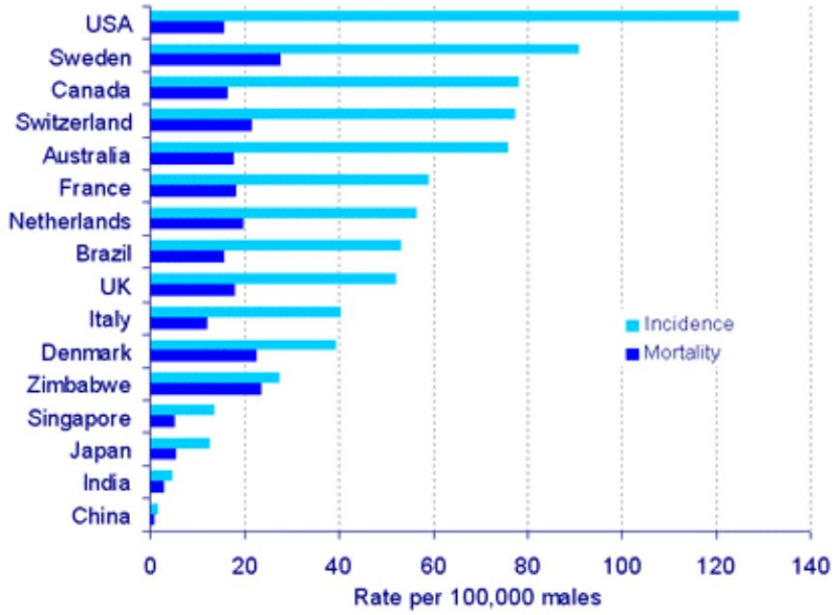


(Cancer Research UK, 2009)

It is estimated from post mortems that half of men in their fifties have histological evidence of prostate cancer and this rises to 80% at age 80. However, only 3.8% of men will die of the disease (Cancer Research UK, 2009).

Worldwide, more than 670,000 men are diagnosed with prostate cancer every year, accounting for one in nine of all new male cancers and it is the second most common cancer in men (Ferlay, et al., 2002). The highest prostate cancer incidence rates are in the developed world and the lowest rates in Africa and Asia (see Figure 1.2).

Figure 1.2: Age standardised (world) incidence and mortality rates, prostate cancer in selected countries, 2002 estimates



(Cancer Research UK, 2006)

The extremely high rate in the USA (125 per 100,000), more than twice the reported rate in the UK (52 per 100,000 may be partly explained by the particularly high rates of PSA (Prostate Specific Antigen) testing in the USA (Gann, 1997).

Box 1.1: The Prostate Specific Antigen (PSA) test

Explanation

PSA is a small protein produced by the prostate and a small amount is normally found in the blood. The test measures the level of PSA in the blood (nanograms of PSA per millilitre of blood). PSA levels are usually raised when a man has prostate cancer. PSA rises with age on a continuous scale, so a man aged 70 will have a higher PSA level than a man aged 50. A 'normal' PSA test result may be below 3.0 ng/ml for a man aged 50 to 59, below 4.0 ng/ml for a man aged 60-69, and below 5.0 ng/ml for a man aged 70 or over.

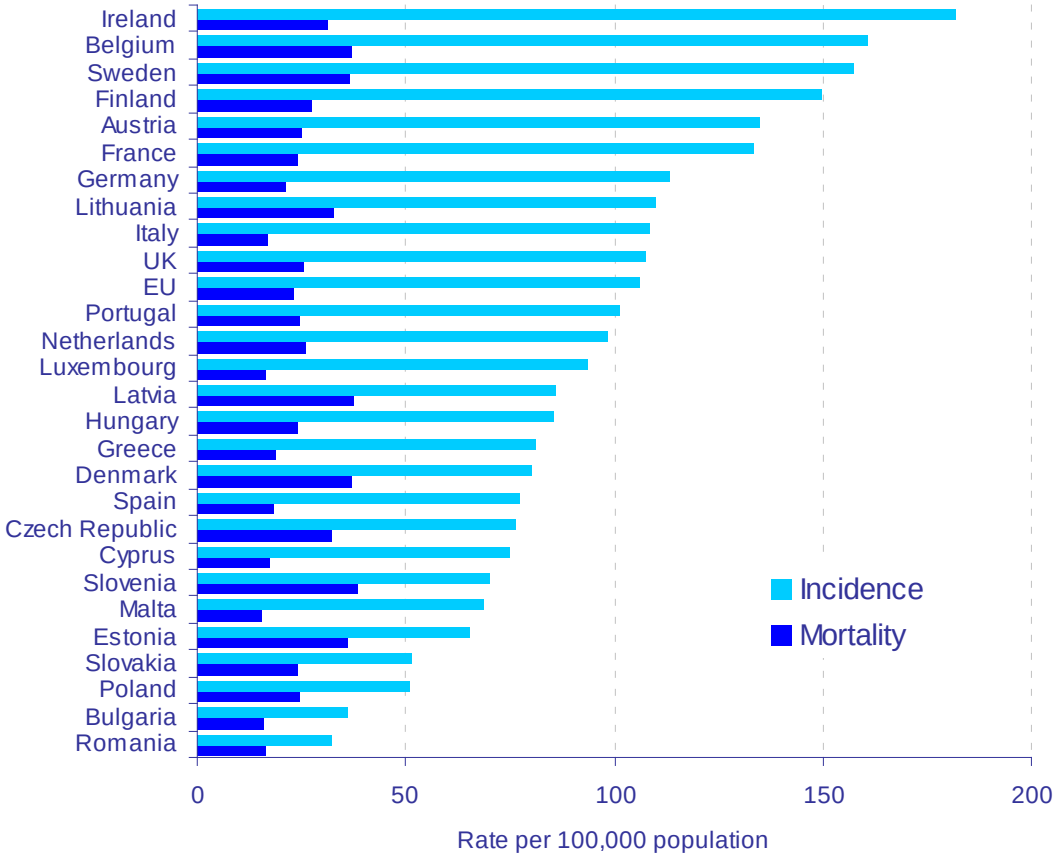
Drawbacks to the PSA test

i. the PSA test is not reliable as an inidcator of prostate cancer as some men with high PSA levels do not have prostate cancer and some men with prostate cancer do not have high PSA levels.
ii. the test cannot tell the difference between prostate cancers that grow quickly and are life threatening, and those that grow slowly and do not require treatment.

(The Prostate Cancer Charity, 2008a)

In Europe around 190,000 cases of prostate cancer are diagnosed each year with the lowest European rates in Bulgaria and Romania and the highest rates in Ireland and Belgium (see Figure 1.3). Figure 1.3 also shows the mortality rates and it is clear that the variation between European countries is much smaller than it is for incidence of prostate cancer. The UK's figures for both incidence and mortality are very close to the average for the EU.

Figure 1.3: Age standardised (European) incidence and mortality rates, prostate cancer in EU countries, 2006 estimates



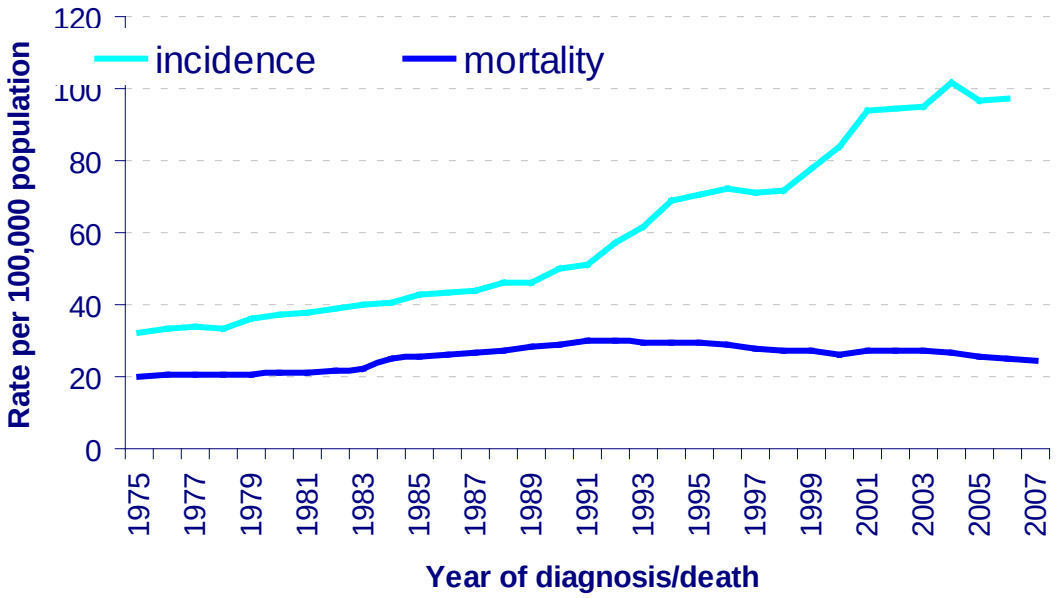
(Cancer Research UK, 2009)

Trends in prostate cancer incidence

Substantial increases in prostate cancer incidence have been reported in recent years for many countries around the world, including the UK (Hsing et al., 2000). Figure 1.4 shows the incidence rates for the UK where the rates almost trebled from 33 per 100,000 in 1975 to 97 per 100,000 in 2006. During the 1980s there were consistently rising rates with an acceleration of the trend in the early 1990s and then a brief levelling off in the mid 1990s, and then another rising trend in the late 1990s continuing into the first decade of the

21st century. Mortality rates have increased slightly during the 1980s but have shown a gradual decline since the 1990s and in 2007 are only slightly above the 1975 rate.

Figure 1.4: Age standardised (European) incidence and mortality rate males, GB, 1975-2007



(Cancer Research UK, 2009).

The increasing incidence is likely to be due to several factors, besides any real increase in the disease. The increasing use of PSA blood tests and the increasing use of transurethral resection (TURP*) of the prostate both play a part in the increased detection rate of prostate cancer (Potosky, et al., 1990). In the USA widespread PSA testing on asymptomatic men from around 1986 resulted in an 82% increase in the recorded incidence of prostate cancer between 1986 and 1991 (Brawley, 1997).

*TURP is a standard surgical treatment for benign prostatic hyperplasia which is a very common non-cancerous condition in older men caused by the enlargement of the prostate. Prostate cancer is an incidental finding in the tissue removed by TURP in around 10% of patients (Cancer Research UK, 2006).

In Western Europe the widespread use of PSA tests began a few years later (around 1989-90), and the level of population screening is still thought to be much lower than in the USA (Levi et al., 2000) where it is estimated that more than half of US white men aged over 50 have had their PSA level tested (Gann, 1997).

In 2006 there were 35,515 new cases of prostate cancer diagnosed in the UK. Table 1.1 shows the numbers and rates of new cases in the UK.

Table 1.1: Number of new cases and rates of prostate cancer, UK, 2006

	England	Wales	Scotland	N.Ireland	UK
Cases					
Males	30,024	2,164	2,506	821	35,515
Crude rate per 100,000 population					
Males	120.5	149.8	101.5	96.2	119.6
Age-standardised rate (European) per 100,000 population					
Males	98.1	108.2	81.6	92.1	97.1
95% CI	*97.0 99.2*	*103.7 112.8*	*78.4 84.8*	*85.8 98.4*	*98.1 101.0*

(Cancer Research UK, 2009)

Prostate cancer is the most common cancer in men in the UK, accounting for nearly a quarter (24%) of all new male cancer diagnoses (Cancer Research UK, 2009). It most commonly affects men over the age of 50, and the risk of developing it varies among different ethnic groups, with African-Caribbean and African-American men more likely to develop prostate cancer, and Asian men less likely to develop prostate cancer. Men who have close relatives with a history of prostate cancer are more likely to develop the disease. In the UK

cancer incidence rates are higher among men from areas of least deprivation but there was no such trend for mortality rates. The increasing gap in the incidence of prostate cancer between the affluent and the least deprived "is the result of a greater increase in incidence amongst the least deprived and suggests the test is being utilised more by those living in these areas." (Rowan, 2007).

1.2.2 Pathology

Nearly all prostate cancers are adenocarcinomas, mainly occurring in the peripheral part of the prostate gland. The causes of prostate cancer are not clear, but androgens, mainly testosterone, are thought to play a part in initiating and promoting prostate cancer. Prostate cancers are usually slow growing and in many cases the disease does not reach a stage where it becomes clinically significant. However, in some cases it can be aggressive, and even the slow growing type may develop early enough in a man's life to have time to progress locally or spread to other parts of the body. The pathological features of the disease include stage (extent or size of the tumour) and grade (differentiation of the tissues), and these have a significant effect on prognosis (O'Reilly, 1999). The four stages of the tumour are described below:

Localised prostate cancer

T1 – the tumour is within the prostate gland but too small to feel

T2 – the tumour is within the prostate gland but is large enough to feel on digital examination

Locally advanced prostate cancer

T3/T4 – the cancer has spread beyond the prostate into the surrounding tissues

Metastatic (or secondary) prostate cancer is where the cancer has spread well outside the prostate and local tissues (e.g. to lymph nodes, bone). (Macmillan, 2009a)

The commonly used method in the UK and USA for grading the cancer is Gleason grading, which scores the two most dominant patterns and adds them together to give the Gleason score. The Gleason system uses a scale running from 2 to 10. However, very few patients have Gleason scores of less than 6, because the lower scores are now thought not to be cancerous. Because of this a Gleason score of 6 is the lowest normally seen on a biopsy.

Table 1.2 Gleason scores and explanations

Gleason Score	**Explanation**
6 or less	Any cancer is less likely to spread. The cells may be described as “well differentiated”, which means that histologically they look relatively similar to normal prostate cells.
7	The cancer is ‘moderately differentiated’, which means the cells look less like normal prostate cells and are more likely to spread.
8-10	The cancer is the most aggressive and most likely to spread. The cells are ‘poorly differentiated’, which means they look abnormal under the microscope

(The Prostate Cancer Charity, 2008b)

1.2.3 Clinical presentation

Patients with prostate cancer may present with or without symptoms, although symptoms are not common in the early stages of development. Those that arise include changes in the urinary stream (e.g. hesitancy, decrease in force) and changes in urinary frequency and urgency. However, all these symptoms may occur for other reasons. The symptoms for localised prostate cancer may be the same as those for benign prostatic hyperplasia (BPH), as enlargement of the prostate gland often causes urinary tract obstruction and difficulty in urinating, and more frequent micturation. In the past, some men with clinically significant prostate cancer presented with symptoms that indicated advanced disease with metastatic progression, including weight loss, bone pain and lethargy. However, with improved public awareness men are presenting earlier (Macmillan, 2009a).

1.2.4 Diagnosis

The National Institute for Health and Clinical Excellence has issued prostate cancer referral guidelines (NICE, 2005):

Box 2: Referral for suspected cancer. A clinical practice guideline.

Patients presenting with symptoms suggesting prostate cancer should have a digital rectal examination* (DRE) and prostate specific antigen (PSA) test after counselling. Symptoms will be related to the lower urinary tract and may be inflammatory or obstructive.

Prostate cancer is also a possibility in male patients with any of the following unexplained symptoms:

- erectile dysfunction
- haematuria
- lower back pain
- bone pain
- weight loss, especially in the elderly

These patients should also be offered a DRE and a PSA test

Urinary infection should be excluded before PSA testing, especially in men presenting with lower tract symptoms. The PSA test should be postponed for at least 1 month after treatment of a proven urinary infection.

If a hard, irregular prostate typical of a prostate carcinoma is felt on rectal examination, then the patient should be referred urgently. The PSA should be measured and the result should accompany the referral. Patients do not need urgent referral if the prostate is simply enlarged and the PSA is in the age-specific reference range.

In a male patient with or without lower urinary tract symptoms and in whom the prostate is normal on DRE but the age-specific PSA is raised or rising, an urgent referral should be made. In those patients whose clinical state is compromised by other co-morbidities, a discussion with the patient or carers and/or specialist in urological cancer may be more appropriate.

Symptomatic patients with high PSA levels should be referred urgently

If there is any doubt about whether to refer an asymptomatic male with a borderline level of PSA, the PSA test should be repeated after an interval of 1 to 3 months. If the second test indicates that the PSA level is rising, the patient should be referred urgently.

*DRE is a standard test for prostate cancer and involves the doctor or nurse inserting a gloved finger into the rectum to feel the prostate gland. If the gland is hard and knobbly then cancer may be present.

The referral will usually lead to a repeat DRE and PSA test as well as further investigations by TRUS biopsy (a biopsy guided by Transrectal Ultrasound) to confirm the presence or absence of cancer. Further tests such as urine flow and repeated TRUS biopsy may also be conducted where the diagnosis is unclear. If the biopsy shows that a cancer is present further tests (e.g. cytoscopy, X-rays, isotope bone scan, CT scan, MRI scan) will be needed to check whether the cancer has spread beyond the prostate (Macmillan, 2009b). Further guidelines on the diagnosis and treatment of prostate cancer have been developed and recently published (NICE, 2008).

1.2.5 Treatments

There is a range of options available to treat patients who have been diagnosed with prostate cancer, and choosing the appropriate one requires consideration of the factors listed below:

- Grade and stage of the prostate cancer
- Whether the cancer has spread beyond the prostate
- Age and general health of the patient
- Impact of the treatment on quality of life (likely side effects)
- Patient's preference
- PSA level at diagnosis

(Macmillan, 2009c)

Of crucial importance in narrowing down the treatment options for prostate cancer is whether the disease is localised, locally advanced or metastatic (spread to other parts of the body). For localised disease radical prostatectomy and radical radiotherapy have been longstanding options. More recently other options are becoming increasingly available, namely laparoscopic prostatectomy (keyhole surgery to remove the prostate), brachytherapy (radioactive seeds implanted into the prostate), cryotherapy (freezing of the cancerous cells which destroys them), and HIFU (High Intensity Focused Ultrasound which focuses sound waves in a targeted area, thereby rapidly increasing temperature causing tissue destruction). Hormonal therapy is the mainstay of advanced or metastatic disease and may be successful in curing some cancers or controlling them for many years. Some patients develop a resistance to the hormonal therapy, and chemotherapy

may be given in these circumstances to reduce the tumour. Radiotherapy can be given to relieve pain (i.e. palliative radiotherapy) if the cancer has spread to the bones. Active monitoring (also called active surveillance or watchful waiting) is an option mainly associated with localised disease and is used after diagnosis to see if the cancer is going to grow fast enough to cause any problems during the patient's lifetime so that active treatments need to be considered. Active monitoring can also be used to monitor patients after they have been actively treated to see if the cancer is growing again.

1.2.6 Outcomes

The outcomes of treatment for patients with prostate cancer will vary as a result of the type of treatment undergone, the success of the treatment and the patient's individual reaction to it. Most treatments for early stage prostate cancer offer the prospect of cure: prostatectomy, radiotherapy, brachytherapy and a combination of radiotherapy and hormonal therapy. However, the risk of side effects from the treatment is relatively high, particularly with regard to incontinence and impotence (see Table 1.3).

Table 1.3: Benefits and disadvantages of treatments for early prostate cancer

Treatment	Benefits	Disadvantages
Active surveillance (active monitoring)	• May avoid unnecessary treatment and has no side effects. • Aims to identify men who need treatment and men who do not. • No disruption of daily life.	• Although you are being closely monitored you may still worry that the cancer may grow or spread. • Treatment may become necessary at a later date.
Radical surgery (prostatectomy)	• The cancer may be completely cured. • PSA monitoring can check for recurrence after the operation.	• Operation may be too late if the cancer has already spread. • Needs one week in hospital for operation and up to six weeks' recovery time. • Tiredness after operation. • Risk of impotence (over 80%). • Risk of incontinence of urine (more than 40% short-term and up to 20% long-term). • Small chance of short-term bowel problems/diarrhoea (less than 10%). • Risk of death related to surgery (1 in 500 men).

External beam radiotherapy	• The cancer may be completely cured. • PSA monitoring can check for recurrence after the treatment (although is more difficult for doctors to interpret than after surgery). • Does not involve operation – no loss of blood. • No anaesthetic needed.	• Need to attend the hospital each weekday for 6–7 weeks for treatment. • Tiredness during and after treatment (may last some months). • Diarrhoea may occur, and cystitis is common during, and for a short time after, treatment (approximately 70%). • Possible long-term damage to bladder and rectum (2–5%). • Risk of impotence (approximately 30–50%).
Brachytherapy (radioactive seed implant)	• The cancer may be completely cured. • Simple procedure (involving several planning sessions and one treatment session). • Quick return to normal life. • PSA monitoring can check for recurrence after the treatment (although is less accurate than after surgery).	• Can cause narrowing of the urethra (making it difficult to pass urine • Causes similar side effects to external radiotherapy. • Only suitable for small prostate cancers. • Long-term side effects are not known as it is a relatively new treatment. • Needs an anaesthetic. • May cause burning sensation for several months when passing urine. • May cause inability to have erections (up to 50%) short-term and long-term. • Has a higher risk of incontinence than external beam radiotherapy. • Higher risk of urethritis (inflammation of the urethra) and cystitis than from external beam radiotherapy.

Hormonal therapy	• Rarely causes diarrhoea or bowel problems. • Can be given as outpatient treatment. Can control prostate cancer for many years. • Effectiveness of treatment can be monitored using PSA test. • Can be used in addition to radiotherapy or surgery.	• Will not get rid of all the cancer cells if it is the only treatment given. • May cause a range of side effects, including breast swelling and tenderness, hot flushes, diarrhoea, inability to have erections and loss of sex drive. Side effects vary for each hormonal therapy.

(Macmillan, 2009d)

The treatment for locally advanced prostate cancer is usually aimed at controlling it using hormonal therapy, radiotherapy or a combination of the two in order to prolong the patient's life, although some locally advanced prostate cancers can be eradicated or cured. However, the side effects of treatment can be significant (see Table 1.5 above). Consequently, elderly men with no symptoms from the cancer, or with co-morbidities, may opt for monitoring rather than active treatment (Macmillan, 2009e).

The outcomes of treatment for patients with secondary, or metastatic prostate cancer, commonly involves hormonal therapy to shrink the tumour and reduce symptoms (e.g. fatigue, problems passing urine, pain). Chemotherapy may be used when hormonal therapy is no longer effective, and similarly acts to shrink the tumour and reduce symptoms. The side effects of chemotherapy are tiredness, nausea and hair loss, although these side effects do disappear once treatment is completed. Other treatments include subcapsular orchidectomy (removal of the testicles) which causes hot flushes and

permanent impotence but does avoid the side effects of breast swelling and tenderness associated with hormonal therapy (Macmillan, 2009e). Survival rates for prostate cancer have been improving for more than 20 years. However, this is likely to have been affected by the increasing proportion of latent, earlier, slow growing tumours detected more recently, typically through PSA testing. Survival from localised prostate cancer at five years is 70% or more, but falls to around 20% where the disease is metastatic (The Prostate Cancer Charity, 2009). Survival rates vary between European countries, with the UK below the average for the EU (see Figure 1.3 above).

1.3 Policy in England

1.3.1 Building services around the preferences of patients

The NHS Plan (Department of Health, 2000a) set out the government's plan for investment and reform across the NHS, "to develop a health service for the 21st century, offering fast, convenient, high quality care, with patients at the centre. The Plan identified cancer services as a high priority to benefit from these improvements and it promised progress on cancer prevention, on research and on improved access to services. The NHS Cancer Plan (Department of Health, 2000b) set out how the improvements would be introduced. Cancer Networks, recommended in the Calman Hine* report (1995), were asked to implement the Cancer Plan, with services planned and resources targeted in accordance with care pathways.

* The Calman Hine Report of 1995 examined cancer services in the UK, and suggested a restructuring of cancer services to achieve an equality of access to high levels of expertise throughout the country.

There are now 34 Cancer Networks in England with responsibility for planning and delivering services across regional boundaries.

Professor Sir Mike Richards, National Cancer Director writes in the foreword to the Cancer National Overview:

> "One of the key aims of the NHS Cancer Plan is to ensure that patients get the right professional support and care as well as the best treatments"
>
> (Department of Health, 2002b, Foreword).

This key aim of the NHS Cancer Plan is to be realised by the introduction of targets for reducing waiting times, improved standards for cancer services and increased staff numbers and training.

The NHS Cancer Plan also acknowledged the current variation in patients' reported experience of cancer care,

> "Some patients say that they receive excellent care, with sensitive and thoughtful communication, clear information about their disease and its treatment, and good support when it is needed. Others report being given bad news in a deeply insensitive way, being left in the dark about their condition and badly informed about their treatment and care. Long waits and uncertainty add to their inevitable anxieties."
>
> (Department of Health, 2000b, p.8)

As part of the NHS Cancer Plan's commitment to detecting cancer earlier, cancer screening was to be extended, and for men with concerns about prostate cancer would mean,

> "PSA testing to detect prostate cancer will be made available, supported by information about the risks and benefits, to empower men to make their own choices"
> (Department of Health, 2000b, p.10)

The Cancer Plan also addressed the needs of patients and their families for information and support and specialist care to help them to cope with living with cancer. To ensure good communication between health professionals and patients, new joint training across professions in communication skills were to be introduced, along with the promise of

> "additional training in communication skills, and in the provision of psychological support. We will ensure that high quality written or other forms of information are available."
> (Department of Health, 2000b, p.14)

The NHS Prostate Cancer Programme (Department of Health, 2000c) was launched to improve care through developing service guidance, investing in urologists, and in developing a Prostate Cancer Risk Management Programme (PCRMP) to improve early detection (Richards, 2002). The PCRMP was intended to ensure men considering a PSA test had the

information they needed to enable them to make an informed choice on testing, and that a systematic pathway was available for individuals whose test result was above the PSA threshold. Through the PCRMP, primary care resource packs were sent to every general practitioner in England. A national Prostate Cancer Advisory Group (PCAG) was established to ensure better collaboration and communication between stakeholder organisations and government.

The new Cancer Reform Strategy (Department of Health, 2007) reported on the improvements that have occurred in the years after the implementation of the Cancer Plan. These include reduced waiting times for assessment and treatment, increases in the numbers of specialists and radiographers, better access to imaging and radiotherapy, and use of a greater range of chemotherapies following NICE appraisals. It also reported continued improvements in survival rates for several cancers. Surveys of patient experience have also been undertaken (see Chapter 1.3.2 below). The Cancer Reform Strategy was developed to build on the NHS Cancer Plan 2000 and sets priorities for the next five years, with emphasis on diagnosing cancer earlier, ensuring better treatment, reducing cancer inequalities and to support and empower patients throughout their cancer journey.

Monitoring and improving patient experience has clearly been one goal of these developments in cancer services. Patient involvement in Cancer Networks has been established, communication skills training has been provided, and information materials have been developed (Department of

Health, 2004). The Cancer Reform Strategy promises that patients will have nationally agreed high quality information tailored to their individual needs and that the National Cancer Intelligence Network (NCIN) will report annually on changes to clinical outcomes and patient experience across the country.

Box 1.3: National Cancer Intelligence Network (NCIN)

Initiated by the National Cancer Research Institute, and identified as a key deliverable within the NHS Cancer Reform Strategy for England, the NCIN is leading in the "cancer data pathway", from collection, through to linkage and information delivery. The NCIN is being developed through a small central NCIN Coordinating Team based within the NCRI in London.

The NICN core objectives are:

- Promoting efficient and effective data collection throughout the cancer journey
- Providing a common national repository for cancer datasets
- Producing expert analyses, to monitor patterns of cancer care
- Exploiting information to drive improvements in cancer care and clinical outcomes
- Enabling use of cancer information to support audit and research programmes

(National Cancer Intelligence Network, 2009)

1.3.2 National patient surveys

There have been two recent major surveys of NHS cancer patients: Cancer National Overview, 1999/2000, and National Audit Office, 2004. The Cancer National Overview 1999/2000 (Department of Health, 2002) was a large-scale survey of patients (over 65,000 responded) with cancer (breast, colorectal, lung, ovarian, prostate or non-Hodgkin's lymphoma). The results measured

patients' experience of care in the NHS, identifying areas of good practice and areas for improvement. The NCSR questionnaire, developed by the National Centre for Social Research (National Centre for Social Research, 1999), included 96 questions in six sections, with questions relating to: the hospital visit leading to the patient being selected for the survey; the first treatment for the cancer; discharge from hospital; referral and diagnosis; the most recent outpatient appointment; demographic information. The questions focused on patients' experiences in secondary care, paying little attention to primary care's role in discussing the pros and cons of screening, the initial testing (PSA, DRE), treatment for those receiving hormone therapy or the on-going monitoring of patients. Virtually all the questions had a closed response format, and asked patients to report on aspects of their care. Various steps were taken during the development of the questionnaire to inform its design, including interviews of patients suffering from different types of cancer and healthcare professionals, as well as assessment of the questionnaire's comprehensibility and acceptability.

To facilitate changes to improve care separate reports were published for each of the 34 Cancer Networks in England. The survey showed that the standard of care was often excellent. However, two important issues emerged, the variations in the experience of patients with different types of cancer, and the variations between patients in different parts of the country. Of particular importance here is the variations in experience of patients with different types of cancer, the key findings from the survey showed that the

experiences of patients with prostate cancer were often worse than those with other cancers.

- Access to care: waiting times

  "Three quarters (75%) of breast cancer patients had hospital treatment within two months of their first hospital appointment and 87% within 3 months. In contrast, of prostate cancer patients fewer than half (46%) had treatment within two months and only 56% within three months."

- First treatment: involvement, being treated with dignity and respect

  "Eleven percent of all patients - but 15% of patients with prostate cancer - said that they would like to have been more involved in decisions about their care."

- First treatment: co-ordination and continuity

  Forty-seven percent of patients said that they had been given the name of the nurse in charge, but only 38% of prostate cancer patients

- First treatment: pain and physical comfort

  "Thirteen percent of patients – but 21% of those with prostate cancer – said that, in their opinion, they were not given enough medicine (or any at all) to help with the pain."

(Department of Health, 2002)

Since then the Government has increased resources to the NHS for improvements in staffing levels, treatment and facilities. Cancer Service Collaboratives (CSCs) were established in 1999 and the CSC Improvement Partnership (CSCIP) aims to improve the patient experience of cancer services and clinical outcomes of care. The CSCIP examines service delivery to discover where improvements can be made and aims to spread good

practice by creating learning for the wider NHS on improving care for people with cancer (Cancer Service Improvement Partnership, 2007).
Cancer Networks are also working to ensure that the views of patients are taken into account.

In a more recent survey (National Audit Office, 2004) a questionnaire was used that included just over 100 questions covering diagnosis, first hospital treatment, leaving hospital, and the most recent outpatient appointment. Since the aim was to track changes since 2000, most of the questions followed the wording of the NCSR questionnaire. The survey involved 49 Trusts and questionnaires were sent to 7,800 patients, of whom 4,323 (55.4%) responded. The focus was on four cancers – breast, bowel, lung and prostate. The survey reported that cancer patients' experience of care given by hospitals improved between 2000 and 2004, although there were still some gaps in supportive and palliative care. However, it also supported the findings of the earlier survey in showing that there were differences between the experiences of different patients according to the type of cancer they had. Patients with prostate cancer responded less positively than patients with other types of cancer.

Table 1.4 shows that the percentage of positive responses had generally improved, but more strongly for patients with cancers other than prostate. This has led to a widening of the gap between the reported experiences of patients with prostate cancer and those with other cancers.

Table 1.4 Prostate cancer patients responded less positively than patients with other cancers

	2000 %		2004 %	
	Patients with prostate cancer	Patients with other cancers	Patients with prostate cancer	Patients with other cancers
Waited more than two weeks from referral by GP to be seen by specialist	72	49	68	37
Not discussed the side effects of treatment	19	15	11	6
Not discussed how treatment had gone	14	8	13	5
Would have preferred more information about how treatment had gone	21	18	20	13
Fully understood explanation of how treatment had gone	67	76	70	81
Have a named nurse in charge of care	43	56	50	61
Home situation not taken into account when discharged from hospital	21	14	13	9
Given information about support or self-help groups	36	66	34	64
Outpatient appointment cancelled one or more times	17	13	19	11

(National Audit Office, 2004, p. 4)

The reasons for the widening of the gap are unclear, although there are a number of possible explanations.

- The characteristics of the condition and service provision: prostate cancer is usually slow growing and in such cases symptoms will not worsen in the short term and the condition is unlikely to result in the patient's death in the longer term. This may be difficult for patients to fully accept, as a diagnosis of cancer is likely to cause significant anxiety and a desire for active treatment as soon as possible. Consequently there may be a mis-match between the speed at which the service responds and the speed with which patients would like it to respond.

- The treatment decision: patients who have early localised disease will have several treatment options available to them and there is no consensus as to the best treatment for early prostate cancer* (Cancer Research UK, 2008). In addition patients also have to weigh up the significant risks of side-effects associated with the different treatments (see Table 1.4 above). Consequently the treatment decision is a particularly difficult one, and patients may well feel anxious about choosing a treatment. The responsibility for choosing a treatment may also be an unfamiliar health care experience, and may cause additional anxiety.
- The characteristics of the patients: patients are exclusively male and are likely to be elderly (65+), so may be more likely to have co-morbidities or may find the treatment and side–effects more daunting and harder to cope with. Much of their previous experience of healthcare is likely to have been paternalistic in its approach to decision-making, with few opportunities to take decisions about their health care.

Amongst the NAO's recommendations from the report were that Cancer Networks should give particular attention to urological cancers, and that all patients should be able to access a urological cancer nurse specialist.

*The ProtecT study (see http://www.epi.bris.ac.uk/protect/) is currently trying to evaluate treatments for localised prostate cancer by comparing surgery (radical prostatectomy), radiotherapy (radical conformal) and active monitoring (monitoring with regular check-ups).

1.4 Measuring patient experience of prostate cancer care

1.4.1 Existing measures of patient experience of prostate cancer care

The measures used in the national surveys of 1999/2000 and 2004 (see 1.3.2 above) were designed for patients with a range of cancers other than prostate cancer specifically. Consequently, they would not be suitable for a detailed investigation of the experiences of patients with a single type of cancer. Furthermore, the many service changes implemented as a result of the NHS Cancer Plan 2000 reforms and increased investment may impact on aspects of the patient's experience that are not addressed by the national questionnaire. Therefore, an up-to-date tool that can measure the impact of these changes on the patient experience of prostate cancer care is required.

An initial literature search did not reveal any such measures of patient experience of prostate cancer care in the UK.

Box 1.4: Literature search

Aims of search
1. To identify any existing tools of patient experience of prostate cancer care
2. To identify any relevant studies of patient experience of prostate cancer care

Search terms used
Patient/carer/user experience
Prostate cancer care
Tools, measures, questionnaires, surveys

Databases searched
PubMed, Ovid, Google Scholar

Among the studies revealed by the search was one undertaken by the Rand Organisation in the USA (Litwin et al., 2000) which recognised the need for measures for assessing quality of care for prostate cancer. However, many

studies have tended to focus on specific aspects of treatment and patient satisfaction (Ruiz-Deya et al., 2001 and Smathers, 2000). One study (Hoffman et al, 2003) surveyed 2,365 patients and identified a range of physical and psychological factors that indicated patient satisfaction with treatment. These included physical functioning, perceptions of being cancer free and preserving social relationships. Patients receiving no active treatment were less satisfied than actively treated men. Other studies of cancer patients have addressed communication issues and identified the importance of the consultation (Onga et al., 2000) and recording of information that has been provided (Hack et al., 1999) in improving patient satisfaction. Psychological support and identifying information preferences have also been linked with the satisfaction of cancer patients with their experience. A US study (Lubeck et al., 2000) to validate a measure for use by patients with prostate cancer contained six individual subscales: overall satisfaction with care, contact with providers, confidence in providers, communication skills, humaneness, and a summary scale (see Box 1.5). The overall satisfaction measure demonstrated good reliability and validity, although the participatory scale could not be recommended for use. However, while this instrument was used successfully with prostate cancer patients it is not suitable for the needs of the NHS for two important reasons. Firstly, it deals with patient satisfaction rather than patient experience of care. Secondly, it is based on a measure developed in the USA (Hall et al., 1990) for assessing global satisfaction with healthcare that differs significantly from the NHS model.

Box 1.5: Components of the Satisfaction and Participatory Style Questionnaire (Lubeck et al., 2000)

Scale/Subscale	No. of Items	Item
Satisfaction scale*	9	Patients are asked to respond to the following regarding healthcare during the past 3 months.
Overall satisfaction	2	I am satisfied with the healthcare I have been receiving. There are some things about the healthcare I have been receiving that could be better.
Amount of contact	2	I have not had as much contact with healthcare providers as I think I should have had. The amount of time I've spent with healthcare providers is certainly adequate.
Communication	2	My healthcare providers could have listened more carefully to what I had to say My healthcare providers have explained completely the reasons for examination procedures or medical tests.
Humaneness	2	My healthcare providers have always treated me with the utmost respect. My healthcare providers could have been kinder and more considerate of my feelings.
Competence	1	I have an extraordinary amount of confidence in the healthcare providers I have been seeing.
Participatory style	6	If there were a choice between treatments would you like to help make the decision?* Would you like to give your opinion or ask questions regarding your treatment?* How often do you make an effort to take control over treatment?† How often do you ask to take some of the responsibility for your treatment?† How often do you ask questions about your treatment?† How often do you give your opinion to your doctor about the care you are receiving?

*Scored from 1 = definitely yes to 6 = definitely no.
*Scored from 1 = definitely yes to 6 = definitely no.
†Scored from 1 = very often to 6 = not at all.

A recent study (Jenkinson et al., 2002a) reported that measuring patients' experiences is likely to be more useful than patient satisfaction scores for monitoring performance. While there appear to be no studies that report tools developed to measure experience of prostate cancer care, a 15-item Picker Patient Experience Questionnaire has been developed for use in in-patient surveys (Jenkinson et al., 2002b). A UK randomised controlled trial, ProtecT, is currently underway (University of Bristol, 2001) to evaluate the effectiveness, cost-effectiveness and acceptability of treatments for men with localised prostate cancer. However, this study does not include the development of a measure of patient experience.

A full literature search undertaken to confirm whether there are any reported measures of patient experience of prostate cancer care is reported in Chapter 2.

1.4.2 Approaches to measuring patient experience of care

The evaluation of healthcare is not new, although the focus on patient evaluation is more recent

"The evaluation of healthcare provision is essential in the ongoing assessment and consequent quality improvement of medical services. Traditionally, assessments have ignored the reports of patients in preference to technical and physiological reports of outcome". (Jenkinson et al., 2002a)

The current policy in England is that health care should become patient-centred (Department of Health, 2000a), the experience of care of cancer patients should be improved (Department of Health, 2000b), and patient experience reported annually to drive that improvement (Department of Health, 2007). Consequently there has been increasing interest in the assessment by patients of not only their treatment but also their wider experience of care (Cleary et al., 1991). The two national surveys of NHS cancer patients in 1999/2000 and 2004 reflected this by asking patients questions about their experiences through the different phases of their care pathway (e.g. access to care, diagnosis, treatment and outpatient appointments) and also by asking about wider issues (e.g. communication, involvement, co-ordination and continuity of care).

Measures for obtaining the views of patients on the health care they have received may be framed in several different ways. Patients can be asked to report what happened, to rate or evaluate the quality of what happened, or to say how they felt about what happened. In past years, most measures concentrated on how patients felt about their care, as contained in the idea of satisfaction. However, this has not always been very illuminating.

"Probably the single most striking image of the patient conveyed by research in both Britain and the United States stems from the consistent finding that all but a minority of respondents are generally satisfied."
(Fitzpatrick and Hopkins, 1983)

Satisfaction is defined as “being satisfied in regard to desire or want” (Oxford Concise Dictionary, 1979). So patient satisfaction may be understood as being satisfied in regard to desire or want in the role of patient. In other words, does the care the patient receives meet their desires or wants? If it does then it would seem fair to presume that the patient will be satisfied. However, the judgement of whether the care meets the patient’s desires or wants will involve not only what care happened but also the patient’s evaluation of whether it met their desires or wants. This evaluation may depend on a number of factors including previous experiences of care, the importance to the patient of the care concerned and expectations of what should happen in care. Consequently, patients may receive very similar care but may not be equally satisfied with it. This complexity can make satisfaction difficult to measure and the findings difficult to interpret.

The difficulty of interpreting findings is demonstrated by the higher satisfaction that has often been recorded with technical aspects of care (e.g. treatment) than delivery of care (e.g. manner, accessibility). Why this should be the case is not clear. One explanation has been that patient satisfaction can only effectively measure those aspects of care which the patient feels competent to judge. Another explanation is that respondents are reluctant to criticise the abilities of doctors.

Furthermore, patient satisfaction surveys have generally not been very helpful in identifying aspects of care that need quality improvement.

“Attitudes to services do not tell us very much about the nature of those services. Surveys of patient satisfaction tend to elicit very positive ratings which are not sensitive to specific problems in the quality of care delivery.” (Jenkinson et al., 2002a)

A development to the patient satisfaction approach has been to obtain a rating or evaluation of the quality of care as this may provide a less difficult approach to asking patients for their views on the care they receive. The most widely used of these is the Likert scale which has been used in the General Practice Assessment Survey (GPAS) questionnaire and the patient career diary (Baker et al., 1999) for example. It typically consists of a statement which the respondent is asked to evaluate using a standardised range of five responses (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree). While there is some disagreement as to whether these categories are equidistant and so produce nominal data, the use of scales does “permit more rigorous statistical analysis” (Bowling, 2002). Nevertheless, the importance of the aspect of care concerned and patient expectations are likely to influence the patient’s evaluation. Coulter also argues that the rating scale approach is not suitable for some questions.

“The type of evaluative or rating-style question that was used to assess technical skills in the GPAS questionnaire is not useful for this purpose. It is difficult enough for a doctor's peers to give them a reliable rating, but well nigh impossible for a patient with no clinical training. Instead of asking patients to rate their care using general evaluation categories (such as excellent, very

good, good, fair, poor), it is better to ask them to report in detail on their experiences of clinical care during a particular consultation (for instance, “Were you given information about any side effects of your medicine?”), a specific episode of care (“Were you given a plan to help you manage your diabetes at home?”), or over a specified period (“Have you had your blood pressure checked in the past 12 months?”). These types of questions are designed to elicit reports on what actually occurred, rather than the patient's evaluation of what occurred, and they produce more reliable results.” (Coulter, 2006c)

Theoretically, patients’ reports of their experience should simplify matters. Reports involve less judgement on the quality of what happens in care, and the findings should therefore be easier to interpret and constitute a clearer guide to providers on the changes that may be needed in their delivery of care to improve patient experience. Consequently, measures of patient experience are becoming more common (e.g. Picker surveys) and increasingly preferred in monitoring health service improvements (Jenkinson et al., 2002b; Coulter, 2002).

However, it should be recognised that patients’ reports of their experiences may not be entirely free from influence by their feelings and priorities. Their reports may be coloured by their view of the quality of the care and their reactions to it. Reports “may indicate how often something occurred but describe nothing about how patients experienced it” (Drain and Clark, 2004). Moreover, it is essential in the development of patient experience measures

that the issues of importance to patients are carefully identified and included in the instruments that are eventually used. If instruments employ closed question formats, eliminate expressions of satisfaction or dissatisfaction, and focus on specific aspects of care, they may limit the information obtained on patient experience unless they address all those aspects of care important to patients.

Consequently, the measure of patient experience to be developed here will adopt a similar approach to those of the Picker instruments which will be to avoid asking patients if they were satisfied with their care and ask whether certain processes and events occurred during the course of a specific episode of care. Particular attention will be given to ensuring that the measure reflects the concerns of prostate cancer patients.

1.4.3 Methods of developing measures of patient experience

Streiner and Norman (1995) identify an approach that may be used to develop a measure of "subjective states", and this may be adopted to develop a measure of patient experience of prostate cancer care. The approach may be summarised as follows:

i. Search the literature and critically review any scales of potential interest. This will involve considering: validity (face, content and criterion) and reliability (internal consistency, stability).

If no suitable measure exists, then

ii. Devise the items. This will involve using one or more of the following: items from other measures, clinical observation, theory, research and expert opinion.

iii. Scaling responses. This will involve deciding where to use categorical and continuous responses, nominal and ordinal scales, interval and ratio variables. The choices made will determine whether parametric statistics (for interval and ratio variables) or non-parametric statistics (for nominal and ordinal data) are used for analysis.

iv. Selecting the items. This will involve eliminating items that are ambiguous or incomprehensible, checking face validity, testing endorsement frequency, checking the homogeneity of the scale of the items (e.g. item-total correlation, split-half reliability) and calculating multifactor inventories (e.g. factor analysis).

v. Biases in responding. Developers of tests consider the following potential biases and should take steps to minimize them where they may occur: social desirability and faking good, deviation and faking bad, acquiescence, end-aversion, positive skew and halo effect.

vi. From items to scales. Developers of tests should consider differential weighting of items, transforming scores into percentiles to allow comparison with other instruments and developing separate age or age-sex norms.

vii. Reliability. Determining if the instrument is measuring something in a reproducible and consistent fashion by applying tests of reliability e.g. ANOVA, test-retest reliability

viii. Validity. Determining if the scale is measuring what it is intended to measure. There are three types of validity to consider: content, criterion and construct.

ix. Methods of administering the questionnaire. The options to consider are: face-to-face interviews, telephone, mail and computer.

1.4.4 Developing a measure of patient experience: the approach adopted

The aim of this study was to develop a valid, reliable and usable measure of patient experience of prostate cancer care suitable for use in routine practice. The methodological stages may, broadly, be regarded as having three principal stages: (1) preparation of the measure; (2) piloting the measure; (3) evaluation of the measure (Streiner and Norman, 1995; Cheater et al., 1999). Consequently, the following objectives were set:

- investigate through interviews and mailed survey the needs of cancer teams for the measures
- review relevant literature and interview patients, carers, and members of cancer networks and multidisciplinary cancer teams to ensure the measure covers all relevant aspects of patient experience
- reduce the number of questions to a minimum through evaluation in pilot tests
- administer the measures to a sample of patients to test validity and reliability
- compare the performance of the measure with other measures of patient experience

A brief outline of the methods used in developing the new measure is described below, with more detailed descriptions of the methods in the Chapters that follow.

The first step in developing a new measure is to determine its focus, what it should contain, and its format. The measure is concerned with patient experience but what aspects of experience should be addressed by the measure, and how should the measure be structured to maximise acceptability and convenience? Two issues must be taken into account in determining which aspects of patient experience should be included in the measure – first, the aspects of care most important to patients in influencing their experience (the salient aspects of care), and secondly, those aspects of care regarded as important by providers. Whilst the importance of recognising the aspects of care important to patients is self-evident, the case for also taking account of providers' perspectives may need explanation. The measure of patient experience of prostate cancer care being developed is intended for use in the improvement of services. Providers must therefore be confident that the measure does capture information on aspects of care subject to quality improvement initiatives. They also require a measure that can be used in practice in different contexts and for different quality improvement projects. Consequently, exploration of providers' perspectives on the content, format and likely uses of the measure needed exploration.

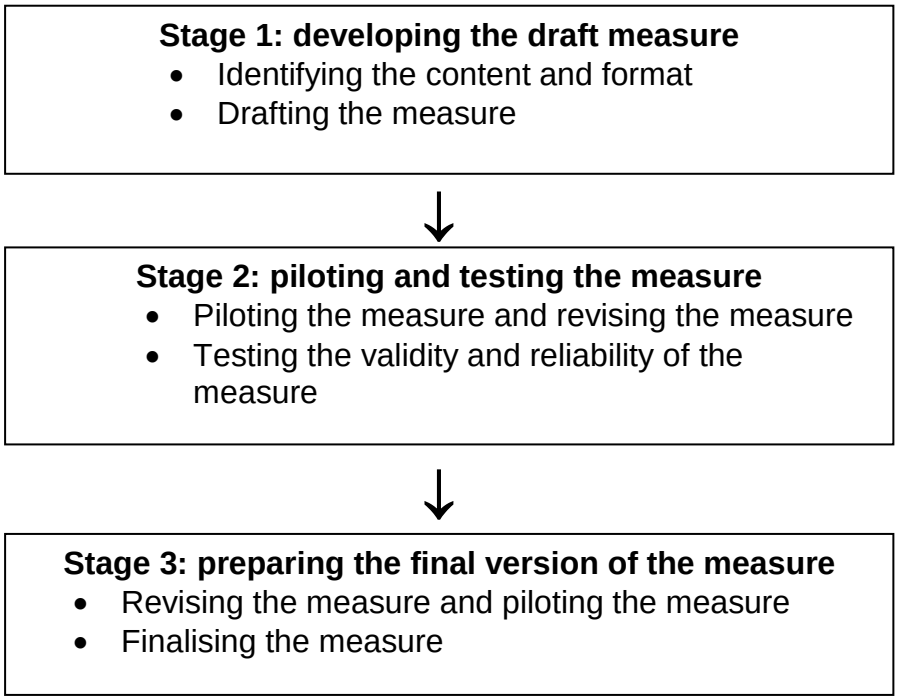
Several methods were used to identify the issues of importance to patients. These included a detailed review of published research of patients'

experiences of prostate cancer care (see Chapter 2) and qualitative interviews of patients and carers (see Chapter 3). The following steps were taken to identify issues important to providers: a questionnaire survey of cancer networks; interviews of health professionals, including service improvement leads, general practitioners, and members of cancer multi-disciplinary teams. Voluntary sector staff who provide services to men with prostate cancer were also interviewed (see Chapter 3).

At the conclusion of this preparatory work a first version of a questionnaire for completion by patients and carers was drafted (see Chapter 4). Samples of patients were asked to complete this questionnaire PCQ-P v1 (Prostate Care Questionnaire – Patients version 1) and the responses were investigated to identify questions that needed amendment or removal. Further samples of patients were then asked to complete the revised questionnaire, PCQ-P v2. Samples of patients were interviewed to check the comprehensibility and acceptability of the measure (see Chapter 5).

A third version of the measure was produced. The measure then underwent further evaluation in order to determine its suitability for use, involving tests to establish validity and reliability (see Chapter 6). Following another piloting phase, final revisions to the questionnaire were made (see Chapter 7). A flow diagram is presented below which summarises the process described above.

Figure 1.5: Flow diagram of the process of developing a measure of patient experience



The strengths and weaknesses of the development methods used are discussed along with issues for further research and recommendations for the use of the measure (see Chapter 8).

NB A measure of carers' experience of prostate cancer care

It became apparent during the research that the carers of men with prostate cancer usually played a very important role in providing a range of support to the patient. As the disease is one that predominantly affects older men their carers may be elderly and may have their own health needs. It follows that some carers are likely to require some support if they are to be effective in caring for the patient. The development of a questionnaire to capture the experiences of carers would help to ensure that their needs were understood and action could be taken by the NHS to meet them. During development of a measure of patients' experience of prostate cancer care, the research team developed an instrument for carers, but this work is out with this thesis.

Chapter 2: Review of the literature on patient experience of prostate cancer care

In this chapter I will report on a literature review of the experiences of care of men with prostate cancer and this will include identifying any existing measures of patient experience of prostate cancer care.

2.1 Introduction

The development of a new measure of prostate cancer care would need to be supported by research to ensure that its form and content effectively captures the experiences of prostate cancer patients throughout the different phases of their care. The first step is to find out what is already known about the experiences of care of prostate cancer patients. The focus of the review was on studies of patient experience of care as they are more likely to report on specific factual aspects of care and are easier to interpret than the rating questions commonly included in patient satisfaction surveys that report on how they felt about what happened and typically have responses such as "good, fair, poor" (Coulter and Cleary, 2001).

Box 2.1: Definition of patient experience

> The measurement of patients' experiences…aims to elicit factual data that may be easier to interpret. Respondents are asked to report on "what happened" in relation to a specific episode of care, rather than "how satisfied were you?"
>
> (Coulter and Cleary, 2001, p. 244)

Moreover, patient satisfaction questionnaires have limitations when the data collected is to be used for planning and reviewing services.

"Questionnaires that ask patients to rate their care in terms of how satisfied they are tend to elicit very strong positive ratings, which are not sensitive to problems with the specific processes that affect the quality of care delivery. A more valid approach is to ask patients to report in detail on their experiences by asking them specific questions about whether or not certain processes and events occurred during the course of a specific episode of care"

(Jenkinson et al., 2002, p. 354)

The two recent literature reviews of patient aspects of prostate cancer that have already been completed focus on psychosocial adjustment in partners of men with prostate cancer (Couper et al., 2006) and why men chose one treatment over another (Zeliadt et al., 2006). There are no up-to-date comprehensive literature reviews that could inform the development of the planned new measure, and therefore a literature review was undertaken to establish what is known about prostate cancer patients' experiences of care. Carers have an important role to play in supporting men through their patient journey and therefore literature on the experience of carers was also sought. The specific objectives of the review were:

a) To identify studies which reported on prostate cancer patients' and carers' experiences of care.
b) To identify any existing measures of patient experience of prostate cancer care.

2.2 Methods

In seeking to identify studies of patients' and carers' experiences of care for prostate cancer all phases of prostate cancer care were included, from screening through to end-of-life, and all aspects of prostate cancer care including information provision, decision-making and psychosocial distress and support. Patient experience was defined as patients' reports of how care was organized and delivered to meet their needs. We excluded studies of the clinical effectiveness of care, for example studies of symptom control, quality of life, the incidence of side-effects or survival, but instead focused on studies of patients' experiences of how the healthcare system and health professionals helped them through care. Thus, studies of the information and support needs of patients and carers relating to pain were included, but studies of clinical interventions to reduce pain were not

a) Search terms

As has been explained (see Chapter 2.1) a preference for measures of patient experience over patient satisfaction in reviewing health services from the patients' perspective has been established. Initial searches also indicated that the term "patient satisfaction" was not useful in limiting results to literature specifically on the patient experience of care. This may be due to the abundance of published research on measuring patient satisfaction with health services, including cancer care. Consequently, the search terms used were "experience, choices and preferences" as they appeared to narrow satisfactorily the results to literature related specifically to the patient experience of prostate cancer care.

b) Search strategy

Through discussion with JCS (an Information Scientist), I developed a search strategy for the following databases: MEDLINE (1966 to December 2006), EMBASE (1980 to December 2006), CINAHL (1982 to December 2006) and PsycINFO (1987 to December 2006). A search of the SIGLE database (System for Grey Literature in Europe) was also undertaken to identify any theses and unpublished reports. The search strategy used is shown in Box 2.2 below.

Box 2.2: Search strategy used in literature review

Research Question

What are the experiences of care of men and their carers at different stages of prostate cancer?

- Need to find out the aspects of care that are important to them, include different age groups, ethnic groups, socio-economic groups, different sexual orientation
- The search should be English Language and go back to at least 1980. It should involve qualitative and quantitative studies.
- Search terms should be limited to prostate cancer and focus on patient and carer experience. Other terms that may be searched for experience include: patients' attitudes, values, feelings, perspective, preferences, choices, reports, information needs, unmet needs. Other terms that may be searched for patients include: consumer and user, and for carers include: wives, partners, spouses, relatives.

Search exclusion criteria

- Cancers other than prostate
- Other experiences than patients/carers

Suggested inclusion criteria for screening articles
(Taken from issues covered by National Survey of NHS Cancer Patients)

- Clinical care
- Access
- Respect and dignity
- Patient involvement/empowerment
- Confidence/trust
- Environment/privacy
- Pain control and distress
- Information and communication, including decision-making

In consultation with JCS (an Information Scientist) a set of search terms was drawn up, which were developed through an iterative process adding terms found in relevant papers. These included both medical subject headings (MeSH) where available, and free text terms, and are summarized in Table 2.1.

Table 2.1: A summary of the search terms used to identify potentially relevant papers

Categories	Search terms: used primarily in health care	Search terms: additional and alternative terms
People	Patient, carer	Consumer, user, spouse, couple, partner, wife, wives, family, families, relative
Disease	Prostate cancer	Exp Prostatic neoplasm/(MeSH), tumour, malignancy
Aspect of care	Experience of care for prostate cancer	Exp patient centred care/(MeSH) Experience, attitude, value, feeling, view, perspective, preference, choice, report, information need, unmet need, involvement, care pathway

c) Inclusion/exclusion criteria

I and another reviewer (SA) independently checked the resulting titles and abstracts against the inclusion and exclusion criteria to identify potentially relevant publications. Studies identified as potentially relevant by at least one reviewer were obtained in full text for further examination. Studies of all types of design were included. Quantitative and qualitative studies published in English were included that involved a minimum of 10 subjects being screened, investigated for, or having been diagnosed with prostate cancer and at any stage of treatment or care, and being concerned with patients' and /or carers' experiences of prostate cancer care.

Studies were excluded for a variety of reasons, most commonly because they proved not to be relevant as they reported on quality of life issues after treatment rather than experience of care. Studies that reported solely on pain, the incidence and management of side-effects following treatment, and developing tools (e.g. designing decision aids) were excluded. Studies involving groups of patients with different types of cancers were also excluded unless they clearly differentiated those with prostate cancer. If the study involved less than ten participants it was excluded on the grounds that the results would not allow reasonably justifiable conclusions to be drawn. Literature reviews were excluded to avoid double reporting of studies, although the studies referenced in such reviews were included. The reference lists of included articles were also scanned for additional papers not identified by the original searches.

d) Data extraction

Standardized forms (see Appendix 1) were used to extract data and review them to decide whether to include or exclude studies. Where I and the other reviewer failed to agree the paper was referred to a third reviewer. The data from each included study were summarized in tables, including: method of data collection, number of participants, country where the study took place, phase(s) of the care pathway, aspect of care and reported experiences of patients and issues considered important by them.

e) Analysis

In view of the heterogeneous designs and methods used in the studies identified, a quantitative synthesis of the findings was not undertaken. Instead, a narrative summary was undertaken. Narrative summary is often used in systematic reviews and typically involves the selection and ordering of evidence to produce accounts of evidence. Narrative summary can ‘‘integrate’’ qualitative and quantitative evidence through narrative juxtaposition – discussing diverse forms of evidence side by side (Dixon-Woods et al., 2005). This process involved repeated study of the summarized findings to clarify the meaning of the data, supplemented by reference to the articles in full when necessary, followed in my review by the organization of the findings into the phases of care experienced by patients.

2.3 Results

The searches identified a total of 1476 articles and after assessment of these 90 studies were judged relevant, met the inclusion criteria and were retained (Table 2.2 below summarises the numbers of studies at each stage of the process).

Table 2.2: Search Results

Total number of articles identified by searches	1476
Number of articles assessed as potentially relevant	123
Number of articles identified from references of selected articles as potentially relevant	36
Total number of articles fully reviewed to assess relevance	159
Number of articles that were relevant and met inclusion criteria	90

The included studies included a total of 14,363 patients and 561 carers. The smallest study included 10 patients and the largest 4226. The 90 studies included 14 trials of interventions. The methods of collecting data were 44 questionnaire surveys, six telephone surveys, three telephone interviews, 10 focus group studies, 35 face-to face interview studies and one set of written logs (some studies used more than one method).

Most studies reported on experiences of the following phases of the care pathway: screening, explanation of diagnosis, the treatment decision, treatment and post-initial treatment. Very few studies reported on experiences of the phases of referral, testing (e.g. biopsy, urine flow), and further treatment and palliative care and no studies reported on monitoring and terminal care (see Table 2.3).

Table 2.3 Numbers of studies that considered different phases of the care pathway

Phase of the care pathway	Number of studies
Screening	15
Referral	1
Testing	1
Explanation of diagnosis	12
Treatment decision	28
Treatment	18
Post-initial treatment	33
Monitoring	0
Further treatment and palliative care	1
End-of-life care	0

The aspects of care predominantly reported on by the studies were knowledge and information, decision making, support and coping (see Table 2.4).

Table 2.4: Aspects of care reported on by the studies

Aspect of care	Number of studies*
Knowledge/information	59
Communication	9
Decision-making	41
Treatment side effects	10
Facilitation of self-care/self-help	7
Support	28
Role of carer	8
Relationship with health professionals	10
Complementary therapies	4
Coping/adjustment/ emotional reactions/ psychological distress/anxiety	26
Satisfaction with care	4

*The total number of studies not given as some studies investigated more than one aspect of care.

The 90 studies included 43 that used qualitative methods and 53 that used quantitative methods (some studies used more than one method) and have been listed in Table 2.5 below.

Table 2.5: a summary of the studies

PAPER	METHOD	SAMPLE/PARTICIPANTS	SETTING	COUNTRY
Arroll et al 2003	Cross sectional telephone survey	120 men with prostate cancer	Primary care	New Zealand
Bailey D.E. et al 2004	Randomized Control Trial	41 men with prostate cancer	Secondary care	USA
Berglund G et al 2002	Randomized Control Trial	211 men with prostate cancer	Secondary care	Sweden
Boberg E.W et al 2003	Focus group, questionnaire survey and in-depth interview	6 focus groups (39 men with prostate cancer), 233/500 responses from men with prostate cancer to questionnaires	Secondary care	USA
Boehmer U & Clark J.A 2001	Focus groups	7men with prostate cancer and their partners	Secondary care	USA
Booker J. et al 2004	Questionnaire	36 men with prostate cancer	Secondary care	UK
Boxhall S & Dougherty M 2003	Focus group	30 men with prostate cancer	Secondary care	Australia
Breau R.H. et al 2003	Semi structured interview	120 men with prostate cancer	Tertiary Care	Canada
Broom A. 2005	Interview	33 men with prostate cancer	Not stated	Australia

Butler L. et al 2000	Interview	21 partners of men with prostate cancer	Secondary care	Canada
Chapple A et al 2002 (a)	Interview	52 men with suspected or confirmed prostate cancer	Primary care	UK
Chapple A et al 2002 (b)	Interview	50 men with prostate cancer	Range of settings	UK
Cohen H & Britten N 2003	Semi structured interview	19 men with prostate cancer	Secondary care	UK
Crawford E.D. et al 1997	Telephone survey	1000 men with prostate cancer and 200 urologists	Secondary care	USA
Davison B.J. et al 1995	Questionnaire	57 men with prostate cancer	Secondary care	Canada
Davison B.J. & Degner L.F. 1997	Randomized Control Trial	60 men with prostate cancer	Secondary care	Canada
Davison B.J et al 1999	Randomized Control Trial	100 men (prior to periodic health examination)	Primary care	Canada
Davison B.J. et al 2002	Control preferences scale and questionnaire	80 men with prostate cancer and their partners	Secondary care	Canada
Davison B.J. et al 2003	Questionnaire	74 men with prostate cancer and their partners	Secondary care	Canada
Davison B.J. et al 2004	Questionnaire	100 men with prostate cancer	Secondary care	Canada
Dube C.E. et al 2004	Focus group	53 men (33 with prostate cancer and 20 with testicular cancer)	Secondary care	USA
Duke J et al 2001	Self-administered questionnaire	650 men with prostate cancer	Secondary care	Australia
Eakin E.G. & Strycker L.A. 2001	Questionnaire	501 patients with breast, colon or prostate cancer (n=151)	Secondary care	USA
Eton D.T. et al 2005	Interview and questionnaire	165 couples	Secondary care	USA
Feldman-Stewart D et al 2001	Questionnaire survey	22/38 families of men with prostate cancer responded to the survey	Secondary care	Canada
Feltwell A.K. & Rees C.E. 2004	Focus group and couple interview	Focus group of 2 men with prostate cancer and their partners (n=4) and 4 men with prostate cancer and their partners took part in interviews (n=8)	Secondary care	UK
Fitch M.I et al 1999	Questionnaire	621 men diagnosed with prostate cancer	Secondary care	Canada
Fitch M.I et al 2000	Questionnaire	120 men with recurrent prostate cancer and 845 men without recurrent disease	Secondary care	Canada
Flood A.B. et al 1996	Questionnaire	Men pre-assigned to view the educational videotape (n=184) or another videotape (n=188). Men scheduled to visit a general internal medicine clinic viewed either the educational videotape (n=103) or no videotape (n=93)	Secondary care	USA

Gray R.E. et al 1997	Semi structured interview	12 men with prostate cancer	Not stated	Canada
Gray R.E. et al 1999	Semi structured interview	34 men with prostate cancer and their partners	Secondary care	Canada
Gray R.E. et al 2000	Interview prior to surgery; 8 to 10 weeks post-surgery; and 11-13 months post-surgery	34 men with prostate cancer	Secondary care	Canada
Gregoire I et al 1997	Questionnaire	54 men with prostate cancer and some family members	Secondary care	Canada
Gwede C.K et al 2005	Questionnaire	119 men treated with radical prostatectomy (44%) or brachytherapy (56%)	Secondary care	USA
Hack T.F et al 1999	Randomised controlled trial	18 men with prostate cancer	Tertiary care	Canada
Hamilton J.B. & Sandelowski M 2004	Interview	13 African American men with prostate cancer	Not stated	USA
Harden J et al 2002	Focus group	42 participants (22 men with prostate cancer and 20 spouse-caregivers)	Secondary care	USA
Hellbom M et al 1998	Questionnaire	527 patients newly diagnosed with breast, colorectal, gastric and prostate cancer (n=197)	Secondary care	Sweden
Heyman E.N. & Rosner T.T. 1996	Focus group and interview	20 men with prostate cancer and their wives	Secondary care	USA
Holmboe E.S. & Concato J 2000	Interview	102 men with prostate cancer (newly diagnosed)	Secondary care	USA
Jacobs J.R et al 2002	Focus interview	5 men with prostate cancer and their spouses, 5 urologic oncologists and 5 oncology nurses	Secondary care	USA
Jakobsson L et al 1997	Interview	11 men with prostate cancer	Secondary care	Sweden
Johnson J.E. et al 1987	Randomized Control Trial	84 men with prostate cancer	Secondary care	USA
Kelsey S.G et al 2004	Focus group	27 men with prostate cancer	Secondary care	UK
Kronenwetter C. et al 2005	Interviews	26 men with prostate cancer	Secondary care	USA
Lintz K et al 2003	Questionnaire survey	210 men with prostate cancer	Secondary care	UK
Maliski S.L et al 2002	Cross sectional interview	20 couples men with prostate cancer	Secondary care	UK
Manne S et al 2003	Randomized control trial	60 partners of men with prostate cancer	Secondary care	USA
Mazur D.J & Hickman D.H 1996	Structured interview	140 men with prostate cancer	Secondary care	UK
McGregor S 2003 (a)	Semi structured interview	10 men with prostate cancer	Secondary care	UK
McGregor S 2003 (b)	Semi-structured interview	10 healthy men and 12 men with localised prostate cancer	Secondary care	UK

Meredith P et al 1995	Questionnaire survey	4226 men with prostate cancer (undergoing prostatectomy)	Secondary care	UK
Miles B.J. et al 1999	Telephone survey	421 men with prostate cancer	Not stated	USA
Moore K.N & Estey A 1999	Semi structured interview	63 men with prostate cancer	Secondary care	Canada
Nathan D et al 2002	Questionnaire	30 men with prostate cancer	Secondary care	USA
Nyman C.R. et al 2005	Questionnaire	150 patients	Secondary care	Sweden
Oliffe J. 2004	Interview	30 men with prostate cancer	Secondary care	Australia
Oliffe J 2006	Interview	35 Anglo-Australian men	Primary care	Australia
Onel E et al 1998	Questionnaire	111 men with newly diagnosed prostate cancer	Secondary care	USA
O'Rourke M.E. 1999	Interview (in couples and separately)	18 men with prostate cancer and their partners	Not stated	USA
O'Rourke M.E. & Germino B.B 1998	Focus group	12 men with prostate cancer and 6 partners	Secondary care	USA
O'Rourke M.E. & Germino B.B 2000	Interview	18 men with prostate cancer and their partners	Not stated	USA
Petry H et al 2004	Interview	10 men with prostate cancer and their partners	Secondary care	Switzerland
Phillips C et al 2000	Interviews with couples together and then separately	34 men with prostate cancer and their partners	Secondary care	Canada
Poole G et al 2001	Questionnaire	240 men with prostate cancer	Range of settings	Canada
Porterfield H.A. 1997	Telephone survey	1000 randomly selected members of US Too International Inc and 200 doctors	Secondary care	USA
Ptacek J.T. et al 1999	Questionnaire	57 men with prostate cancer and their partners	Secondary care	USA
Ptacek J.T et al 2002	Questionnaire	57 men with prostate cancer	Secondary care	USA
Rees C.E. et al 2003	Questionnaire	39 partners of men with prostate cancer	Secondary care	UK
Salmenpera L et al 2001	Questionnaire	190 men with prostate cancer	Tertiary care	Finland
Schapira M.M. et al 1999	Questionnaire	112 men with prostate cancer	Secondary care	USA
Schapira M.M. & Vanruiswyk J 2000	Questionnaire (Randomized Control Trial)	257 men aged 50-80	Primary care	USA
Sculpher M et al 2004	Interviews	129 men with non-metastatic prostate cancer	Secondary care	UK
Scura K.W et al 2004	Randomized Control Trial	17 men with prostate cancer	Secondary care	USA
Sheridan S.L. et al 2004	Questionnaire	188 men	Primary care	USA
Slevin T.J. et al 1999	Cross sectional survey	400 men	Secondary care	Australia
Smith R.L et al 2002	Postal questionnaire, Focus group	112 men with prostate cancer, 66 urologists	Not stated	USA

Steginga S.K et al 2001	Questionnaire	206 men with prostate cancer	Not stated	Australia
Steginga S.K. et al 2004	Questionnaire	111 men with prostate cancer (newly diagnosed)	Not stated	Australia
Templeton H & Coates V 2003	Structured interview	90 men with prostate cancer	Secondary care	UK
Templeton H. & Coates V. 2004	Randomized Control Trial	55 men with prostate cancer	Secondary care	UK
Van Tol-Geerdink J.J et al 2006	Questionnaire, interview	150 patients	Secondary care	Netherlands
Volk R.J. et al 1997	Interview	10 couples (men were asymptomatic)	Primary care	USA
Volk R.J. et al 1999	Randomized Control Trial	160 men	Primary care	USA
Weber B.A. et al 2004	Randomized Control Trial	30 men with prostate cancer	Secondary care	USA
Wolf A.M.D. et al 1996	Interview (Randomized Control Trial)	160 men	Primary care	USA
Wolf A.M.D. & Schorling J.B. 1998	Questionnaire	104 elderly men (65+) with no history of prostate cancer	Primary care	USA
Wong T.F et al 2000	Questionnaire	101 men with prostate cancer	Tertiary care	Canada
Woolf S.H. et al 2005	Questionnaire	161 primary care patients	Primary care	USA

A table with further information for each study is presented in Appendix 2. It reports on: method of data collection, number of participants, country where the study took place, phases(s) of the care pathway, aspect of care reported, and reported experiences of patients and issues considered important by them.

The following sections summarize the aspects of care identified from the literature at each phase of the care pathway.

Screening

The studies that reported on screening for prostate cancer indicated that although men tended to regard screening positively, (Arroll et al.,

2003;Chapple et al., 2002) their knowledge of prostate cancer was often poor (Volk et al., 1999) and they experienced deficiencies in pre-test information (Arroll et al., 2003; Chapple et al., 2002; Volk et al., 1999) and discussion (Slevin et al., 1999; Dube et al., 2005). Interventions to improve patients' knowledge were reported as successful in increasing knowledge (Volk et al., 1999; Schapira and Vanruiswyk, 2000) and enabled men to assume a significantly more active role in making a screening decision (Davison et al., 1999). However, the effect of improved patient knowledge was often to reduce interest in being screened (Wolf and Schoring, 1998; Wolf et al., 1996; Sheridan et al., 2004; Flood et al., 1996). One small qualitative study of 10 couples reported that husbands were found to prefer a no screening strategy, while their wives preferred screening for their husbands (Volk et al., 1997). Many of the 33 patients in one study preferred more discussion to share the screening decision with a professional (Dube et al., 2005), while a larger study of 161 patients reported almost a quarter experienced greater decisional control than they wanted (Woolf et al., 2005). As regards experiences of the tests themselves, a small study reported that patients preferred the Prostate Specific Antigen (PSA) test to the Digital Rectal Examination (DRE) as it was less physically invasive and produced quantitative standardized results (Volk et al., 1997).

Referral

In the only study to report on referral, all 35 patients with an elevated PSA and ⁄or abnormal DRE accepted their GP's recommendation to see a consultant (Oliffe, 2006)

Testing at the hospital

One study reported on the testing of 30 patients following referral. It found that men were anxious before the biopsy and during the biopsy experienced discomfort and embarrassment, in addition to needling pain. They felt that they had not been prepared for the level of pain experienced (Oliffe, 2004).

Explanation of diagnosis

The two small studies (n = 34 and n = 21) relating to the period of diagnosis reported that patients and their partners were often shocked by the diagnosis of prostate cancer (Oliffe, 2004; Gray et al., 1999) which could then affect their relationships positively or negatively (Gray et al., 1999; Kronenwetter et al., 2005). The diagnosis caused many couples to seek information from a variety of sources (e.g. internet, library, charities) before discussing treatment options with the clinician (Gray et al., 2000; Maliski and Heilemann, 2002). While most patients (over 70%) wanted detailed information on their disease, treatment, survival, self-care and empowerment (Wong et al., 2000) there was poor agreement amongst patients about their information priorities, and also between patients and their carers (Feldman-Stewart et al., 2001). Patients found specialist nurses were acceptable providers of information, and patients valued the extra time available to them compared with doctors (Boxhall and Dougherty, 2003). Interventions reported as helpful to recently diagnosed patients included a combination of information and physical training (Berglund, 2003), provision of an audiotape of the consultation (Hack et al., 1999), and individual psychological support (Hellbom, 1998).

Treatment decision

Mens' information needs centred on the stage of the disease, types of treatment available and survival (Wong et al., 2000; Davison, 1995). Patients in two small studies experienced difficulties in understanding and remembering information, especially at the time of diagnosis, and patient knowledge of prostate cancer was often incomplete (McGregor, 2003a; Nathan, 2002). Patients found written materials helpful (Schapira, 1999), and the provision of information tailored to individual needs was associated with reduced distress and enabled patients to participate in the treatment decision (Davison et al., 2003). A large study reported that more than 80% of patients obtained information from the urologist alone (Miles et al., 1999), although where a small number of patients experienced several different sources, this could lead to confusion (Schapira et al., 1999; O'Rourke and Germino, 1998). Interventions (e.g. video, interactive CD-ROM) to improve knowledge were reported as effective (Nathan, 2002; Onel et al., 1998), reduced anxiety (Davison and Degner, 1997), and helped patients to play a more active role in decision making (Onel et al., 1998; McGregor, 2003b). Several studies found that many patients and their partners wanted to be informed and were involved in treatment decisions (Butler et al., 2000; Wong et al., 2000; Davison and Degner, 1997; Porterfield, 1997) which they preferred (Davison et al., 2002) even though they may experience difficulty and distress while making the treatment decision (Gwede et al., 2005). In another study, smaller numbers of patients reported that they had played a passive role either through choice (58%) (Davison et al., 1995) or because the shock of the

diagnosis left them unable to participate in the decision-making process. Initially they had welcomed the doctor's directive role, but months later some were critical of the decision-making process (Nathan et al., 2002; Cohen and Britten, 2003; Boehmer and Clark, 2001). Almost all of the 150 patients in one study who were fully informed through discussion and written information reported that they were sure about their treatment choice, and were satisfied with their choice after 3 months of treatment (Nyman et al., 2005). Patients' choice of treatment depended on the disease, age, personal values, vicarious and personal cancer experiences, the physician–patient relationship, (O'Rourke and Germino, 1998; Mazur and Hickman, 1996) and the potential for cure and risk of recurrence (O'Rourke, 1999). Patients experienced problems with the information provided on treatment options and felt that sometimes doctors did not give some of the treatment options serious consideration (Miles et al., 1999; O'Rourke, 1999). Over half of patients opted for surgery in one study, including patients who had received information suggesting that an alternative treatment would have been more appropriate (Mazur and Hickman, 1996) and the most common reason for patients rejecting watchful waiting was fear of future consequences (Holmboe and Concato, 2000). Patients in a small qualitative study reported that they rarely experienced an opportunity to re-visit the treatment decision and felt reluctant to re-open discussion themselves because they did not want to challenge the clinician (Cohen and Britten, 2003). However, patients tended to be satisfied with the treatment decision following therapy (Miles et al., 1999; Onel et al., 1998). Several studies (Gwede et al., 2005; Cohen and Britten, 2003; van Tol-Geerdink et al., 2006) found that most patients chose treatments on the

basis that they offered better quality of life rather than better prospects of cure, and presented with the opportunity to explore trade-offs between life expectancy and side-effects, men were willing to trade-off some life expectancy to be relieved of troublesome side-effects such as limitations in physical energy and, in the case of men under 70, erectile dysfunction (Sculpher et al., 2004). One study of patients' treatment choice reported surgery being chosen as a treatment promising cure by 53%, and that concern about potential side-effects did not deter men from choosing surgery (Mazur and Hickman, 1996). However, care should be taken in drawing conclusions as further analysis revealed that different realities are constructed by couples and reveal different pictures of the decision-making process (O'Rourke, 2000).

Treatment

One small study (27 men) of experience of radiotherapy reported that some patients experienced a fragmented approach to their care, as well as having unmet information needs (Kelsey et al., 2004). The information patients wanted at the treatment stage was about their disease and treatment (Wong et al., 2000; Templeton and Coates, 2003), in particular information about the likelihood of the cancer spreading, and to address concerns about the worries of close family and changes in sexual feelings (Templeton and Coates, 2003; Lintz et al. 2003; Meredith et al., 1995). Lack of appropriate information may in part be due to patients, partners and professionals having different opinions on the most troublesome problems associated with treatment (Jacobs et al., 2002), and patients not stating their unmet needs (Jakobsson et al., 1997). A

pre-operative class that developed couples' expectations of the treatment and recovery period helped them feel more in control of the situation and less anxious (Maliski and Heilemann, 2002). Almost half of patients in one study (Kronenwetter et al., 2005) thought that the use of complementary therapies was beneficial (Salmenpera¨et al., 2001), and the most commonly adopted were dietary changes, vitamins and herbal and nutritional supplements, with their use being associated with lower psychological distress (Steginga et al., 2004). An intervention that combined a diet and exercise regime contributed to feelings of optimism (Kronenwetter et al., 2005). Information and educational interventions (e.g. tape recordings of patients' experience, booklets and nurse teaching) helped patients cope with treatment, maintain usual activities (Johnson et al., 1989) and improved quality of life and satisfaction with care (Templeton and Coates, 2004). An intervention of five weekly telephone calls from a nurse for men who had opted for active monitoring (watchful waiting) helped participants manage the uncertainty (Bailey et al., 2004). However, in a qualitative study (n = 50), some patients opting for watchful waiting experienced pressure from family members, doctors or support groups to change their decision (Chapple et al., 2002b).

Post-initial treatment

Patients who had undergone radical prostatectomy placed emphasis on regaining control over their lives and recovering their physical capacity quickly (Petry et al., 2004; Phillips et al., 2000). However, patients often experienced unmet informational needs (Lintz et al., 2003; Boberg et al., 2003) which changed over time (Heyman and Rosner,1996; Rees et al., 2003), with

particular needs at the time of discharge from hospital (Moore and Estey, 1999; Harden et al., 2002; Davison et al., 2004; Booker et al., 2004). The need for information at this time was due in part to failure to retain information that had been given pre-treatment (Moore and Estey, 1999; Steginga, 2001). Both patients and spouses wanted information about treatment side-effects and ways to manage them (Wong et al., 2000; Harden et al., 2002), as well as information on emotional reactions and alternative therapies (Fitch et al., 1999). Patients were often unaware of the self-help resources that were available and were not directed to them (Breau et al., 2003; Eakin and Strycker, 2001). In a large study (n = 650), many patients wanted help with emotional well-being, living with side-effects and information (Duke, 2001). They needed a supportive environment in order to cope (Ptacek, 2002; Ptacek, 1999), and experienced self-help groups as useful in terms of accessing information (Gregoire et al., 1997; Gray, et al., 1997; Smith et al., 2002) and providing emotional support (Crawford et al., 1997). They also obtained information from fellow patients and medical staff (Poole et al., 2001), via the telephone (Scura et al., 2004), face-to-face (Weber et al., 2004), and online (Broom, 2005). Little has been reported about the support needs of ethnic minorities with prostate cancer, although the support used by African Americans has been reported as centring on family, friends and church (Smith et al., 2002; Hamilton and Sandelowski, 2004). Partners' information-seeking behaviour was individualistic, with some seeking voluminous information and others avoiding information. In a small, in-depth study (six patients, six partners), some partners changed their information-seeking over time and their needs differed from the patients (Feltwell and

Rees, 2004). General distress in spouses did not differ from patients, and was reported as modest in spouses of men treated for early-stage prostate cancer (Eton et al., 2005). The same study (n = 165) also found that distress was more likely to be predicted by psychosocial than medical factors. Couples needed more information to help them look after themselves at home (e.g. catheter care) but many men managed their own care (Kronenwetter et al., 2005). Wives' efforts focused on emotional support and working out care routines with their husbands (Petry et al., 2004). Improvements in wives' adaptive coping and indicators of psychological growth were reported as a result of a psycho-educational group intervention (Manne et al., 2004). A study of men with recurrent disease found that this group of patients experienced particular problems with side-effects of treatment, anger and pain. Although they received help for their pain, healthcare professionals did not satisfy their needs to talk with someone about their cancer. They were also dissatisfied with the information they received about their medical condition and possible side-effects (Fitch et al., 2000).

2.4 Discussion

A key theme running through the studies we identified was the need of patients and carers for information at appropriate times during the care pathway to enable them to understand the diagnosis, treatment options, self-care and support available, and to participate in decisions as they wish. Interventions that improved the provision of information helped patients cope, reduced anxiety and influenced decision-making. The importance of information in the management of men with prostate cancer reflects the state

of knowledge regarding the investigation of suspected prostate cancer and the uncertainties surrounding the choice of an appropriate treatment option. Patients and the professionals who care for them are faced with alternatives. Yet, it is clear that patients often experience a lack of information at crucial times. In designing services around the varying needs of men with prostate cancer, initiatives to improve the planned provision of tailored information should be a priority.

The studies of patient experience of prostate cancer care in this review were limited to those published in English with most having been conducted in the USA, Canada or the UK. It is likely that relevant studies published in other languages have been omitted. However, the search strategy was reasonably broad and the most important studies meeting the inclusion criteria have probably been identified. The respondents in the reported studies were predominantly white and not socio-economically disadvantaged, in spite of attempts to recruit more widely, and therefore the findings should be extrapolated with caution to other ethnic or disadvantaged groups. The experiences of African-Caribbean men, who have a higher incidence of prostate cancer, are under-reported and need further investigation. It should also be noted that experience of services in other countries might not be directly applicable to the NHS.

The narrative summary approach adopted succeeds in summarizing the data from a variety of studies to produce this overview. However, it is an approach that is not without difficulties and is sometimes criticized. For example, in

summarizing the data from a number of studies, the reporting of individual experiences of care of prostate cancer patients and their carers is lost and there are difficulties in quantifying experiences from different studies involving a range of methods and undertaken in different healthcare systems. Information on the size, location and methods of the studies is available in Appendix 2. Despite the variety of settings and methods used in the included studies, there was a striking consistency in the finding that patients and carers need information and support throughout care, but often this need is not met. It should also be noted that there were relatively few randomized trials of interventions to improve patient or carer experience. There is relatively little evidence about patients' experiences of: referral when the possibility of prostate cancer is first indicated; diagnostic investigation; experiences of receiving treatment; long-term monitoring after initial treatment; the management of relapse and palliative and terminal care. Further research into patients' experiences of these aspects of care is required.

The review also has implications for clinical practice. Healthcare professionals need to be aware that patients' knowledge of prostate cancer is often poor and need better pre-test information and discussion. The diagnosis of prostate cancer is a shock for many couples and offering a break before discussing treatment options would allow them to regain their composure so that they are better able to understand the explanation of the treatment options before any treatment decision is made. The provision of information and sources of information is crucial for many couples to help them come to terms with the diagnosis. Support should also be offered at this

stage. Interviews with patients and their carers suggest that where specialist nurses have been introduced into hospitals information and support needs are more likely to be met. Clear and unbiased explanations of all the treatment options, including active monitoring (watchful waiting), are needed for patients to understand what choices they have, and they need time to weigh up their relative merits. It is crucial that patients and carers are made aware of the side-effects associated with the different treatment options so that they make an informed choice and are aware of the (potential) implications of their choice. While many patients want a shared approach to the treatment decision, healthcare professionals should be sensitive to the preferences of the individual patient, which range from wanting to make the decision themselves to asking the healthcare professional to make the decision for them. Providing patients and their carers with support and informing them of sources of support before, during and after treatment are essential to help them deal with their stress. Patients and their carers need to be clear when they are discharged what to expect and how to care for themselves.

2.5 Implications for the development of a measure of prostate cancer care

No standard measure of patients' experience of prostate cancer care was identified in the review, and a review of outcome measurement in prostate cancer has also found no standard measures of patient satisfaction related to prostate cancer screening or treatment (McNaughton et al, 2004). Therefore, the development of a measure to inform service improvement is appropriate. The measure should be usable throughout the care pathway, and although it

should seek patients' experiences of receiving information and taking part in decisions, it is important that it also assesses their experience of coping with anxiety and self-care, the availability of support, the management of treatment effects and the continued monitoring of their condition. The measure will be informed by the literature review in the phases of the care pathway that have been investigated in the studies identified, namely: screening, explanation of the diagnosis, treatment decision, treatment, and post initial treatment. The findings of the literature review will also be used in the development of a topic guide for interviews of prostate cancer patients in a later stage of the research (see Chapter 3). The further research undertaken to develop the measure will now be described in Chapter 3.

Chapter 3: Research to inform the development of the initial version of the measure of patient experience of prostate cancer care

In this chapter I will describe the research conducted to inform the format and content of the measure.

3.1 Survey of Cancer Networks

The Calman/Hine Report (Department of Health, 1995) set out a strategic framework for the creation of a network of cancer care in England and Wales. Cancer networks were to reach from primary care to cancer units and bring together health service commissioners and providers, the voluntary sector and local authorities. The responsibilities of Cancer Networks were identified in the NHS Cancer Plan (Department of Health, 2000b). The Cancer Network is managed by a Management Board which ensures representation of patients, carers, health professionals, managers and the organisations forming the Network to ensure involvement at a local level to identify, and meet, both local and national cancer priorities (Yorkshire Cancer Network, 2009). Typically a network services a population of around one to two million people, and in 2010 there were 28* cancer networks covering the whole of England. It is likely that Cancer Networks would be instrumental in the administration of any new standardised measure of patient experience adopted by the NHS. Consequently, it is important to learn from any experience they had already acquired in administering measures of patient experience as well as their thoughts on the content and format of a new measure.

* as a result of amalgamations the number has reduced from the 34 cancer networks established in the 1990s

A questionnaire was designed to meet these twin aims and sent to all Cancer Networks. This was followed up in a sample of Cancer Networks with interviews of key staff and patient representatives to explore these issues in greater depth.

3.1.1 Questionnaire survey

3.1.1.1 Methods

A covering letter, an information sheet explaining the purpose of the study and that the SILs (Service Improvement Leads) had been chosen because of their role in managing improvements, a stamped addressed envelope and a copy of a questionnaire were posted to SILs at all 34 Cancer Networks in England. The questionnaire was designed to elicit SILs' experiences of using measures of patient experience and to gain their suggestions for features of a new measure. A draft questionnaire was developed initially as a basis for discussion by members of the research team and was revised to take account of the comments made. Consequently, the questionnaire was short (nine questions) and used mainly open questions. It is summarised below (see Box 3.1) and the full version is in Appendix 3.

Box 3.1 Questionnaire for Service Improvement Leads: a summary of key questions about measures of patient experience

1. The purpose and development of measures of patient experience that they had used
2. The administration of measures of patient experience that they had used
3. Benefits and problems of using measures of patient experience (including reasons for not using a measure if they have not done so)
4. Features (format and content) of a new measure of patient experience of prostate cancer care

A reminder letter was sent to non-responders after two weeks and a further verbal reminder given at a conference by the National Manager for Urology at the Cancer Services Improvement Partnership Collaborative. The data were entered into an Access database and the analysis involved calculation of frequencies, and the collation of comments from open text responses.

3.1.1.2 Results

A total of 26 out of 34 (76.5%) completed questionnaires were received.

a. Experience of using a measure of patient experience

Most of the Cancer Networks, (n=22, 85%), reported that they had used some form of a measure of patient experience in the last two years.

b. Development of the measure

Most of the measures, (n=14, 64%), had been self-developed (i.e. by staff of the Network or its clinical teams themselves) either within the Cancer Network or in collaboration with health care professionals. Urology teams and nurse specialists often played an important part in the process of developing the measures. The other measures (n=8, 36%) had been developed by a variety of people outside the Cancer Networks, but were not standard instruments that had been tested and available for use by others.

c. Type of cancer patient the measure was used for

Just over half of the measures (n=12, 55%) were used either exclusively for prostate cancer patients or alongside other cancer patients. The other measures (n=10, 45%) were used with other cancer patients.

d. Purpose of the measure

Half of the measures (n=11, 50%) were used to help with service redesign, four (18%) were used for routine monitoring of services and seven (32%) had

been used for a combination of the two. Others reasons given for using a measure of patient experience included assessing the impact of a new clinical nurse specialist (CNS) and satisfaction with a one-stop prostate assessment clinic.

e. Type of measure

Questionnaires were the most commonly used method (Table 3.1). However, many respondents did not give a clear answer to this question.

Table 3.1 Types of measures used by Cancer Networks

Type of measure	Number of Cancer Networks where the measure had been used
Questionnaires	10
Focus group	2
Interview	1
Patient shadowing	1
Combination of questionnaires, focus groups and/or interviews	3
No clear answer / did not answer	9

Patient shadowing is a less commonly used method, and this involved a patient being shadowed or followed by a Service Improvement Facilitator to record their experiences of care.

f. The benefits of using the measure

Gaining a patient (and in some cases a carer) perspective was the benefit identified by half of the Cancer Networks (n=12, 50%), and this was then used to review or change services. Other benefits included patients becoming more aware of service improvements and being able to share experiences and develop ideas for service re-design.

g. Problems of using the measure

While three respondents reported that there were no problems in their use of a measure, the other 21 respondents identified the following issues:

- Response rate: difficulties in getting a good response rate to questionnaires; difficulties in recruiting a cross section of patients for a focus group
- Sensitivity: conducting interviews and focus groups requires sensitivity
- Resources: recruiting and interviewing patients was time consuming; resources were required to use the measure and analyse the data, and needs to be an on-going process. It was described as "not part of the day job".
- Designing a measure: difficulties designing a measure that can be used across the Cancer Network because of the differences in structures and processes in individual Trusts; difficulties designing a measure that identifies issues important to specific groups of patients, that is easy to complete (including for people unable to read English) and analyse
- Implementing findings: difficulties in implementing the findings (clinical staff may be sceptical of the evidence from measures of patient experience).

h. Reasons for not using a measure of patient experience

Four Cancer Networks said that they had not used a measure of patient experience. The reasons given for not using a measure were that:

- their measures were still in the preparation stage
- they do not have the resources (time, support) and poor infrastructure

- they are not aware of a suitable measure and need support to develop and implement one
- they have other priorities (service improvement has focused on patient waiting times and communications between hospital departments and primary care).

i. Desirable features of a new measure of patient experience for prostate cancer patients

The measure should find out what patients feel, and should cover the whole patient journey. This includes patients' experiences in primary care leading up to deciding whether to have a PSA test, their experiences of being tested for prostate cancer in secondary care and the communication skills of staff, and the follow-up procedures following treatment. The measure should also be used with long standing patients, such as those who opt for watchful waiting or are receiving hormone therapy. All the specific care issues that the measure should assess are listed in Box 3.2.

Box 3.2 Key issues for the content of the measure

Primary Care

Advice/support from GP
Information given in primary care
Accessibility of PSA testing
Informed consent of patient for PSA test

Secondary Care

Preparation for tests and examinations at clinics
Pain score for TRUS/Biopsy and use of anaesthetic
Maintaining dignity and privacy
Time and support for decision-making, including access to a specialist

All treatments including complications, side effects and quality of life

Information provision and quality of different treatments

Support

Waiting times

Staff attitudes (ward staff and out patients)

Communication skills of medical staff, including breaking bad news

Experience of "one-stop services" (i.e. all tests are conducted on the same day)

Access to cancer nurse specialist

Sign-posting/use/experience of support groups

Moving between healthcare professionals and their experience of them (oncologist and urologist)

Follow-up care

Health and social needs

Continence care

Experience of patients in the long term (e.g. patients on watchful waiting and hormone therapy

As regards the format of the new measure, it was most respondents' view that the measure should be a written questionnaire. Several responses suggested that the measure be a combination of oral (focus groups or interviews) and written formats, and one respondent suggested that it be a focus group. The key issues are listed in Box 3.3.

Box 3.3 Key issues for the format of the measure

It should:

Be short and a combination of closed responses and optional open comments

Cater for those with special needs (e.g. those who don't speak English, poorly sighted, low literacy levels)

Include a section for carers to complete

Be divided into a series of smaller measures that could be used at different points in the patient journey and for differing stages of the disease (including palliative care)

Offer flexibility for patients/carers to highlight issues of importance to them in the patient journey

3.1.1.3 Discussion

The survey elicited responses from 26 of the Cancer Networks covering the majority of England and both rural and city populations. The questionnaire sought to capture their experiences of using measures of patient experience of cancer care in the last two years. It included closed questions (e.g. who developed the measure, what was the measure used for) as well as a number of open-ended questions (e.g. benefits of using the measure, what features should a new measure have). Consequently, some of the data have been quantifiable and some presented as issues organised into appropriate categories. While the closed questions provided useful background to the development and use of the measures, it was the open-ended ones that provided information on experiences and suggestions for the development of a new measure. SILs generally thought that the format should be a written questionnaire, with a simple response format for ease of completion and analysis. It should be divided into sections to enable administration at different stages in the patient journey, and it should include a section for carers. Respondents identified issues for potential questions, as well as potential problems in administering the measure and implementing the findings.

3.1.2 Interviews at Cancer Networks

The issues raised in the questionnaire survey described above helped to identify issues to be aware of in devising and administering measures of

patient experience. However, the survey was not able to explore these issues in depth so a series of interviews with key staff and patient representatives was arranged at a sample of six Cancer Networks.

3.1.2.1 Methods

The six Cancer Networks that took part in these interviews were selected, in consultation with the National Manager for Urology at the Cancer Services Improvement Partnership Collaborative, as covering different geographical regions of the country with differing patient populations. The Cancer Networks that were contacted by email and follow up telephone calls were: CCA (Teeside), Yorkshire, Greater Manchester, LNR (Leicester, Northants and Rutland), Kent and Medway, and Peninsula (Devon and Cornwall). London Cancer Networks were excluded at the time of the interview study because they faced a range of difficulties including an on-going re-organisation that involved changes of personnel.

Having contacted the Service Improvement Lead (SIL) to gain their agreement to take part, arrangements were made to visit each of the six Cancer Networks to conduct interviews with staff (Service Improvement Lead, Service Improvement Facilitator, Lead Nurse, Lead Clinician) and a patient representative. The interviews were held at the various Cancer Networks with the exception of three staff who were interviewed by telephone.

The interviewees had different roles in their respective cancer networks and so needed to be given the opportunity to discuss their respective areas of knowledge and experience. Consequently, semi-structured interviews were used because they involve a series of open-ended questions that provide

opportunities for some topics to be discussed in more detail (Wilson et al., 2000).

Referring to the survey of Cancer Networks reported on above, I drafted an interview schedule which was reviewed by the team before it was finalised. The interview schedule is shown in Box 3.4.

Box 3.4 Interview schedule for Cancer Network interviews

1. Use of measures of patient experience

In your Cancer Network, have you used a measure of patient experience for cancer patients?

If, yes:

Who was the measure developed by?

What was it used for? (e.g. routine monitoring/service re-design?

What type of patient was it used with? (prostate cancer, other cancer)

Can you explain how the measure worked?

What were the benefits of using the measure?

Were there any problems or disadvantages in using the measure?

Did you get any feedback from patients on their experience of the measure?

If, no:

Could you explain why you have not used a measure of patient experience?

(Emphasise that this is not a criticism, but that it is important to explore the reasons as they need to be addressed if the new measure is to be used widely and successfully)

Prompts: time, support, availability/knowledge of measures, other priorities

2. Features of measures of patient experience

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

Are there any particular uses the measure should meet?

Are there any particular obstacles or problems when using measures of patient experience? (especially with regard to prostate cancer patients)

Are there ways to overcome these obstacles or problems?

Are there any contextual factors (e.g. service configuration, patient population characteristics including ethnicity) that would have to be taken into account in the development of a standard measure intended to be widely applicable?

3. Other comments: Is there anything else that you would like to add regarding measures of patient experience of care for prostate cancer patients?

Using the interview schedule, the semi-structured interviews were conducted mostly by myself with the rest being conducted by two other researchers (AP and KB). The interviews were recorded and transcribed and then were coded and analysed by two researchers (myself and KB) independently. Coding was carried out using NUD*IST N5* (Computer Assisted Qualitative Data Analysis Software). Charting (Ritchie and Lewis, 2003) was then undertaken to reduce and order the data to identify the issues raised by the interviewees to inform the development of the measure. Discussions were held to review and agree the coding and the charting.

3.1.2.2 Results

a. Interviewees

The six Cancer Networks contacted all agreed to take part and of the 30 interviews that had been planned, 27 were conducted: two patient representatives declined to take part and one Cancer Network was without a Service Improvement Facilitator at the time of the interviews. The details of the interviewees are summarised in Table 3.2.

Table 3.2 Types of people interviewed at Cancer Networks

Job title/role	Number of interviewees
Service Improvement Lead	6
Service Improvement Facilitator	5
Patient Representative	4
Lead Clinician	6
Lead Nurse	6
Total	**27**

b. Using measures of patient experience

The interviewees made clear that the purpose of using measures of patient experience and patient satisfaction was to review new and existing services from the patient's perspective. This included assessing a new one-stop clinic, the impact of the specialist nurse's role and to compare findings with those of a previous survey. In some instances the process contributed to the re-design of the service. Staff had used a range of measures that most commonly took the form of patient satisfaction questionnaires, but also included focus groups, patient shadowing and interviews. In addition, patient representatives reported holding meetings of patients and carers at which experiences were discussed and fed back to staff. Questionnaire surveys were often administered by the Audit Departments in the Hospital, and were typically distributed by staff to patients attending the hospital. Patients usually took the questionnaires away to complete and returned them by post. Response rates were generally considered by respondents to be good, especially where time had been taken to fully explain the purpose of the questionnaire and that responses would be anonymous.

Among the benefits identified by interviewees of using measures of patient experience and patient satisfaction was that they were confident that they captured the patient's perspective rather than relying on assumptions of what they thought patients wanted. In addition, patients identified issues which staff may not have been aware of and could thereby influence both clinical practice and the allocation of resources. Some staff were also motivated by the positive feedback that came from using these measures.

Interviewees reported a number of problems encountered when using measures of patient experience and satisfaction. Postal questionnaire surveys can have distribution and completion problems, for example if the patient is keeping their condition secret they may not want to receive or complete a questionnaire sent to their home. The response rate had been found to be higher when staff at the hospital handed out questionnaires, but this may be seen as extra work by staff. Planning is important to try to ensure patients are not being presented with too many questionnaires from different sources so that they feel overloaded and, if the Audit Department is to be involved, the survey may need to be planned some time in advance to fit into their programme of work. Resources were not always available for the distribution, return and analysis of the questionnaires.

Interviewees reported that patients, especially older ones, may be reluctant to be critical in their responses for fear of the effect on the way they are treated or it having a detrimental effect on a member of staff. It was thought that some patients might not want to participate as they don't want to be reminded of their condition. Interviewees were concerned that considerable time may be required to ensure that patients are clear about the use to which the results

will be put and that their responses will be anonymous. Some respondents reported use of focus groups but they encountered difficulty in recruiting a range of people required and recognised that the facilitator needed to be expert at handling such groups. Patient shadowing involved a Service Improvement Facilitator (SIF) trying to get a patient perspective of care by following a prostate cancer patient during their visit to hospital and recording what happened. However, it had several drawbacks including, being time consuming, risked the "shadower" putting their interpretation on events, and was also potentially embarrassing for the patient and "shadower" given the nature of the disease.

Comments that applied to using patient measures in general were that resources and support are required to implement them properly and that these were not always available. Interviewees also felt that some staff were reluctant to engage in what they regarded as non-clinical and therefore less important issues because of time pressures, whilst others were unwilling to accept negative comments about the service that they provided. Some consultants had concerns about the use the results of the measure will be put to. The tension between meeting targets and providing a quality service was also raised. In several instances the results of measures of patient experience and satisfaction were used to modify the service and also added weight to arguments for change with consultants who had been unwilling to change practice. Although the importance of giving feedback to patients about the results of the measure was generally agreed upon, there were few

instances of this happening (e.g. minutes of a focus group, presentation to a support group).

c. A new measure of patient experience

Content of a new measure

There was general agreement that the content of a new measure of patient experience should cover the whole patient journey from initial presentation through to end of life care. It was also felt that the measure should be administered at intervals coinciding with different phases of care (e.g. after referral, after the treatment decision, and during monitoring) and cover the quality of care as this can be overlooked when there is an emphasis on targets. The quality of the procedures of the tests and treatment was identified by some as the most important aspect of care and therefore central to the measure. This included having the choice of attending a one-stop clinic, punctuality of procedures, cleanliness and ward noise, and pain management. Other issues that should form part of the measure were the information provided (timing and quality), communication (including breaking bad news and the primary/secondary care interface), support (including having a contact number), and guidance on decision-making (including the opportunity to re-visit the treatment decision). However, there was also a note of warning to be clear about what topics the measure was covering, to ensure that non-care issues (e.g. car parking) were not commented on. The measure needed to be flexible enough to cover the experiences of each patient, but there were different opinions as to whether the measure should be used with people tested for, but found not to have, prostate cancer.

Format of a new measure

Almost all of the interviewees favoured the use of questionnaires as the most appropriate format for the new measure, although some favoured the use of other formats in addition to the questionnaire to give more depth or a more complete picture. The supplementary measures suggested were interviews, patient shadowing, focus groups and patient/professional meetings. Patient diaries were suggested as a way of helping patients to record events soon after they happened and could be referred to when completing a questionnaire. A number of comments were made about specific desirable features of a new measure, including font, layout and section headings. These are summarised in Box 3.5.

Box 3.5 Desirable features of a new measure

1. Easy to complete: suitable font (e.g. Arial 12), black print on yellow paper, simple scales (e.g. smiling faces), use of tick boxes with some spaces for comments, choice of paper or electronic versions
2. Easy to manage sections: a section covers part of the patient journey e.g. diagnosis, post initial treatment and six month survival
3. Different version(s) for non-English speakers (e.g. translated and/or audio recorded versions)
4. A separate section for carers: they may have different needs and views from patients, may be more willing to express criticisms and could be the main source of information for patients nearing the end of life

Administration of a measure of patient experience

Interviewees identified problems that had been encountered when trying to engage patients to participate in measures of patient experience or satisfaction and in some instances, suggested solutions. The timing of the

administration of the questionnaire (or any other measure) was seen as crucial if useful data were to be captured, and it was important to be aware that patients' perceptions would probably change over time. Another concern was that patients might be asked to complete several measures because different bodies conducted surveys independently. Any new measure of patient experience should be planned and co-ordinated with others to avoid duplication and patient burden. It was also suggested that the process of measuring patient experience of care should also be an on-going one, either with questionnaires always available for completion (e.g. in an Information Room), or administered periodically (e.g. every two years). It was recognised that completing the questionnaire on the hospital premises may affect patients' responses.

Approaches to administration of the questionnaire attracted a number of suggestions, including using receptionists or members of the medical team to hand them out. This would provide an opportunity to explain to the patient the purpose of the survey and was felt likely to produce a good response rate. However, interviewees pointed out that patients may be less frank in their responses, especially if the completed questionnaires were going straight back to the Multi Disciplinary Team* (MDT) responsible for their care. The Audit Departments of Hospital Trusts were identified by some interviewees as able to distribute, receive and analyse the questionnaires, relieving the MDT of the work and capable of lending the process a degree of

* MDTs may vary in composition but will typically include a Lead Clinician, an Administrator, a Surgeon, an Oncologist, a Radiologist, a Hispathologist, a Clinical Nurse Specialist who meet to discuss all new cancer patients and the continuing care of other patients.

impartiality from the patients' perspective. A letter from the MDT accompanying the questionnaire may be used to try to ensure a good response rate. An alternative approach (suggested by one interviewee who had talked to the head of MORI) to get a good response rate and clear answers was the use of trained people with clipboards who asked the questions and recorded the responses. Clearly this approach would have significant cost implications. The involvement of Patient Support Groups in the process (e.g. receiving completed questionnaires by post, or running focus groups) was also proposed to minimise the workload on staff and reassure patients of the anonymity of their responses. Many hospitals have a Patient Support Group which is a voluntary group formed by patients and their carers for those suffering a particular illness. However, concerns were raised as these groups have a variety of different aims, status and methods of functioning that may make them unsuitable or unable to carry out this work. A further complication would arise if different questionnaires were used for patients at different phases of their journey and undergoing different treatments, as this would require those distributing the questionnaires to know or ascertain which questionnaire was relevant to each patient. A final point raised by many interviewees was that having involved patients, feedback should be provided to them about what action had been taken.

d. Implications of the results for a new measure

The questionnaire survey and the interviews with Cancer Network staff and patient representatives were undertaken to inform the development of the new measure of patient experience. The findings have implications for the design,

development and use of the new measures. These are summarised below and grouped into four themes: the administration, data analysis and feedback of data; the format of the measure; the focus of the measure; and the content of the measure.

Administration, data analysis and feedback of data.

i. Consideration should be given to the pros and cons of postal questionnaires versus questionnaires handed out in clinics. These methods have different issues associated with them, including cost, convenience, response rate, and anonymity. Clinics may wish to use one or other approach depending on circumstances, and guidance for both approaches should be included in any User Guide developed.

ii. Planning, administration time and resources were all raised as concerns and a User Guide should address these to ensure that staff are clear about the implications of using the measure. Efforts should be made to ensure that administration of the questionnaire is quick and easy, with appropriate software for data entry and analysis being freely available and easy to use

iii. There were concerns about getting unbiased replies from patients, who may be reluctant to criticise the staff who have cared for them. It may be helpful for the questionnaire to be administered with a degree of independence, for example, questionnaires being returned to the hospital Audit Department rather than to the clinical department. It

will also be important to emphasise to patients the value of both positive and negative feedback in reviewing services

iv. Some groups may be difficult to access (e.g. patients in hospice care); this issue should be explored during the piloting

v. Patients should be given feedback on results and any action to be taken.

vi. There may be problems in implementing findings, for example, resistance from clinical staff. Sensitive introduction of the survey is essential to gain staff support before the measures are used

vii. Benchmark data may be useful for hospitals to compare their performance against.

Format of the measure

i. Interviewees favoured a paper questionnaire

ii. The questionnaire should be simple, user-friendly, and suitable for different patient groups (e.g. elderly, non English speakers). Alternative forms e.g. audio / translated versions should be made available.

iii. Clinics may want to use other methods alongside a questionnaire (e.g. patient shadowing, focus groups).

Focus of the questionnaire

i. The questionnaire should cover the whole patient journey (from primary care through to discharge or palliative care; include follow-up

care (e.g. continence care), and long term care (e.g. watchful waiting, hormone therapy)

ii. The questionnaire should include questions about interfaces, particularly the primary-secondary interface, and care after discharge

iii. There should be different 'stand alone' sections for different types of treatment and for different phases of care

iv. There should be a section for carers

v. The questionnaire should be administered to all those patients who are tested for prostate cancer, including those whose test results do not indicate prostate cancer.

Topics and themes for the questionnaire content

In addition to highlighting issues to consider in the administration, format and focus of the new measure, the Cancer Network questionnaire survey and interviews also indicated topic areas for specific questions, as summarised below.

i. Timeliness: referral times; timely tests; choice of one stop clinic; timing of appointments/procedures; waiting times

ii. Quality of medical care: quality of medical care (tests and procedures); accessibility of PSA test; pain management; pain score for TRUS/biopsy and use of anaesthetic; outcomes of surgery (e.g. side effects, complications)

iii. Communication: clear and timely information and explanations about tests and examinations, referral, waiting times, diagnosis (including breaking bad news), the disease, treatments and side effects

iv. Support: advice/support from GP, somebody to guide patients through the process, access the cancer nurse specialist as required including telephone number for queries, ongoing monitoring, signposting of support groups, follow-up care for health and social needs, support for psychosexual needs

v. Decision making: informed consent for PSA test, time to come to terms with the diagnosis and make treatment decision, guidance and support on decision making, opportunity to re-visit the treatment decision, access to specialist nurse

vi. Continuity: experience of moving between healthcare professionals (e.g. oncologist and urologist)

vii. Respect: enough being done, taking wishes into account, maintaining dignity and privacy, appropriate staff attitudes (on wards and in out-patients)

viii. 'Hotel issues': cleanliness, ward noise

3.1.2.3 Discussion

The interviews were focused and semi-structured, covering many of the issues raised in the survey of Cancer Networks. They varied in length from shorter telephone interviews (around 15 minutes) to much longer face-to-face

interviews (around 45 minutes) that enabled issues to be explored in greater detail. The interviewees were administrators, clinicians and patient representatives, thus ensuring that a wide range of perspectives were included. The main findings confirmed those of the survey: the format for the new measure should be a questionnaire that is easy to use, it should cover the whole patient journey and carers' responses should be included. Many of the issues that were identified by the survey as important and appropriate for questions were also identified by interviewees. The main addition to the survey findings was the consideration given to the administration of the measure, both the problems that had been encountered and to be aware of, and recommendations on administering the measures. Issues in relation to implementing the findings were also discussed.

3.2 Interviews with healthcare professionals and voluntary sector staff

3.2.1 Introduction

In addition to investigating the views of Cancer Network staff, I investigated the views of healthcare professionals and voluntary sector workers who provide care and support to people with prostate cancer and their carers. Their perspectives were sought on both the content and use of measures of patient experience.

3.2.2 Methods

In addition to patients and carers who were to be interviewed later, the following groups were identified as having experience of delivering services to

prostate cancer patients and were contacted by phone, email or letter and invited to be interviewed.

i. The Cancer Services Collaborative (CSC) have responsibility for driving improvements in the way cancer services are delivered to patients. The CSC National Leads selected for interview all had responsibilities which included prostate cancer patients. These were the National Leads for Urology, Radiotherapy, Palliative Care and Patient Experience who all agreed to take part and were interviewed

ii. General Practitioners have responsibilities for caring for prostate cancer patients and this may include the initial consultation and tests as well as treatment and monitoring. Three GPs practising in areas of Leicester that served predominantly different ethnic groups (African Caribbean, South Asian and White) were identified to capture any particular needs that these different patient groups had. All three agreed to take part and were interviewed. To gain a national perspective and to be aware of the latest developments the GP Clinical Governance/Cancer Lead was also interviewed.

iii. Local and national charities (Cancerbackup, Coping with Cancer, Cancer Black Care, The Prostate Cancer Charity) which provide services for prostate cancer patients were invited to take part and representatives were interviewed.

iv. Professional organisations (British Association of Urological Surgeons and British Association of Urological Nurses) which provide much of the care for prostate cancer patients were invited to take part. BAUN agreed and a

representative was interviewed, but in spite of several reminders BAUS did not reply to the invitation.

v. A consultant in Palliative Care was invited for interview to explore care issues for patients who receive palliative care. The consultant agreed and was interviewed.

The approach adopted was to use semi-structured interviews because the interviewees needed to be given the opportunity to discuss their respective areas of knowledge and experience. Two interview schedules were developed from the research already conducted, one for GPs (which concentrated on the care of patients in primary care and the key issues for patients, see Box 3.6) and one for the CSC Leads, charities and other healthcare professionals (which concentrated on their experiences of using measures of patient experience/satisfaction and the desirable features of a new measure, see Box 3.7).

Box 3.6. Summary of interview schedule for interviews of GPs

Questions were asked about each of the different phases of care that GPs were involved in

Initial presentation: what do you usually do at the initial appointment?

Tests and results: what tests do you normally do?

Referral to hospital: what do you usually do when referring a patient to hospital?

Treatment: what do usually do when treating a patient?

Follow-up care after discharge from hospital: what are the arrangements for patients when they are discharged from hospital?

Other comments: are there any other comments on aspects of care that you think are particularly important for patients and/or carers?

(Prompts were used to promote discussion of the needs and behaviour of patients and their carers.)

Box 3.7. Summary of interview schedule for interviews of CSC Leads, charities and other healthcare professionals

Questions were asked to explore experiences and views about measures of patient experience, and to discuss ideas for a new measure of patient experience of prostate cancer care

1. Experiences of measures of patient experience: have you been involved in managing or using a measure of patient experience for cancer patients?

2. Features of a new measure of patient experience: what features do you feel a measure of patient experience of prostate cancer care should have?

3. Additional comments: is there anything else you would like to add regarding measures of patient experience of care for prostate cancer patients?

(Prompts were used to promote discussion of their experiences and ideas)

The interviews were recorded on audiotape and transcribed. The interviews were coded using NUD*IST N5 by two researchers (myself and KB) independently. Charting (Ritchie and Lewis, 2003) was then undertaken to reduce and order the data to identify the issues raised by the interviewees to inform the development of the measure. Discussions were held to review and agree the coding and the charting.

3.2.3 Results

A total of 14 interviews (9 face-to-face and 5 telephone) were conducted. The findings have been presented in two separate sections below: interviews of GPs, interviews of CSC Leads, voluntary sector workers and other healthcare professionals

a. Interviews of GPs

Comments were made by GPs about the characteristics and behaviour of the patients and their responses to them. Most of the issues related to the different phases of prostate cancer care have been summarised in those phases. Separate sections have been created for general issues that relate to patients throughout their care, and for comments about the format of a new measure.

Testing

The reported experience of the GPs interviewed was that patients mainly presented on their own, as a result of the symptoms that they were experiencing. They were then tested for prostate cancer, using the PSA (Prostate Specific Antigen) blood test, and a digital rectal examination (DRE) was usually carried out as well. GPs were divided about whether to mention the possibility of prostate cancer at this stage. A reason in favour of mentioning it was because tests may be positive and it would then be necessary to refer the patient. This could come as a big shock to patients who were unaware that they had been tested for prostate cancer. A reason against mentioning the purpose of the tests was to avoid causing the patient anxiety. GPs did not report giving written information to patients at this stage

"I don't think they do receive at any point printed information. It's probably a good idea actually isn't it? Because patients do come to the consultation and they only take a small percentage of the consultation away with them so something for them to go back and read and reflect on."

(GP Interview No. 3)

Asymptomatic patients who presented may be given information by the GP or have a discussion about the tests and prostate cancer. It may also be suggested that they reconsider and discuss it with their partner. However, it is usually left to the patient to decide whether to go ahead with the tests and invariably they decide to have the tests as they are still concerned about the possibility that they may have prostate cancer.

Referral and Diagnosis

Being sensitive and reassuring the patient were regarded as an important part of the GP's role in this consultation. The GPs generally favoured using the word cancer at this stage, although one said that they would only use the word if the patient did. A very small number of patients were referred under the two week wait, but it was regarded as important to explain to such patients the reasons for this. The priority for patients was felt to be that they were seen as soon as possible and at a local hospital. Being given a choice of hospital was not thought to be important to most patients. One GP mentioned a trial being conducted using a "key worker" to provide support to cancer patients from this stage on.

Treatment decision and treatment

GPs felt that it was the responsibility of secondary care to inform patients at this stage, although they were unaware of what information was provided. One of the GPs offered an appointment to patients two weeks after their tests at the hospital so that the patient could get any further explanations they needed and this offer of an appointment was always taken up by patients. Primary care provided hormone therapy and palliative care for most of the patients receiving them and it was thought that patients preferred this because it was more convenient for them. It was felt that watchful

waiting/active monitoring could equally well be provided by primary or secondary care.

Post treatment

GPs said that primary care was responsible for most of the care provided at this stage, although the important role played by specialist nurses, especially in getting access to consultants, was recognised. It was felt that primary care also met the information needs that some patients had about their treatment, for example clarifying that hormone therapy is not curative. One GP identified that some carers may need support when they are looking after the patient, and should be made aware of the option of respite care.

General issues relating to patients and carers

Appropriate and timely communication was seen as vital to the quality of patient care. Specific issues raised were: the need to respond to patients individually and sensitively; to ensure that the care between primary and secondary was seamless; and that patients need access to a healthcare professional when they want to discuss issues relating to their condition/treatment, rather than relying solely on written information.

The only issue raised regarding the needs of different ethnic groups was that South Asians tend to rely more on family support. It was observed that carers are usually involved in the care process from secondary care onwards.

Comments on desirable features of a new measure of patient experience

A new measure should be simple, divided into sections (keeping screening separate) and available in languages other than English to enhance the response rate.

b. Interviews of Cancer Service Collaborative Leads, Voluntary Sector workers and other healthcare professionals

The responses of all the interviewees have been divided into those relating to content, format and administration of a new measure of patient experience.

Format

There was unanimity that the format of the measure should be a questionnaire, although there was a suggestion that combining it with another format such as a focus group would strengthen the results. There was a suggestion that eliciting the experiences of carers would be valuable, but most of the comments were specific suggestions about aspects of the format of the questionnaire to ensure that it was effective in capturing the experiences of patients. The issues have been listed in Box 3.8.

Box 3.8 Issues about the format of a new measure of patient experience

1. The language used should be sensitive and clear
2. The layout should ensure the accuracy of responses
3. It should be divided into different sections to cover the whole patient journey (e.g. referral for investigation, diagnosis, post treatment, and post relapse).
4. It should be short, in a big font and adopt a friendly tone
5. It should use tick boxes and provide additional space for comments
6. Questions should be designed to elicit constructive criticism
7. The questions should be based on the questions used in the National Cancer Patient Questionnaire survey of 1999/2000
8. There should be a core, standardised set of questions to allow for national comparisons and the opportunity to add on sections to cover local interests (this should encourage local ownership)
9. Those who do not read/speak English should have an alternative format to the printed questionnaire (e.g. telephone interview, touch screen with symbols at the hospital, focus groups)

Content

There were a great number of comments made about the content of the questionnaire. These have been organised under the different phases of the care pathway for patients, with issues relating to carers and across different phases of care reported in separate sections.

i. Initial presentation by the patient

Questions should focus on how the patient was treated by the GP. The patient may be embarrassed and should be dealt with sensitively and their concerns taken seriously. GPs should ensure that the patient is clear about the possible causes of the symptoms and that he makes an informed choice about whether he wishes to be tested for prostate cancer. The test results should be delivered clearly to the patient. If a patient is referred to the hospital for further investigation it is important that he understands the referral arrangements and this takes place within a time frame that the patient is comfortable with.

ii. Experience at the hospital

Questions should focus on the patient's visit for tests, receiving the diagnosis and making the treatment decision. Patients need to be informed of the process when they attend the hospital for tests and be prepared for the possible pain of the biopsy. The waiting time for the diagnosis should be acceptable to the patient, and details of the diagnosis should be delivered clearly and sensitively. Information should be provided so patients understand the options available and outcomes of treatment, especially the potential side effects. The specialist nurse should be available to provide further explanations as required. Patients should have time to absorb the

information given and have the time that they need to be ready to discuss their treatment decision. The decision making process should meet the needs of each patient, and they should be clear that they could change their mind about which treatment to have. A specialist nurse should be available to have further discussion with and to provide information (e.g. including their contact details and support organisations).

iii. Treatment

Questions should be asked to check whether the patient understood what they should/should not do prior, during and after treatment. Practical arrangements should also be investigated, checking whether the patient had easy access to treatment, and if there were any related problems (e.g. transport, parking, punctual appointments).

iv. Post treatment

Questions should be asked about discharge and follow-up arrangements. When patients are discharged from hospital or have completed their treatment, they need to be informed about what happens next and the support available (e.g. Macmillan Nurse, voluntary organisations). The GP should be informed of the patient's discharge or completion of treatment from hospital and should contact the patient to provide reassurance, as they often feel depressed at this time. Patients should have their symptoms managed and controlled.

v. Relapse and final stages

Questions should focus on the treatment of patients whose cancer is not responding to treatment. Relapse should be detected without delay and managed appropriately, including pain control. Patients should also have

been made aware of the services available to them (e.g. Macmillan nurses, district nurses, social services) and, if patients/carers ask, have been made aware of the dying process.

vi. Carers

Questions should be asked to check whether the needs of carers have been addressed. Subject to the agreement of the patient, carers should have had the opportunity to be involved in all the discussions relating to the care of their partner/relative/friend. Carers should have been made aware of the counselling services and other sources of support available (practical and emotional). Carers should have had the option of discussing home care issues separately from the patient.

vii. Issues across different phases of care

Some issues required questions to address them in more than one phase of care. Patients' information and support needs should have been responded to appropriately (e.g. counselling, complementary therapies, relaxation groups; support services and groups; telephone line for those who don't want face-to-face contact; financial support). Patients should have been able to book convenient appointments, and have a key worker who is a contact point for the patient throughout their care.

Administration

The administration of the questionnaire was also addressed in the interviews. Suggestions were made about the introduction of the questionnaire, its distribution and completion as well as acting on the findings.

i. Introducing the questionnaire

The purpose of the questionnaire should be explained to patients, and if distributed by hand, patients should be re-assured about confidentiality and anonymity. The administration of the questionnaire by the Audit Department or the involvement of a patient support group/forum to receive completed questionnaires would help to reinforce this. The introduction of the measure to healthcare professionals is also important because some may not see the need for the measure.

ii. Distributing the questionnaire

Distributing questionnaires by a nurse known to patients (e.g. Urology nurse) would encourage a high return rate, however, the time required for administering the measure (including explaining it) may be problematic. An alternative means of distribution that would minimise the workload is to post the questionnaire to patients. There were some concerns that older patients may not want to complete a questionnaire and completing it on their behalf may change the responses.

iii. Completion of the questionnaire

The questionnaire should be easy to return (e.g. by post or at the hospital while waiting for treatment), and questionnaires given out to patients undergoing radiotherapy have a good response rate, as there are multiple opportunities to return it. Patients may feel constrained in their answers if they complete the questionnaire during the course of their treatment or if it is administered by one of the people responsible for their care. The carer could be a reasonable proxy for patients too ill to complete a questionnaire themselves.

iv. Findings from the questionnaire

Administration of the questionnaire by the Multi Disciplinary Team may improve their commitment to implement the findings (as opposed to administration by an Audit Department for example). Patients who have taken part in the questionnaire should be given feedback. There were a number of specific cultural issues that were raised by interviewees in relation to South Asian patients and their carers which should be considered when devising the questionnaire (see Box 3.9).

Box 3.9 Cultural issues relating to designing a questionnaire for prostate cancer patients

1. Completing the questionnaire

Questionnaires may be problematic for some sections of the community (e.g. Bengalis in London) as they may be seen as official and therefore not be completed

The level of understanding of the questionnaire may be low

Patients may prefer to express themselves orally in their mother tongue, so interviews or focus groups may be better for this group.

Administration of the questionnaire at the GP practice or hospital would help to ensure that the patient completes it rather than another family member

2. Sensitivity of patients to prostate cancer care

Some men may be reluctant to go to the GP with their symptoms

Some men may be embarrassed by terminology used and may not want women present when discussing sensitive issues

It is important for patients to be treated with respect and to establish trust

It is important to be aware/find out if there are any issues that are particularly sensitive for different groups (e.g. attitudes to different surgical procedures)

3. Support for patients and carers

The information and support needs of carers may not be met (e.g. provision of suitable leaflets)

Extra practical support may be required (family support should not be assumed)

Carers support needs may not be easily detectable

Ethnic patients should be referred to a cultural support worker as appropriate
The condition may result in the loss of status/financial independence
Some patients may suffer emotionally as they may feel that no one at home understands what they are feeling

3.2.4 Discussion

The interviews proved to be helpful in developing an understanding of both the patient experience and the perspective of healthcare professionals with regard to diagnosis and treatment for prostate cancer. They also enabled some interviewees to share their experience of involvement in measures of patient experience/satisfaction. While the main strength of carrying out these interviews was the opportunity to explore the interviewees' perspectives of assessing prostate cancer care and their experiences of using measures with patients, only a small number of people were interviewed in total. However, this did comprise people from three groups who had relevant experiences from the different roles they performed, and the findings were suited to informing the development of the new measure. Nevertheless, it should be noted that the sample cannot be regarded as fully representative of the various groups included. It should also be noted that the interviews were not extended, in-depth interviews, but semi-structured and firmly focused on measures of patient experience.

The questionnaire format was recommended by all interviewees for its ease of use, although some were concerned that a printed version might not be suitable for all patients. A computer touch screen version and the use of symbols were suggested along with interviews and focus groups. The

questionnaire itself should be divided into sections that follow the different phases of care and include a separate section for carers whose involvement and importance in the care process was recognised. The questions should be informed by the NCSR 1999/2000 survey (Department of Health, 2002), and ideally allow comparisons between hospitals as well as some flexibility for hospitals to focus on areas of particular interest.

The administration of the measure raised two issues. First, there is the need to be sensitive to both patients and healthcare professionals when the measure is introduced. Patients need to have their cultural sensibilities respected and be clear about both the purpose of the measure and that confidentiality and anonymity will be observed. The support of healthcare professionals is crucial to the success of the measure, so they also need to be clear about confidentiality and anonymity and that the measure will be used to help improve prostate cancer care and not to criticise or scapegoat individuals. The second issue is how to administer the measure to ensure a high response rate and also to help patients feel free to be frank in their responses. Postal distribution of the measure is often quick and may minimise the administrative burden, particularly when larger numbers of patients are involved. Using the Audit Department or a patient group may encourage frank responses from patients, but may not yield a high response rate because they may seem distant from the providers of the care that they are receiving. Personal distribution of the measure by a healthcare professional is likely to improve the response rate, especially if it is completed at the GP practice or hospital where it was issued. However, this approach may affect the freedom that patients feel to be frank in their responses.

Recommendations as to how these issues may be addressed will be made in the discussion.

3.3 Interviews of patients and carers

3.3.1 Introduction

The literature indicated that patients with prostate cancer often experience a lack of information at crucial times. However, many of these studies included in the review took place outside the UK. In addition, there was relatively little evidence about patients' experiences of: referral when the possibility of prostate cancer is first indicated; diagnostic investigation; long term monitoring after initial treatment; and the management of relapse and palliative and terminal care. In order to identify all of the issues in prostate cancer care that were important to patients in England, patients and carers were interviewed about their experience of prostate cancer care. These issues will then be used to inform the development of a new measure of patient experience.

3.3.2 Methods

a. Choosing the method of data collection

Two key types of qualitative research, in depth interviews and focus groups, could be used. The arguments in favour of each type were considered on three factors: the type of data sought, the subject area, and the nature of the study group. These are summarised in Table 3.3 below.

Table 3.3 Applications of in-depth interviews and focus groups

	In depth interviews	Focus groups
Nature of data	For generating in-depth personal accounts To understand the personal context For exploring issues in depth and detail	For generating data which is shaped by group interaction – refined and reflected To display a social context – exploring how people talk about an issue For creative thinking and solutions To display and discuss differences within the group
Subject matter	To understand complex processes and issues e.g. motivations, decisions, impacts, outcomes To explore private subjects or those involving social norms For sensitive issues	To tackle abstract and conceptual subjects. Where enabling or projective techniques are to be used, or in difficult or technical subjects where information is provided For issues which would be illuminated by the display of social norms For some sensitive issues, with careful group composition and handling
Study population	For participants who are likely to be less willing or able to travel Where the study population is geographically dispersed Where the population is highly diverse Where there are issues of power and status Where people have communication difficulties	Where participants are likely to be willing and able to travel to attend a group discussion Where the population is geographically clustered Where there is some shared background or relationship to the research topic For participants who are unlikely to be inhibited by group setting

(Ritchie J. and Lewis J. (Eds.), 2003. p.60)

The decision to use interviews to gain the views of patients and their carers was taken because it offered the most effective method of eliciting what they felt was important to them in prostate cancer care. This would be based on their individual experiences as a patient or carer, and allow them the time and space to explain the important aspects of their care. A semi-structured approach to interviews was chosen because interviewees could be guided through their experiences and, what was important to them, drawn out. Other qualitative methods (e.g. focus groups) were considered but were not as suitable for exploring the issues important to individuals, and would not have allowed the privacy needed by some patients for discussing sensitive issues (Ritchie and Lewis, 2003). Quantitative methods (e.g. questionnaires) were considered and would have been a quicker method of gaining the views of 30 patients, but did not offer such a good prospect of exploring the issues important to them in sufficient depth.

b. Selecting the sample

In order to identify the full range of issues that were important to patients a sample of patients was needed that was likely to have had a wide range of experiences of prostate cancer care. Recruiting patients from one hospital ran the risk of capturing patients' experiences that were peculiar to that hospital, so to minimise bias from this cause, patients were recruited from two hospitals in the East Midlands. Since patients at different stages of the disease and its treatment may have different experiences, I aimed to recruit a purposive sample (see Box 3.9) of approximately 30 individuals in four categories: (1) those patients with a new diagnosis and prior to treatment [a]

localised and [b] locally advanced or metastatic disease, (2) those on an active monitoring management plan, (3) those who appear disease-free after radical therapy or radical prostatectomy, including some several years after therapy and (4) those who have had first-line hormonal therapy but whose disease has become hormone resistant.

Box 3.10 Purposive sampling: an explanation

"Members of a sample are chosen with a 'purpose' to represent a location or type in relation to a key criterion. This has two principal aims. The first is to ensure that all the key constituencies of relevance to the subject matter are covered. The second is to ensure that, within each of the key criteria, some diversity is included so that the impact of the characteristic concerned can be explored."

(Ritchie and Lewis, 2003. p79)

Both the National Cancer Overview (Department of Health, 2002) and the literature review had highlighted that patients experienced variations in care. For example, the younger the patient the longer the wait for confirmation of the hospital diagnosis and there were some indications of minority ethnic patients being disadvantaged. Consequently, patients were recruited from different age groups (under 55; 55-70; over 70), from ethnic subgroups, and a small number of carers. Two approaches to recruitment were used. First, medical and nursing staff invited patients attending Urology Clinics at the two participating hospitals to take part in the study, providing a letter from the patient's clinician and an information sheet, reply slip and prepaid addressed envelope. Secondly, invitations were posted to patients who had either been tested or treated for prostate cancer who were identified from the hospitals' patient registers. Included in the pack was an invitation to carers to be

interviewed which patients were invited to pass on to their carer if they had one. Patients and carers who indicated that they were interested in taking part in the study and gave their contact details on the reply slips were contacted to arrange a home visit to seek full consent and then interviewed.

c. Designing the interview schedules

Two semi-structured interview schedules were developed for use with patients and carers respectively to elicit narratives about their experiences of care. They were developed from the findings of the literature review, focusing on the issues that patients and carers had reported as important in prostate cancer care. A draft interview schedule was discussed at the first meeting of the Users' Group (Box 3.11), along with how to conduct the interviews of patients and carers.

Box 3.11 Users' Group

In order to develop an effective method of measuring patient experience of prostate cancer care we established a Users' Group to give advice during the study. Their advice was sought on the acceptability of the draft questionnaires and the conduct of patient and carer interviews.

The Users' Group was convened following guidance from INVOLVE (a national advisory group funded by the Department of Health: http://www.invo.org.uk/). Invitations were sent to national and local patient groups. These included a job description and personal specification so that it was clear what was involved and to help them to decide whether to accept the invitation. Thirteen people (12 prostate cancer patients, 1 Patient Advisory and Liaison Service representative) agreed to be members of the Users' Group and were invited to an induction session that was held at the Leicester General Hospital where the study was explained, any questions answered and their role on the Users' Group discussed. They also agreed to be part of the panel involved in reviewing the questionnaires.

Following the Users' Group meeting the interview schedules were finalised (see Appendices 4 and 5) and the issues are summarised in Box 3.12 below.

Box 3.12: Issues for the interview schedules

In order to capture all of patients' and carers' experiences of care questions were asked about all phases of the care pathway:

- information given to patients at the initial presentation
- tests performed and explanations given
- referral (explanations of reasons and process)
- experience of being tested for prostate cancer
- delivery of the diagnosis
- making the treatment decision
- experience of treatment
- discharge/end of treatment explanations and arrangements
- monitoring

Patients were also asked about the involvement of their carer/relative/friend and how they were treated, and given the opportunity to make any other comments on aspects of care that were important to them. Carers were asked about their involvement and how they were treated and were given the opportunity to comment on any aspects of care that they felt were particularly important.

d. Conducting and analysing the interviews

The semi-structured interviews were undertaken mainly by myself with help from another experienced interviewer (AP) in the patient's own home and took place over a six month period in 2005. They were audio taped and fully transcribed for coding using the available CAQDAS, NUD*IST N5. Initial coding was carried out using NUD*IST N5 software, and the data analysed using the Framework approach (Ritchie and Lewis, 2003). The issues reported in the interviews were coded according to a framework based on phases of the care pathway. Some data referred to experiences that were not linked with any one phase of the care pathway and so these were coded as other comments. Within each phase of care, major themes were generated

inductively from the data. A second researcher independently coded and analysed a sample of interviews. An interview mediated by a translator for non-English speaking patients was offered, with any such interviews to be translated into English prior to analysis.

3.3.3 Results

The characteristics of the patients included in the study are shown in Table 3.4 below.

Table 3.4: Characteristics of patients interviewed

Stage of disease/treatment	**Number of patients interviewed**	**Age of patients interviewed**	**Ethnic origin of patients interviewed**
Newly diagnosed: localised (prior to treatment)	2	55-70: 1 Over 70: 1	White
Newly diagnosed: locally advanced or metastatic disease (prior to treatment)	1	55-70: 1	White
Patients actively monitored without treatment (no diagnosis of cancer)	3	Over 70: 3	White
Patients actively monitored without treatment (diagnosed with prostate cancer)	4	Under 55: 1 Over 70: 3	White
Patients who have had curative treatment (prostatectomy or radiotherapy, or a combination of radiotherapy and hormone therapy)	17	Under 55: 4 55-70: 7 Over 70: 6	White: 8 South Asian: 4 Afro-Caribbean: 5
Hormone therapy	8	55-70: 4 Over 70: 4	White: 8
Patients with hormone refractory prostate cancer	0		
	Total 35	Under 55: 5 55-70: 13 Over 70: 17 **Total 35**	White: 26 South Asian: 4 Afro-Caribbean: 5 **Total 35**

Only two patients from ethnic minority groups were initially recruited and to ensure that both South Asians and Afro-Caribbeans were properly represented in our sample two cancer charities were contacted, Coping with Cancer (Leicester) and Cancer Black Care (London). They contacted seven patients (two South Asians and five Afro-Caribbeans) who gave their permission to be approached to gain their consent and be interviewed. No patients who had become hormone resistant were recruited. A total of 35 interviews of patients were selected to meet the sample criteria. Interviews of 10 female carers of the patients (White 8, Afro-Caribbean 1, South Asian 1) were also conducted.

Patient and carer experiences across the stages of prostate cancer care are presented below.

a. Initial presentation

Patients often had urinary problems (e.g. nocturia, difficulty urinating) and this led them to consult their GP. These men were usually unaware that their symptoms might be caused by prostate cancer and GPs did not routinely explain this. Only four of our sample of 35 patients were asymptomatic and had requested a prostate specific antigen test (PSA) test. In response to the reported symptoms of patients, GPs almost always carried out a PSA test and sometimes a digital rectal examination (DRE) as well. However, little or no explanation of the purpose of the tests was given, patients being unaware that they were being tested for prostate cancer or having the opportunity to participate in the decision whether or not to be tested.

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 a specialist at the local hospital]. (patient no.45).

One patient who did receive an explanation from his GP reported that he was unable to understand it

…I didn't understand it anyway, they were talking some big words, I mean God, BPH and benign and all that (patient no.54)

Some patients, although by no means all, were told the results of their tests before they were referred to hospital for further investigations. Only one patient, as a result of participating in a trial, was given any written information. He reported that it was very helpful to receive a written explanation of the purpose of the PSA test, the results and their implications

you can never remember everything what's going on err, and it's useful to have something to refer to, to read again and if necessary to look up on, on internet and, and look and find bit a little bit more about what they're talking about. (patient no.47)

Carers often encouraged their partners to go to their GP with their symptoms but did not attend the appointment with the GP themselves. Consequently their understanding of the situation was often limited by the extent of the GP's explanation and the ability of their partner to remember and report what had been said.

b. Referral

Patients had variable experiences of referral. Some reported that the reason for referral was clearly explained, while others were given no explanation. Some patients reported that GPs gave partial explanations such as the PSA score but no mention of prostate cancer, or were ambiguous: "*something*

wasn't right" (patient no.15). Patients sometimes reported that their GP reassured them*: "it's a little bit swollen, nothing to worry about, don't think it's anything serious like cancer uh but I'll refer you"* (patient no.2). Nevertheless, patients were often worried because they were being referred to hospital and some patients reported anxiety while waiting to attend the referral appointment. Those patients who were reassured by the GP or unclear why they had been referred often reported the biggest shock when they were later diagnosed with prostate cancer. The responses of some carers revealed that neither they nor their partners understood the reason for referral

I had never heard of a PSA test um obviously I read up about it afterward and I know a little bit about it now but at the time I didn't know that's how a diagnosis, you know one of the ways of diagnosing (carer no.4)

No patients reported being advised to take a partner/relative/friend with them when they attended the hospital outpatient clinic for further tests or being invited to go back to their GP to ask questions afterwards.

c. Tests

Patients reported a number of minor irritations when attending the hospital for further tests (e.g. difficulty finding the ward, lack of refreshments, inconvenient appointment time, clinic running late), and parking problems were not unusual. However, there were good experiences too, with some patients commenting on the positive attitude of staff and the amount of time spent with them.

The practice nurse and, and the consultant, who was doing it were excellent. Put me at ease err, and I just got on with it. (patient no.47)

Two issues were frequently reported by patients here: the experience of the biopsy and communication by staff. Patients' experience of the biopsy was that they often felt unprepared for it:

when I went to have the biopsy I was not told that's what was going to happen. So that did take me by surprise (patient no.15).

For some it was at best an uncomfortable experience, and for others an extremely painful one (one patient found the first biopsy so painful that he had the second under general anaesthetic). The communication by the doctor carrying out the tests was a problem for some patients, either because of the lack of explanation of their purpose (some patients were still unaware that they were being tested for prostate cancer), or poor communication skills, for example the doctor talking to himself rather than the patient

I went, came away again and went back on another day for the trans-rectal examination and again he was talking to himself but not to me. (patient no.21)

One patient reported that "*at the biopsy the consultant said if this isn't prostate cancer I don't know what is*" (patient no.2) and when asked to explain it to his wife the consultant went into the waiting room and gave the explanation in front of the other people in the waiting room. Carers usually accompanied their partners when they attended the hospital for further tests even though they had not been invited or encouraged to do so by the GP or the hospital. They were pleased that they had attended the hospital to support their partner and reported positive experiences (e.g. the hospital facilities and their treatment by staff), as well as negative ones (e.g. unclear what was happening and felt ignored or excluded during explanations).

d. Diagnosis

Many patients reported problems with the communication of the diagnosis. These included being given the wrong diagnosis, and being given the diagnosis with no explanations or discussion of treatment options "*nothing about what they were going to do or what I should do or in fact what anybody else should do*" (patient no.8). For some patients the diagnosis was the first time prostate cancer had been mentioned:

"my whole world just collapsed under me, legs, everything, I mean I was, you know, my mind just went completely blank" (patient no.54)

Even for those who knew that they had been tested for prostate cancer the shock was considerable "*I was just err, well I was just stunned"* (patient no.27). The shock of the diagnosis made it difficult for patients to take in further information or take the opportunity to ask questions. However, for those patients who saw a specialist nurse there was the opportunity to spend the time they needed to get further explanations, ask questions and receive written information. Carers generally attended this consultation with their partners as they felt it important to give support and one South Asian patient was accompanied by his son in case of possible language difficulties. One carer reported that she had more information needs than her partner and that these had not been identified.

e. Treatment decision

Patients reported a wide range of experiences of how the treatment decision was made. Some consultants made the treatment decision without explanation or discussion of other treatments, and patients sometimes felt they did not know enough to ask questions. Other consultants passed the decision over to the patient, which some found disconcerting, and one patient

who was distressed by this pleaded with the consultant to make the decision for him

I looked straight at the consultant, I said what do you think. He said it's not down to me, your choice. I said I'm asking you please…I said my life is in your hands…and he said I'm gonna do surgery, I recommend you have surgery" (patient no.53)

These directive and non-directive approaches to choosing treatment by consultants only suited some patients, as they were not usually tailored to the wishes of the patients. One patient said that he would have preferred a more collaborative approach to the decision and a patient who had gone on his own regretted this

I was sitting round a table, me, the consultant, a registrar and a nurse…I should have had someone with me" (patient no.53)

A common comment by patients was that explanations and information (e.g. on treatment options, side effects) were not provided by the consultant. However, the specialist nurse often played an important role in meeting these needs and some patients reported that they subsequently searched the internet for information. One patient requested an MRI scan to help him make the treatment decision, and although the consultant refused, the specialist nurse arranged it. Carers confirmed their partners' reports of not being given a choice of treatment, and that specialist nurses provided an important source of information. The provision of written information was identified as useful, and it was important that the carer was invited to attend the consultation because having heard what was said first hand they found that it was easier to take part in subsequent discussions.

f. Treatment

Patients “wanted to get on with it” and were concerned about how long they had to wait until their treatment started, finding some re-assurance in there being no delay and anxiety at any prolonged delay. Patients receiving hormone therapy and radiotherapy were not always clear about how their treatment was organised, and some patients found problems with parking, waiting for radiotherapy treatments, and inconvenience in having to attend the hospital everyday. However, there were also positive reports of things running smoothly, pleasant staff and one patient who found the waits for radiotherapy provided him with a welcome opportunity to talk with other patients. Carers were keen to support their partners, by accompanying them and asking questions about issues that their partner was unlikely to raise. Some felt that their concerns were not taken seriously or that they were perceived as trouble, as the consultant gave the impression that they did not wish to be questioned. Carers sometimes had to take the initiative to be included in consultations, and in one instance their partner excluded them. Where carers reported that they had their own information and support needs these were not met.

g. Post initial treatment

Several patients reported that the follow up arrangements were clearly explained, and that there was good co-ordination between different healthcare professionals. However, some patients reported unsatisfactory experiences including being discharged too early and a lack of follow-up care. Other issues were staff making contradictory statements, lack of information and help with the practicalities of incontinence, and no explanation of the success

of the treatment. One patient suggested that providing written information that patients could refer to would be useful and that they should be told about where they can get support (e.g. charities, support groups). Carers echoed the concerns raised by their partners about the importance of being clear what the practical arrangements were (e.g. where to get supplies of continence pads) and the longer term issues

Erm I think one thing that I didn't have at that stage which might have been helpful is to have a one to one with somebody just on my own cos I don't think that ever happened (carer no.44)

In addition carers had unmet needs themselves, such as practical support like shopping and support for themselves. One carer reported that they made regular contact with a charity to build a supportive relationship.

h. Monitoring and further treatment

Patients valued being monitored as they found this re-assuring, although the length of wait between PSA tests caused some patients anxiety if it had not been explained and if appointments were postponed

You've sort of, you've got to wait till the next appointment, which is a - three months apart, and that's if they don't cancel it again. They altered the first one… twice. (patient no.31)

Patients were monitored either at their GP's surgery or the hospital depending on their preferences. However, the results of the monitoring tests were not always discussed with patients, which they found unsatisfactory. Some patients took the opportunity at this appointment to discuss their erectile dysfunction caused by the treatment. Carers reported also being re-assured by the on-going monitoring of their partners and some took a leading role, developing a better understanding of the process and asking for tests for their partner.

i. Other comments

Patients raised a number of issues about their experiences of care that did not fit into any one phase of the care pathway. These included: the importance of being told how to find out more information (e.g. via websites, charities, individual patients or support groups); the importance of the consultant's communication in helping patients to understand their experiences of care and the treatment decision; and the important role played by specialist nurses (e.g. providing explanations, organising appointments). Many of the carers referred positively to their experience of attending a support group and the access they had to the specialist nurse at these meetings. One carer thought it important that carers should have the opportunity to talk to health care professionals on their own. Several carers also raised concerns about their partner's co-morbidities.

3.3.4 Discussion

It is important to note that the interviews did not reveal widespread patient dissatisfaction with their care, and some very positive experiences were reported. However, these interviews show considerable variation in the experiences of prostate cancer care which can in part be explained by changes in service provision, such as the introduction of specialist nurses. Where experiences were less positive, they suggest an approach by health care staff that may be described as paternalistic, and together with a failure of services to consistently recognise patients' and carers' needs, may explain the poor rating of prostate cancer care in comparison with other cancers in the 1999/2000 and 2004 national surveys (Department of Health, 2002, National

Audit Office, 2004). This is evident in two key areas. First, patients (and carers) reported a lack of explanation and information at crucial times (e.g. when the patient first presents with symptoms, the reasons for the referral) and in appropriate formats (e.g. written information that the patient or carer can refer to later). Consequently patients were often unclear that they were being tested for prostate cancer and were shocked when diagnosed with it. The lack of written information meant that patients had nothing to refer to for assisting their memory or understanding. The second area is the role of the patient in decision-making, in particular with regard to the screening and, later on, the treatment decisions. Several non-symptomatic patients asked to be screened for prostate cancer but none of them reported being involved in the decision to proceed with the tests. The treatment decision-making process appeared to be more a function of the consultant's preferred style rather than a response to the patient's needs. This varied from the consultant making the decision with no patient input, to passing the decision entirely over to the patient. Many patients reported some level of dissatisfaction with the decision-making process that they had encountered. Although from the treatment decision stage onwards, when the specialist nurse became involved, this situation improved. Carers focused primarily on supporting their partners through the phases of the care pathway. They too, often had unmet information needs particularly in relation to help with coping and on-going support post initial treatment.

The interviews were semi-structured but were not time limited. Consequently patients' and carers' experiences and the issues important to them in prostate

cancer care were explored in some depth. A range of patients was interviewed to ensure a spread of experiences, and a small number of carers were also interviewed. A limitation was that most of the interviews were with patients who had completed their treatment and were recalling some experiences that took place a year or more earlier. This was the case particularly with the earlier phases of their care, for example in primary care or the diagnostic tests at the hospital.

Chapter 4: Developing the initial version of the measure of patient experience of prostate cancer care

In this chapter I will summarise the findings of the research conducted and its implications for a new measure of patient experience of prostate cancer care, and then describe the process of drafting the measure of patient experience so that it is ready for piloting.

4.1 Drafting the new measure

4.1.1 Introduction

The issues that were identified as important in prostate cancer care were predominantly ones of communication. The literature review identified the unmet information needs of patients, and that their involvement in the treatment decision making process was invariably determined by the clinician. The patient and carer interviews confirmed these findings, although with regard to the treatment decision there had been some change as some patients reported that clinicians passed the decision over entirely to the patient. The interview findings added that there was inadequate communication in relation to other aspects of care, including testing, discharge from hospital and sources of support. Patients' lack of knowledge and understanding throughout different phases of care was confirmed by interviews with those working for charities that offer support. It should be noted that the findings did not indicate dissatisfaction with the treatment patients received or a problem of patients generally not being treated with respect and dignity. The role and value of the specialist nurse in prostate

cancer care emerged as an important theme, with patients reporting very positive experiences of care when they were involved.

The research findings concerning the format of the measure were clear. The new measure will be a questionnaire that covers the patient care pathway from initial presentation in primary care to monitoring post treatment. While it is important to recognise the need to have a measure of patient experience for patients who relapse and require palliative care and end-of-life care, this is a specialist area that requires specific research to identify the appropriate content and format of such a measure. Consequently this phase of care will not form part of the new measure being developed here. The importance of the role that carers play in supporting prostate cancer patients, and in some cases caring for them, became clearer as the research progressed and there was strong evidence to include carers in a new measure. In order to separate patients' and carers' experiences and to ensure that carers' needs are identified, it is intended that the measure developed here will be for patients, and that a separate measure be developed for carers to complete.

In developing the questionnaires, it was intended that the issues identified as important to patients, carers and healthcare professionals should be included, and that the format should take account of the preferences that had been expressed. The development stages are summarised below and then described:

1. Drafting the questionnaires: I drafted questions to cover each of the issues identified as important and these were commented on by another team member.

2. Reviewing the questionnaires: questions were reviewed by the research team and by a Panel of healthcare professionals and patients.

3. Checking the content and comprehensibility of the questionnaires: patients and carers were interviewed.

4.1.2 Methods

The approach to developing the initial drafts of the questionnaires was designed to achieve two aims. Firstly, in order to support content validity, it was essential to ensure that the questions covered the issues identified as important (Streiner and Norman, 1995). Second, in the interests of acceptability and ease of completion, we sought to phrase the questions using easily understood English, avoiding ambiguity and using medical terms only if strictly necessary.

a. Types of questions

It had been decided previously (see Section 1.4.2) that the new measure was to be one that measured patient experience rather than patient satisfaction. Consequently the questions were generally worded to collect reports rather than ratings (see Box 4.1).

Box 4.1 Types of questions

Rating questions are evaluative, collecting information about how patients feel about their experience, e.g.

How do you rate the following: How well the doctor explains your problems or any treatment that you need?

Very poor□ Poor □ Fair□ Good□ Very good□ Excellent□ [1]

Report questions collect information about 'what happened', e.g.

When you had important questions to ask a doctor, did you get answers that you could understand?

Yes, always□ Yes, sometimes□ No□ I had no need to ask□ [2]

[1] General Practice Assessment Questionnaire (GPAQ), NPCRDC, University of Manchester and Safran/NEMCH [Online] Available at: http://www.gpaq.info/about%20GPAQ.htm [Accessed 31 July 2009]

[2]NHS Inpatient questionnaire, 2005. Picker Institute Europe. [Online] Available at: http://www.biomedcentral.com/content/supplementary/1472-6963-7-161-S1.pdf

[Accessed 31 July 2009

We used a patient report approach that incorporated an evaluative component in order to identify whether care met patients' needs (see Box 4.2 for an example).

Box 4.2 Identifying whether care met patients' needs

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

Yes, the explanation was clear □

Yes, but the explanation could have been clearer □

No explanation was given □

I did not want/need an explanation □

This approach is particularly suited to service monitoring and re-design because it can identify the actions required to improve service delivery. It was appropriate here because the new measure is intended for use in both monitoring and service improvement initiatives.

b. Use of Terminology

Cancer

The NCPS (National Cancer Patient Survey) questionnaire (Department of Health, 2002, National Audit Office, 2004) had chosen not to use the word cancer to avoid distressing patients and carers. The issue of whether to use the term prostate cancer in the questionnaire had to be considered, particularly if it was to be a postal questionnaire that may be seen by people other than the intended recipient. Initial attempts to write questions without using the term prostate cancer introduced ambiguity into questions and would therefore have rendered the answers much less reliable. Consequently, the approach adopted was to draft a statement for the cover of the questionnaire that stated it was intended for those people who had been tested for prostate cancer. If they had not been tested for prostate cancer the questionnaire had been sent in error, and an apology was made.

Carer

The use of the term “carer” is problematic not least because the term is used to describe a type of healthcare professional. In the phases of prostate care provided by the NHS prior to treatment the patient may not have, or need anybody to fulfil the role of a carer as they may be able to carry on living much as before (although there will be emotional or psychological needs in

adjusting to the diagnosis and reaching a decision on the treatment choice). Immediately post-treatment patients may need a carer but this will often cease to be the case as side effects diminish. However, there is no commonly used alternative to the term carer and it has been used throughout this thesis.

c. Drafting the questions

Each question was written to cover a particular issue that had been identified as important to include in the new measure. Reference was made to the questionnaire used in the National Cancer Patient Survey 1999/2000 (Department of Health, 2002) to inform both the wording of the questions and the response options. Almost all of the questions were written with closed response options (as shown below in Box 4.3) to facilitate completion and analysis of the questionnaires.

Box 4.3 An example of identified issues and the questions drafted

Your visit to the GP with this condition

Symptoms and concerns

Issue: Patient should be treated sensitively as symptoms are potentially embarrassing

Question: When you first visited the GP for this condition were you treated with respect?

Yes, definitely □ Yes, to some extent □ No, definitely not □

Issue: The GP has provided an appropriate explanation of the possible cause of the symptoms

Question: Did the GP explain what might be causing your symptoms?

Yes □ No □ I did not have any symptoms □

A small number of open-ended questions also allowed respondents to expand on their answer in free text (see Box 4.4)

Box 4.4 An example of a question with closed and open responses

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

……

d. Creating sections

In accordance with the research findings the questions were grouped into sections, each covering a separate phase of care, enabling administration of separate sections soon after a patient had experienced a particular phase of care. This would allow patients to answer the questions from their recent experience, thereby reducing possible memory effects. The questions in each Section were reviewed independently by myself and another researcher to check whether they covered the issues appropriately and to identify potential improvements to the phrasing of the question or the response options. Discussions took place to resolve any concerns of either researcher.

4.1.3 Results

The process described above resulted in a questionnaire for patients that was divided into the phases of prostate cancer care that had been suggested by the clinical members of the research team and corroborated by the findings of the interviews of professionals and patients. These were created by grouping questions into the appropriate phase of care. The sections were given titles to make the subject of the questions clear to respondents (see Table 4.1 below).

Table 4.1 The phase of care and the corresponding sections in the questionnaire

Phase of care	Patients' section in the questionnaire
1. Initial presentation, tests and referral	A. Going to your GP's practice
2. Tests for prostate cancer at the hospital	B. Going to the hospital
3. Diagnosis	C. Your visit to hospital for your test results
4. Treatment	D. Your treatment
5. Monitoring	E. Monitoring (checking) your condition

A final section in the questionnaire (Section F: About you) was included to gather socio-demographic data about respondents. The content of this section was drawn from General Practice Assessment Questionnaire (GPAQ). GPAQ is a patient questionnaire which has been developed at the National Primary Care Research and Development Centre at The University of Manchester for the 2003 GP contract (available online at: http://www.gpaq.info/about%20GPAQ.htm). Building on several years of development and testing, GPAQ helps practices find out what patients think about their care.

4.1.4 Discussion

The drafting of the questionnaires had drawn on all the research findings to ensure that the questions addressed all the issues that had been identified as important to patients and their carers. The draft questionnaires were now

ready for a comprehensive review by patients, healthcare professionals and voluntary sector workers.

4.2 Reviewing and revising the questionnaire

4.2.1 Introduction

The value of the findings of the patient experience questionnaire when used by NHS Trusts will rest on the extent to which it collects information about aspects of care or services that are important in influencing patient experience. Therefore, to ensure that questions on important aspects of care had not been omitted, the content of the draft questionnaire required review. An informed view of the content of a patient experience questionnaire had been built up from the literature review and the interviews of health care professionals, voluntary sector workers and patients and carers. Furthermore, our research team included clinicians who treated patients for prostate cancer and researchers with experience of developing measures of patient experience. However, reliance on the research team alone to review the draft questionnaire for content validity would have been inappropriate. The perspective may have been too limited, and led to important issues being overlooked. Therefore, a panel of clinicians and patients was convened, and using a modified Delphi approach, they were asked to review the questionnaire as well.

4.2.2 Methods

The draft questionnaire was circulated to the research team who were asked to comment on whether the questions covered the issues appropriately and to

suggest any changes that might improve the wording. A team meeting was then held to discuss the comments and suggestions, and to make revisions to each of the sections. The sections were subsequently redrafted and sent to the team for further comment before the initial draft was finalised. The draft questionnaire was then mailed to the Panel for their comments and suggestions (Murphy et al., 1998). The Delphi method is a consensus process that allows 'harnessing the insights of appropriate experts to enable decisions to be made' (Jones and Hunter, 1996). Its features include anonymity, feedback and iteration. In comparison with focus groups and other face-to-face methods, this technique avoids domination of the decision process by forceful personalities and the disrupting effects of interpersonal dynamics in face-to-face groups (Linstone and Turoff, 1975).

To enable a range of perspectives, we included both healthcare professionals and patients. The patients were recruited from the Users' Group and the healthcare professionals were recruited from individuals who had taken part in interviews. We used a modified Delphi approach in which the Panel was asked to review drafts of the questionnaires by responding to specific points put to them (see Box 4.5). Contact with the Panel was by email and post, including reminders to non-responders. Two cycles of consultation with the Panel were undertaken.

Box 4.5 The process of reviewing the questionnaire: instructions to Panel

We have used the research that we have carried out to draft a series of questionnaires to find out what patients' experiences are at different stages of prostate cancer care

We are sending the draft questionnaire to the panel that you are part of to review the questionnaire and make any comments about any aspects of the questionnaire, for example

is the introduction clear?

are the questions clear?

are the response options appropriate?

is the questionnaire too long/too short

are the questions in the right order?

are there any questions which should not have been asked?

are there any questions which should have been asked?

is the layout clear?

(patients may find it helpful to try to complete the questionnaire to see if that shows up any problems – your responses will not be recorded!)

Please return the draft questionnaire to us with your comments.

We will review the questionnaires in the light of all the comments we receive.

All the changes suggested by members of the Panel in the first round were collated and reviewed at a meeting of the research team. The suggested changes were discussed to achieve a consensus on which of the changes should be implemented. The revised questionnaire was then sent to the Panel for a second review to allow comments to be made on the changes made from the first round. The review process was repeated, resulting in further changes from the second round of consultation with the Panel.

4.2.3 Results

Of the 27 people who were invited to join the Panel 22 agreed, although three dropped out before the first review. The 19 members of the panel included 10 patients, 7 healthcare professionals and 2 voluntary sector staff. At least half of the members of the Panel responded to each set of questionnaires in three of the four consultation cycles (Box 4.6).

Box 4.6 The Panel's responses

Sections	**1st round**	**2nd round**
1,2,3,4	**10/19**	**7/19**
5,6,7,8	**13/19**	**10/19**

While the questionnaire met with broad approval there were a number of specific comments and suggestions to improve the questionnaires made by patients, healthcare professionals and voluntary sectors workers. Most of the comments and suggestions related to clarifying the questions, to make them unambiguous and the language easier to understand. These can be grouped into three main types: clarifying the wording of existing instructions and questions; suggesting new questions to cover aspects of care not fully addressed; and revising the format of the questionnaire to make it easier to complete. See Box 4.7 below for examples of the changes suggested.

Box 4.7 Types of revisions recommended by the Delphi Panel

1. Clarifying the wording (e.g. simplifying the language, eliminating ambiguity)

Questionnaire v1: Section B (Tests at the hospital) Question 20.

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

Suggested change

Did the doctor or nurse explain to you how long you would have to wait for the results of your test(s)?

2. Suggesting new questions (e.g. about an aspect of care not covered)

Questionnaire v1 Section E (Monitoring)

Were you told about the reliability of the PSA test?

3. Revising the format (e.g. using the same question in more than one section, changing the order of the questions, adding response options, making the routing directions more noticeable)

Questionnaire v1 Section B (Tests at the hospital)

Questions 13-19; it was suggested that these questions were re-ordered so that the questions about explanations and information about the Gleason score came after the questions about the tests

The team meetings to review the comments and suggestions made in each round of the modified Delphi process involved discussions of each point raised. The discussions continued until a consensus was achieved over the changes to be made to the questionnaire.

4.2.4 Discussion

The process of sending the draft questionnaire to a panel of patients, healthcare professionals and voluntary sector workers ensured that they were thoroughly reviewed. The first review round enabled the Panel to make their own comments and suggestions without influence from other Panel members. The second review round enabled the Panel to see the changes made by the team as a result of all the comments and suggestions made, and enabled the Panel to review the changes made by the research team.

During this review and revision of the questionnaire it was important that there were responses that indicated that the questionnaire did address the issues important to prostate cancer patients during their care. The review process strengthened the questionnaire and it was now ready for the next development stage, the consultation with patients to check the content and comprehensibility.

4.3 Checking the content and comprehensibility of the questionnaire

4.3.1 Introduction

The questionnaire was developed from our interviews of patients, carers and professionals, and a review of relevant publications. It was also informed by the questions and their response options used in the National Cancer Patient Survey (Department of Health, 2002). Although the initial review indicated that they addressed the issues important to patients and could be understood, they had not been considered in detail by patients themselves, and this was therefore the next step in the development of the measure. In this stage, the particular focus was the comprehensibility of the questionnaire.

4.3.2 Methods

Interviews were selected as the best method to test the comprehensibility of the questionnaire because they would allow patients and carers to discuss aspects of the questionnaire and explore how improvements could be made. This approach facilitated an in-depth consideration of the questions and the acceptability of the response options, including the opportunity to seek

opinions on the comments and suggestions made by other patients and carers. A purposive sample of patients and their carers was identified from replies received in response to a written invitation to them to be interviewed. The sample included patients and carers of different ethnic groups, from a range of age groups, from two different hospitals sites, and who had received one of a range of treatments for prostate cancer.

The interviews were arranged to take place in respondents' own homes, where they were given a copy of the questionnaire to complete up to their present phase of care. Patients and carers were able to draw on their own experiences of care to answer the questionnaire. I then went through the questionnaire with them to see if there were any issues or difficulties and how they might be resolved (see Box 4.8 for a summary of guidance for the interview).

Box 4.8 Guidance for the interview

1. Give patients the questionnaire, to review up to their current phase of care.
2. Ask them to read the introduction and complete the questionnaire
3. Go through the questionnaire with them and check that
   - the introduction is clear
   - each question is clear and that the response options are appropriate
   - the order of the questions is logical

At the end: ask if there are there any other comments that they wish to make.

Thank them for their time and tell them they will receive an update on the progress of the study.

The comments made by the patients and carers were recorded in writing on the questionnaire by the interviewer at the time. Once all the interviews had been completed the comments were collated on one questionnaire, thereby bringing all the comments about each question into one place.

4.3.3 Results

A total of 18 patients were interviewed. The theoretical sample described above was achieved for patients (see Table 4.2 below).

Table 4.2 Sample of patients interviewed to check the content and comprehensibility of the questions

Treatment	**Number of patients**
Newly diagnosed	3
Monitored	4
Radiotherapy & hormone therapy	3
Prostatectomy	4
Hormone Therapy	3
Not recorded	1
Total	**18**
Ethnic group	**Number of patients**
White	12
South Asian	3
African-Caribbean	2
Total	**18**

Interviewees understood the importance of the process and were prepared to give up as much time as necessary to go through the questionnaire, with interviews taking between one and two hours. The comments made by patients confirmed the relevance of the questions in the questionnaire and

very few comments or suggestions were made about adding new questions. However, all the interviewees raised some issues, either about the questions, the response options or the instructions. Possible changes were discussed and most interviewees made suggestions about how to improve the questionnaire. The changes that were made to the questionnaire were too numerous to list in full here, so the types of changes have been summarised in Box 4.9, with examples of how questions were changed.

Box 4.9 Types of changes made to the questionnaire suggested by patients, with examples

1. Clarifying the questions (e.g. re-wording the questions so that the meaning is clearer)

Questionnaire v1: Section B Question 2

At which hospital did you have your first appointment?

In Question v2 this was changed to:

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

2. Revising the response options (e.g. adding/changing response options to capture patients' and carers' experiences more accurately)

Questionnaire v1: Section C Question 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?

Too short

About right

Too long

No opinion/not important

Questionnaire v2: Section C

The last response option was changed to:

I did not discuss my test results with a specialist nurse

3. Making the questionnaire easier to use for respondents (e.g. changing the title, changing the order of the sections)

Questionnaire v1: front cover used for title of questionnaire heading and text explaining purpose of questionnaire

Questionnaire v2: changed the title to make it explicitly about prostate cancer, changed the order of the Sections so that the socio-demographic section (About You) was last rather than first, logos of organisations responsible for the questionnaire included

4.3.4 Discussion

The stakeholders involved in the use of a measure of patient experience of prostate cancer care had been consulted so that the new measure would meet their needs. The measure developed was a questionnaire and the content reflected the issues identified as important in prostate cancer care, not least by the patients themselves. Initial drafts of the questionnaire were also reviewed by the stakeholders, so that they were ready to be piloted with patients in hospital settings. Patients drew on their experiences of different care pathways, different treatments and different standards of care when completing the questionnaires. The subsequent interviews allowed them as much time as they needed to comment on the questionnaire and make suggestions for improving it. The content of the questionnaire appeared to address all the issues important to patient experience. The questionnaire was however, revised in response to the comments on comprehensibility prior to piloting it with patients different hospitals (see Appendix 6 for a copy of the questionnaire – PCQ-Pv1). The next chapter will describe the piloting of the questionnaires in three hospital settings.

Chapter 5: Piloting the prostate cancer care questionnaire

In this chapter I will describe the research conducted to pilot the prostate cancer questionnaire designed to capture patient experience of care.

5.1 Introduction

The purpose of piloting the questionnaire was to review how it performed in practice. Piloting is a crucial stage in the development of a questionnaire and undertaken to ensure that

- all the relevant issues are included
- the order is correct
- ambiguous or leading questions are identified
- pre-codes are correct

(Wilson et al., 2000)

The measure, whose development was described in the previous chapter, was named and abbreviated for ease of identification as it would require a number of revisions to be piloted and tested before arriving at a final version. The name decided upon was Prostate Care Questionnaire for Patients, or PCQ-P. The use of the term “Prostate Care” was to indicate that the questionnaire was concerned with all aspects of care, including initial screening. This title recognises that some patients completing the initial sections of the questionnaire (e.g. going to the GP’s practice, having further tests at hospital) would later be found to have no evidence of prostate cancer. The diagnosis in these cases would not be known until the GP or specialist

investigation stage of the care pathway. However, the experience of these patients who were tested by GPs and those who were referred to hospital for further tests should be captured to give a complete picture of the care provided. The inclusion of “Patients” in the questionnaire’s name emphasised that the questionnaire was intended for them to complete.

The research conducted had revealed the important role that carers played in supporting men through the different phases of care and that their experiences should be captured in the new measure (see Chapter 3). However, after some consideration and discussion with members of the research team it was decided that a separate measure for carers would be developed because two separate questionnaires would:

- help to ensure that the views of carers and patients were gained independently of each other (rather than a consensus)
- help to keep both the questionnaires to manageable lengths
- allow for a full exploration of the experiences of carers

The development of a separate questionnaire for carers was undertaken alongside the questionnaire for patients but is beyond the remit of this thesis.

5.2. Piloting the questionnaire: PCQ-Pv1

5.2.1. Introduction

The piloting of the first version of the questionnaire (PCQ-Pv1) had two aims:

- first, to test the feasibility of administering the questionnaire by analysing both the distribution and the return of completed questionnaires;

- second, to test the acceptability to patients of the questions and response formats through analysis of response patterns.

The results of the first pilot were to be used to inform the further development of the questionnaire leading to Version 2.

5.2.2 Methods

PCQ-P v1 (see Appendix 6) consisted of six sections, five of which followed the different phases of the patient's care pathway and the sixth, which contained socio-demographic questions. The development of the pilot questionnaire has been described in the previous chapter. The title of each section and the number of questions in each section are described in Box 5.1.

Box 5.1 Patient Questionnaire (PCQ-P v1)

Section A: Going to the GP's practice for the first time because of your possible prostate problem (35 questions)

Section B: Having tests/further tests for possible prostate cancer at the hospital (24 questions)

Section C: Discussing your test results for possible prostate cancer (31 questions)

Section D: Your treatment (28 questions)

Section E: Monitoring (checking) you (17 questions)

Section F: About you and your health (11 questions)

The purpose of piloting the questionnaire in hospitals was to test it with samples of patients drawn from the group of patients who would complete the final version of the questionnaire. This is important because as Tanur (1992 cited in Bowling, 2002) and Mallinson (1998 cited in Bowling, 2002) have pointed out, "research has shown that respondents may interpret questions, including questions on health status, in different ways to the investigator".

The following issues were considered in identifying a suitable sample of patients:

Table 5.1: Constructing the patient sample to pilot the questionnaire

Issue	Action
To avoid the potential bias associated with sampling patients from one hospital	Identify two hospitals willing to pilot the questionnaire in different parts of the country
To ensure BME patients are included	Ethnicity not recorded in patients' records so hospitals were identified in areas serving multi ethnic communities
To ensure patients are able to recall early phases of care (initial consultation and tests) which may have occurred five or more years ago	Sample to be restricted to patients diagnosed in the last two years
To ensure the sample includes patients who have had different treatments	Lists of hospital patients to be reviewed by a member of the MDT to ensure a range of treatments are represented
To avoid upsetting patients and their family	Lists of hospital patients to be reviewed by a member of the MDT to ensure questionnaires were not sent to patients inappropriately e.g. patients who had not been told their diagnosis or had recently died.

Two hospitals agreed to take part. Hospital 1 was a teaching hospital in a city in the East Midlands and Hospital 2 was also a teaching hospital and located in London. Questionnaires were posted to 300 patients; 150 in each hospital, with one reminder letter to non-responders.

5.2.3 Results

Overall, 159 patient questionnaires were returned completed (53%), 102 (a response rate of 68%) of the patients from Hospital 1, and 57 (a response rate of 38%) of the patients from Hospital 2. The characteristics of patients are

described in Table 5.2. Seventy-four (47.1%) responders reported having been actively treated for prostate cancer in the past year.

Table 5.2 Characteristics of respondents

Age	**Number of Patients (%)**
<55	4 (2.5%)
55-64	49 (31.2%)
65-74	75 (47.8%)
75-84	19 (12.1%)
85+	2 (1.3%)
Ethnic origin	**Number of Patients (%)**
White British	110 (70.1%)
White other	15 (9.5%)
Indian	5 (3.2%)
African/Caribbean	17 (10.8%)
Health Status	**Number of Patients (%)**
Very good (9-10)	44 (28.0%)
Good (7-8)	67 (42.7%)
Fair (5-6)	17 (10.8%)
Poor (<5)	13 (8.3%)
Employment status	**Number of Patients (%)**
Employed (full or part time)	33 (21.0%)
Retired	97 (61.8%)
Unable to work due to illness	13 (8.3%)
Other	10 (6.3%)
Type of most recent treatment (some reported more than one treatment)	**Number of Patients (%)**
Prostatectomy	45 (28.7%)
Radiotherapy	22 (14.0%)
Hormone therapy	31 (19.7%)
Planned combination of treatments	39 (24.8%)
Active monitoring	23 (14.6%)
Other	7 (4.5%)

N.B. Percentages may not add to 100 due to missing values.

Response patterns

The distribution of responses for each question was examined in the questionnaire in order to identify potentially non-discriminatory, confusing, or unnecessary questions. Questions for which responses showed little variation across patients (i.e. did not discriminate between different patient experiences), and questions with a high proportion of missing responses, were examined and revised or excluded in the subsequent draft of the questionnaire. Table 5.3 shows the distribution of scores, and missing values, for all questions in each section of the questionnaire. The questionnaire included some filter questions, where respondents are instructed to skip a number of questions that are not appropriate to them. An example is provided in Box 5.2 where question D14 from the questionnaire asks patients to answer if they were treated in the hospital (as it is likely that some patients would be treated at the GP practice) and if they answer 'no' they are instructed to omit questions D15 and D16 about their evaluation of inpatient care.

Box 5.2: Example of a filter question in PCQ-Pv1

D14. Did you have your most recent treatment in hospital?

Please tick one box

Yes	☐ 1	
No	☐ 2	If no, please got to Question 16

The distribution of scores, and missing values, are adjusted for filter questions, in other words, respondents who should have skipped the question

based on their response to the filter question are excluded. The following tables show the distribution of scores for each question, in all sections of the PCQ-P v1 (see Appendix 6 for a copy of the questionnaire and information about response options). Where response options are not numbered on the questionnaire, the first option has been coded as 1, the second as 2 and so on. The 'Error' column shows the number of people completing the question incorrectly (e.g. ticking two boxes where they should only have ticked one).

Table 5.3: PCQ-P v1 pilot: distribution of scores and missing values

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

Question	N ticking each response option						Error	Missing n (%)	Total
	1	2	3	4	5	6			
A2. When you went to the GP's practice who did you see?	122	15	4	3	.	.	2	11 (7.0)	157
A3. Was this the person you wanted to see?	127	0	21	.	.	.	1	8 (5.1)	157
A4. What was your reason(s) for going to the GP's practice?	76	14	38	20	26	.	0	18 (11.5)	157
A5. Did the doctor or nurse take note of your concerns?	111	7	6	24	.	.	1	8 (5.1)	157
A6a. Overall, did you have confidence and trust in the doctor that you saw?	130	12	2	0	.	.	0	9 (5.9)	153
A6b. Overall, did you have confidence and trust in the nurse that you saw?	3	1	0	0	.	.	0	0	4
A7. Did the doctor or nurse give you an explanation of what might be causing your symptoms?	81	18	17	32	.	.	1	8 (5.1)	157
A8. Did you have a PSA/blood test organised by the GP's practice?	126	25	.	.	.	.	0	6 (3.8)	157
A9. Where was your first PSA test carried out?	75	6	42	1	.	.	0	2 (1.6)	126
A10. Before the test, did the doctor or nurse give you an explanation of what the PSA test was trying to find out?	57	7	15	5	.	.	0	0	84
A11. Before the test, did the doctor or nurse give you an explanation of what might happen if the PSA test was abnormal?	47	7	29	1	.	.	0	0	84

A12. Before the test, did the doctor or nurse explain that the PSA test is not always accurate?	51	5	25	3	.	.	0	0	84
A13. Did the doctor or nurse offer you any written information about the PSA test?	21	62	.	.	.	.	0	1 (1.2)	84
A14. Did the doctor or nurse involve you in the decision on whether to have a PSA test?	7	65	10	.	.	.	0	2 (2.4)	84
A15. Did the doctor or nurse advise you to avoid ejaculation 24/48 hours before the PSA test?	7	75	.	.	.	.	0	2 (2.4)	84
A16. Did the doctor or nurse give you an explanation of the results of your PSA test?	54	13	14	.	.	.	0	3 (3.6)	84
A17. Did the doctor or nurse give you the results of your PSA test in a considerate way?	55	18	3	4	.	.	0	4 (4.8)	84
A18. Did you have a DRE organised by the GP's practice?	96	49	.	.	.	.	0	12 (7.6)	157
A19. Where was your first DRE carried out?	66	29					1	0	96
A20. Before the test, did the doctor or nurse give you an explanation of what the DRE was trying to find out?	50	6	7	3	.	.	0	1 (1.5)	67
A21. Before the test, did the doctor or nurse give you an explanation of how the DRE is carried out?	50	6	6	4	.	.	0	1 (1.5)	67
A22. Did the doctor or nurse offer you any written information about the DRE?	2	60	.	.	.	.	0	5 (7.5)	67
A23. Before the test, did the doctor or nurse give you an explanation of what might happen if the DRE was abnormal?	34	3	24	5	.	.	0	1 (1.5)	67
A24. Did the doctor or nurse involve you in the decision on whether to have a DRE?	11	53	2	.	.	.	0	1 (1.5)	67
A25. Did the doctor or nurse give you an explanation of the results of your DRE?	54	6	5	.	.	.	0	2 (3.0)	67
A26. Did the doctor or nurse give you the results of your DRE in a considerate way?	52	8	2	3	.	.	0	2 (3.0)	67
A27. 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?	72	38	17	3	12	3	0	12 (7.6)	157
A28. How did you feel about the time the GP took to refer you to the hospital for further tests?	10	124	5	.	.	.	1	14 (9.1)	154

A29. Did the doctor or nurse give you an explanation of why you were being referred to hospital?	111	15	13	6	.	.	0	9 (5.8)	154
A30a. Did the doctor or nurse give you a choice of which hospital you wanted to go to?	27	117	10	.	.	.	0	10 (6.5)	154
A30b. Did the doctor or nurse give you a choice of how soon you wanted to be seen?	17	103	.	.	.	.	0	34 (22.1)	154
A31. Did you have any particular needs when the referral arrangements were made?	9	135	.	.	.	.	0	10 (6.5)	154
A32. Were these needs taken into account when the referral arrangements were made?	6	3	.	.	.	.	0	0	9
A33. Did the doctor or nurse give you an explanation of how soon you would be seen at the hospital?	57	7	66	13	.	.	0	11 (7.1)	154
A34a. Overall, did the doctor treat you with respect and dignity?	128	12	2	0	.	.	0	8 (5.3)	150
A34b. Overall, did the nurse treat you with respect and dignity?	3	1	0	0	.	.	0	0	4

Question	**N ticking each response option**										**Error**	**Missing n (%)**	**Total**
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**			
A35. Overall, please show how good or bad your experience of care was	0	2	1	1	3	3	16	33	35	39	2	9 (5.8)	154

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

Question	**N ticking each response option**						**Error**	**Missing n (%)**	**Total**
	1	**2**	**3**	**4**	**5**	**6**			
B1. Who referred you for tests/further tests at the hospital?	87	60	1	.	.	.	1	5 (3.2)	154
B2. At which hospital did you have your first appointment?	110	9	.	.	.	.	0	35 (22.7)	154
B3. Were you given enough information to help you with your visit to the hospital for tests?	147	6	.	.	.	.	0	1 (0.6)	154
B4. How long did you wait between the date you were referred and the date of your first appointment at the hospital?	35	57	29	12	14	7	0	7 (4.5)	154

B5. Did you need to change your first appointment?	5	147	.	.	.	.	0	2 (1.3)	154
B6. How did you feel about the length of time you had to wait for your first appointment at the hospital?	4	119	29	.	.	.	0	2 (1.3)	154
B7a. Appointment cancelled or postponed	14	112	4	.	.	.	0	24 (15.6)	154
B7b. Getting there (e.g. transport)	5	113	5	.	.	.	0	31 (20.1)	154
B7c. Finding a parking space	61	50	16	.	.	.	0	27 (17.5)	154
B7d. Kept waiting (e.g. more than 30 minutes)	62	63	6	.	.	.	0	23 (14.9)	154
B7e. Getting time off work	7	83	30	.	.	.	0	34 (22.1)	154
B7f. Availability of your medical notes for doctors when required	13	96	10	.	.	.	0	35 (22.7)	154
B7g. Cleanliness	16	97	10	.	.	.	0	31 (20.1)	154
B8a. Waiting area	30	61	51	8	0	.	0	4 (2.6)	154
B8b. Availability of refreshments	21	44	37	13	22	.	0	13 (8.4)	154
B8c. Toilets	29	53	59	4	2	.	0	7 (4.5)	154
B8d. Rooms where the tests were carried out	39	54	50	5	0	.	0	6 (3.9)	154
B9a. Were you treated considerately by the doctor(s)	142	6	3	0	.	.	0	3 (1.9)	154
B9b. Were you treated considerately by the nurse(s)	124	7	1	0	.	.	0	22 (14.3)	154
B9a. Were you treated considerately by the receptionist(s)	120	10	2	0	.	.	0	22 (14.3)	154
B10. Did you have enough privacy while the doctor or nurse was examining you?	150	3	.	.	.	.	0	1 (0.6)	154
B11. Did the doctor or nurse give you enough privacy while you were having tests (e.g. urine flow)?	133	2	17	.	.	.	0	2 (1.3)	154
B12a. Explanation of purpose of TRUS/biopsy	118	14	3	6	.	.	0	13 (8.4)	154
B12b. Explanation of purpose of urine flow	75	11	4	40	.		0	24 (15.6)	154
B12c. Explanation of purpose of PSA	107	20	5	4	.	.	0	18 (117)	154
B12d. Explanation of purpose of DRE	101	23	2	8	.	.	0	20 (13.0)	154
B13. Did the doctor or nurse give you an explanation of your Gleason score?	58	30	56	1	.	.	0	9 (5.8)	154
B14. Did the doctor or nurse offer you any written information about your Gleason score?	43	102	.	.	.	.	0	9 (5.8)	154

B15a. Explanation of what test would involve – TRUS/biopsy	115	17	7	4	.	.	0	10 (6.5)	154
B15b. Explanation of what test would involve – urine flow	76	11	5	37	.	.	0	25 (16.2)	154
B15c. Explanation of what test would involve – PSA	110	21	3	3	.	.	0	17 (11.0)	154
B15d. Explanation of what test would involve – DRE	102	17	7	6	.	.	0	21 (13.6)	154
B16. Did the doctor or nurse explain to you that the biopsy might be painful?	92	34	21	6	.	.	0	1 (0.6)	154
B17. When you had your biopsy were you offered local anaesthetic?	45	99	.	.	.	.	0	4 (2.7)	148
B18. Did the doctor or nurse explain to you that the biopsy may cause an infection?	102	16	29	.	.	.	0	1 (0.7)	148
B19. Were you offered any medication (e.g. antibiotics) to control any infections from your biopsy?	98	47	.	.	.	.	0	4 (2.7)	148
B20. Did the doctor or nurse explain to you how long you would have to wait for your test results?	104	18	26	.	.	.	0	6 (3.9)	154
B21. Did the doctor or nurse offer you any support while you were waiting for your test results?	68	80	.	.	.	.	0	6 (3.9)	154
B22. Did the doctor or nurse explain to you what would happen next?	105	19	25	.	.	.	0	5 (3.2)	154
B23a. Overall, did you have confidence and trust in the doctors that you saw?	139	11	3	0	.	.	0	1 (0.6)	154
B23b. Overall, did you have confidence and trust in the nurses that you saw?	104	14	2	0	.	.	0	34 (22.1)	154

Question	**N ticking each response option**										**Error**	**Missing n(%)**	**Total**
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**			
B24. Overall, please show how good or bad your experience of care was	0	2	0	2	6	8	22	49	28	34	1	2 (1.3)	154

SECTION C: Discussing your test results for possible prostate cancer

Question	N ticking each response option								Error	Missing n (%)	Total
	1	2	3	4	5	6	7	8			
C1. At which hospital did you discuss your test results?	115	8	31	.	.	.	.	.	0	31 (20.1)	154
C2. Which tests had you had at the hospital?	136	79	126	118	9	.	.	.	0	5 (3.2)	154
C3. 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)?	28	122	.	.	.	.	.	.	0	4 (2.6)	154
C4. Would you have liked a choice of how you wanted to be given your test results?	45	74	.	.	.	.	.	.	0	3 (2.5)	122
C5. How long did you have to wait for your test results?	49	62	23	6	6	.	.	.	0	8 (5.2)	154
C6. How did you feel about the length of the time you had to wait for your test results?	4	109	33	.	.	.	.	.	0	3 (1.9)	154
C7. 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?	62	85	.	.	.	.	.	.	0	7 (4.5)	154
C8. When you went back to the hospital to discuss your test results, who did you see?	132	1	2	.	.	.	.	.	16	3 (1.9)	154
C9. Did you have enough privacy when you discussed your test results?	149	2	.	.	.	.	.	.	0	3 (1.9)	154
C10 Did the doctor or nurse explain the results of your tests to you?	134	17	0	.	.	.	.	.	0	3 (1.9)	154
C11. Did the doctor or nurse explain to you your test results in a considerate way?	125	18	8	.	.	.	.	.	0	3 (1.9)	154
C12. Did the test results show that you had prostate cancer?	150	2	.	.	.	.	.	.	0	2 (1.3)	154
C13. After getting your test results, did the doctor or nurse offer you the chance to talk to a specialist prostate cancer nurse?	129	18	5	.	.	.	.	.	0	5 (3.3)	152
C14. How soon after the doctor or nurse gave you your test results did you discuss them with the specialist prostate cancer nurse?	91	9	9	14	5	.	.	.	0	6 (4.5)	134
C15. How did you feel about the length of time you had to wait to discuss your test results with the specialist prostate cancer nurse?	4	103	7	9	.	.	.	.	0	6 (4.7)	129
C16a. Were you given enough written or printed information by hospital staff about the results of this test/these tests?	100	36	7	.	.	.	.	.	1	8 (5.3)	152

C16b. Were you given enough written or printed information by hospital staff about watchful waiting/active monitoring?	96	24	6	.	.	.	.	.	0	26 (17.1)	152
C16c. Were you given enough written or printed information by hospital staff about active treatment?	71	32	11	.	.	.	.	.	0	38 (25.0)	152
C17. Would you have liked a break between being given your test results and discussing your treatment options?	23	118	.	.	.	.	.	.	0	11 (7.2)	152
C18. How long a break would you have liked before discussing your treatment options?	7	3	3	7	.	.	.	.	0	3 (13.0)	23
C19. Which treatment options were you offered?	66	67	78	59	21	6	48	3	0	13 (8.6)	152
C20. Did the doctor or nurse explain these treatment options to you?	112	22	11	1	.	.	.	.	3	3 (2.0)	152
C21. Did the doctor or nurse explain the side effects or consequences of these treatment options to you?	107	32	6	3	.	.	.	.	1	3 (2.0)	152
C22. Did the doctor or nurse explain what could be done about the side effects or consequences of these treatment options?	80	37	24	6	.	.	.	.	1	4 (2.6)	152
C23. Would you have liked an explanation of why the other treatment options were not suitable?	69	64	.	.	.	.	.	.	0	19 (12.5)	152
C24a. Did the doctor or nurse offer you any written or printed information about the treatment options?	95	46	.	.	.	.	.	.	1	10 (6.6)	152
C24b. Did the doctor or nurse offer you any written or printed information about the side effects or consequences of the treatment options?	85	41	.	.	.	.	.	.	0	26 (17.1)	152
C24c. Did the doctor or nurse offer you any written or printed information about what could be done about the side effects?	64	58	.	.	.	.	.	.	0	30 (19.7)	152
C25. Who decided which type of treatment you were to have?	90	33	76	13	4	.	.	.	0	6 (3.9)	152
C26. Did the doctor or nurse involve you enough in the decision about which treatment to have?	19	103	24	.	.	.	.	.	1	5 (3.3)	152
C27. After the treatment decision had been made did the doctor or nurse tell you that you could again discuss your treatment decision?	86	61	.	.	.	.	.	.	0	5 (3.3)	152

C28. Did the doctor or nurse tell you that you could change your mind about which treatment to have?	77	66	.	.	.	.	.	.	0	9 (5.9)	152
C29. Did the doctor or nurse tell you that you could get help from any of the following (e.g. advice, support)?	116	14	35	24	27	16	13	1	0	8 (5.3)	152
C30a. Overall, did you have confidence and trust in the doctors that you saw?	135	10	2	0	.	.	.	.	0	5 (3.3)	152
C30b. Overall, did you have confidence and trust in the nurses that you saw?	119	10	2	1	.	.	.	.	0	20 (13.2)	152

Question	**N ticking each response option**										**Error**	**Missing n(%)**	**Total**
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**			
C31. Overall, please show how good or bad your experience of care was	0	1	1	0	3	6	19	43	33	38	1	7 (4.6)	152

SECTION D: Your treatment

Question	**N ticking each response option**								**Error**	**Missing n(%)**	**Total**
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**			
D1. Which treatment have you most recently had?	39	44	21	30	3	2	22	2	13	6 (3.9)	152
D2. Where did you have your most recent treatment?	62	33	23	.	.	.	.	.	1	32 (21.1)	152
D3a. Before you started your treatment, did a doctor or nurse help you understand what your treatment would involve?	123	13	4	.	.	.	.	.	0	9 (5.9)	152
D3b. Before you started your treatment, did a doctor or nurse help you understand the possible side effects/consequences of your treatment?	98	22	11	8	.	.	.	.	0	13 (8.6)	152
D3c. Before you started your treatment, did a doctor or nurse help you understand why your treatment was starting on the date arranged?	78	11	21	23	.	.	.	.	0	19 (12.5)	152
D3d. Before you started your treatment, did a doctor or nurse help you understand whether you had a choice about where the treatment took place?	36	12	57	30	.	.	.	.	0	17 (11.2)	152

D3e. Before you started your treatment, did a doctor or nurse help you understand what you should do during your treatment?	75	19	22	18	.	.	.	.	0	18 (11.8)	152
D3f. Before you started your treatment, did a doctor or nurse help you understand what you should not do during your treatment?	68	14	28	20	.	.	.	.	0	22 (14.5)	152
D4. While you were being treated, were you offered the opportunity to discuss any concerns about your treatment with the doctor or nurse?	114	19	.	.	.	.	.	.	0	19 (12.5)	152
D5a. Appointment cancelled or postponed	29	104	5	.	.	.	.	.	0	14 (9.2)	152
D5b. Getting there (e.g. transport)	9	116	5	.	.	.	.	.	0	22 (14.5)	152
D5c. Finding a parking space	57	50	27	.	.	.	.	.	0	18 (11.8)	152
D5d. Kept waiting (e.g. more than 30 minutes)	51	75	7	.	.	.	.	.	0	19 (12.5)	152
D5e. Getting time off work	4	83	21	.	.	.	.	.	0	24 (15.8)	152
D5f. Availability of your medical notes for doctors when required	12	103	16	.	.	.	.	.	0	21 (13.8)	152
D5g. Cleanliness	18	104	5	.	.	.	.	.	0	25 (16.4)	152
D5h. Ward noise	18	89	22	.	.	.	.	.	0	23 (15.1)	152
D6. 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?	73	4	58	.	.	.	.	.	0	17 (11.2)	152
D7. While you were being treated, were you ever in pain or discomfort?	47	90	.	.	.	.	.	.	0	15 (9.9)	152
D8. While you were being treated, were you given enough medication to control your pain or discomfort?	32	13	.	.	.	.	.	.	0	2 (4.3)	47
D9. Did the doctor or nurse tell you about any of the following sources of help for coping?	88	12	25	19	17	24	29	4	0	17 (11.2)	152
D10. Was this enough information about coping?	67	15	.	.	.	.	.	.	0	21 (20.4)	103
D11. Did the doctor or nurse offer you any information about complementary therapies?	19	124	.	.	.	.	.	.	0	9 (5.9)	152
D12. Was this enough information about complementary therapies?	16	3	.	.	.	.	.	.	0	0	19
D13. Did you have your most recent treatment in hospital?	85	56	.	.	.	.	.	.	0	11 (7.2)	152
D14a. Nursing	42	26	10	2	2	.	.	.	0	3 (3.5)	85

D14b. Food/drink	12	19	24	7	14	.	.	.	0	9 (10.6)	85
D14c. Ward (e.g. privacy, noise, cleanliness)	12	20	21	11	13	.	.	.	0	8 (9.4)	85
D15. While you were in the hospital as an inpatient, were your spiritual needs met (e.g. appropriate food, prayer room)?	19	3	4	39	.	.	.	.	0	20 (23.5)	85
D16. Did the doctor or nurse explain how well the treatment was going/had gone?	89	27	18	.	.	.	.	.	0	18 (11.8)	152
D17. Did the doctor or nurse explain what would happen after you were discharged from hospital?	68	15	13	39	.	.	.	.	0	17 (11.2)	152
D18. Did the doctor or nurse offer you any written or printed information about caring for yourself at home?	46	50	38	.	.	.	.	.	0	18 (11.8)	152
D19. Did the doctor or nurse tell you about a support or self-help group for people with your condition?	39	57	39	.	.	.	.	.	2	15 (9.9)	152
D20a. Were you given equipment or supplies to use at home to help you care for yourself - catheter?	40	6	11	65	.	.	.	.	0	30 (19.7)	152
D20b. Were you given equipment or supplies to use at home to help you care for yourself – continence pads?	20	18	60	61	.	.	.	.	0	37 (24.3)	152
D21a. A district nurse	37	25	65	.	.	.	.	.	0	25 (16.4)	152
D21b. A community nurse	8	31	62	.	.	.	.	.	0	51 (33.6)	152
D21c. A health visitor	0	32	61	.	.	.	.	.	0	59 (38.8)	152
D21d. A physiotherapist	1	32	61	.	.	.	.	.	0	58 (38.2)	152
D22. Did the doctor or nurse tell you who to contact if you were worried about your treatment or side effects of treatment?	56	61	46	14	2	1	15	.	0	33 (21.7)	152
D23. Did the doctor or nurse offer you any financial information on welfare or benefits?	6	121	.	.	.	.	.	.	0	25 (16.4)	152
D24. At the end of your treatment, in hospital were you contacted by your GP's practice?	14	7	5	60	35	27	.	.	0	20 (13.2)	152
D25a. Have staff in different places worked well together when caring for you for this condition – GP's practice and hospital?	92	21	9	8	.	.	.	.	1	21 (13.8)	152

D25b. Have staff in different places worked well together when caring for you for this condition – hospital and hospital?	62	16	6	18	.	.	.	.	0	50 (32.9)	152
D26a. Overall, did you have confidence and trust in the doctors that treated you?	126	8	2	1	.	.	.	.	0	15 (9.9)	152
D26b. Overall, did you have confidence and trust in the nurses that treated you?	113	11	2	1	.	.	.	.	0	25 (16.4)	152
D27a. Overall, did the doctors treat you with respect and dignity?	126	8	2	1	.	.	.	.	0	15 (9.9)	152
D27b. Overall, did the nurses treat you with respect and dignity?	115	11	2	1	.	.	.	.	0	23 (15.1)	152

Question	**N ticking each response option**										**Error**	**Missing n (%)**	**Total**
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**			
D28. Overall, please show how good or bad your experience of care was	0	3	0	1	2	5	9	37	44	33	2	16 (10.5)	152

SECTION E: Monitoring (checking) you

Question	**N ticking each response option**							**Error**	**Missing n (%)**	**Total**
	1	**2**	**3**	**4**	**5**	**6**	**7**			
E1. Were you offered a "key worker" (a person to contact throughout your care)?	59	82	.	.	.	.	.	0	11 (7.2)	152
E2. Have you found it useful to have a "key worker"?	41	12	4	.	.	.	.	0	2 (3.4)	59
E3. Do you have regular tests for prostate cancer (e.g. PSA/blood test, DRE/internal examination)?	137	8	.	.	.	.	.	0	7 (4.6)	152
E4. Where do you discuss the results of your tests (e.g. PSA, DRE)?	101	17	1	.	.	.	.	0	18 (13.1)	137
E5. Did the doctor or nurse explain why you have these regular tests?	116	12	3	2	.	.	.	0	4 (2.9)	137
E6. How often are you currently tested for prostate cancer?	3	2	41	7	3	69	5	0	7 (5.1)	137
E7. Did the doctor or nurse explain the length of the wait between these tests?	82	13	30	9	.	.	.	0	3 (2.2)	137
E8. Were you offered a choice of where to have these tests?	42	91	.	.	.	.	.	0	4 (2.9)	137
E9. 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)?	26	107	.	.	.	.	.	0	4 (2.9)	137

E10. Would you have liked a choice of how you wanted to be given your test results?	32	71	1	.	.	.	.	0	3 (2.8)	107
E11. Did the doctor or nurse explain your test results to you?	109	21	3	.	.	.	.	0	4 (2.9)	137
E12. 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?	90	44	.	.	.	.	.	0	3 (2.2)	137
E13a. Did the doctor or nurse ask you if you had any of the following needs? Emotional (e.g. patient support group)	20	117	.	.	.	.	.	0	15 (9.9)	152
E13b. Did the doctor or nurse ask you if you had any of the following needs? Spiritual/religious (e.g. someone to talk to)	7	125	.	.	.	.	.	0	20 (13.2)	152
E13c. Did the doctor or nurse ask you if you had any of the following needs? Financial (e.g. benefits)	6	128	.	.	.	.	.	0	18 (11.8)	152
E13e. Did the doctor or nurse ask you if you had any of the following needs? Day-to-day (e.g. help with housework)	8	127	.	.	.	.	.	0	17 (11.2)	152
E14a. 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)? – GP practice & hospital	100	22	9	6	.	.	.	0	15 (9.9)	152
E14b. 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)? – hospital & hospital	72	11	6	19	.	.	.	0	44 (28.9)	152
E15a. Overall, did you have confidence and trust in the doctors that you saw?	126	17	2	.	.	.	.	0	7 (4.6)	152
E15b. Overall, did you have confidence and trust in the nurses that you saw?	116	20	0	.	.	.	.	0	16 (10.5)	152
E16a. Overall, did the doctors treat you with respect and dignity?	132	5	1	.	.	.	.	1	13 (8.6)	152
E16b. Overall, did the nurses treat you with respect and dignity?	119	8	1	.	.	.	.	0	24 (15.8)	152

Question	**N ticking each response option**										**Error**	**Missing n (%)**	**Total**
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**			
E17. Overall, please show how good or bad your experience of care was	0	0	2	1	3	9	11	38	37	38	1	12 (7.9)	152

Changes to the questionnaire

The first version of the questionnaire was then revised on the basis of the results of the pilot. The changes made to the questionnaire are summarised in Box 5.3.

Box 5.3 Summary of changes to PCQ-Pv1

Layout/design

Cover redesigned to make it look more attractive, easier to read and use: text reduced and placed in boxes; space for hospital name on front cover; size of logos reduced; contact details for further information put on front cover

Section descriptions shortened and clarified

Clearer routing (white text in capitals in a black box)

Moved return instructions from back cover to end of questions

Numbering changed to incorporate the Section letter before question number (e.g. A1)

Questions

The number of questions was reduced by:

- combining questions : e.g. questions about PSA and DRE testing in v1 Section A10-26 became A8-15 in v2
- deleting questions: e.g. where responses did not discriminate between respondents' experience of care, , (question A3, *Was this the person you wanted to see* yes =127, no=0, did not mind =21)

Added several questions (e.g. D1*. Is your current treatment watchful waiting or active monitoring?*) to help with the flow of the questionnaire and to help clarify what was being asked.

Modified some questions by adding an extra response option to make the question easier to answer (e.g. *D22 I did not want any financial information on welfare or benefits*)

Added an invitation and a few lines at the end of each section for patients to add comments about any of their experiences during that phase of care (e.g. D27 *Overall, how would you rate the quality of care provided by your hospital when you were treated? (added) Please write any comments you would like to make here*……)

Modified the language in some questions to make them clearer e.g. D20 used the term *"aftercare services"* rather than list a number of different healthcare professionals

Changed the overall rating questions to the format used by NAO 2004 questionnaire to try to get clearer discrimination between responses Reduced routing of some questions by revising the question and response options (e.g. C4 *How were you given your test results? Face-to-face/Over the telephone/In a letter/If other please write how you were given the test results here……*) Distinguished between private and NHS patients, routing private patients to only complete sections where their experience was as an NHS patient (question D4) Modified some of the questions in Section F (About you) to clarify what was being asked (e.g. F11. *How many cars are there in your household?*)

5.2.4 Discussion

The piloting of the questionnaire was an important stage in the development process as it provided feedback from patients using them in real settings. The difference between the response rates for the two hospitals is difficult to interpret. There were some difficulties with communicating with Hospital 2, as responses to emails were often slow and it was difficult to establish telephone contact, which may be indicative of a less effective organisation. While both hospitals did send out reminders to non-responding patients, Hospital 1 sent them out two weeks after the questionnaire as planned but Hospital 2 sent reminders much later and this may have affected the response rate. The different populations in the two areas served by the hospitals may also partly account for the difference in the response rate. It is worth noting that the PCQ-Pv1 was a lengthy questionnaire, comprising 6 sections and 146 questions in all. Although most of the questions were closed response style questions that can be answered quickly, some patients would doubtless have found the length of the questionnaire daunting and been discouraged from completing it.

However, the combined response rate for completing and returning the questionnaire was 53% (n=159) which was sufficient to pilot the questionnaire successfully. The analysis of these responses reported on above led to refinements to the questionnaire ready for a second pilot to test the changes made.

5.3. Piloting the questionnaire: PCQ-Pv2

5.3.1. Introduction

Version 2 of the questionnaire (PCQ-P v2) was pilot tested using a similar approach to that employed in the first pilot.

5.3.2 Methods

The structure of six sections used in PCQ-Pv1 (five of which followed the different phases of the patient's care pathway and the sixth which contained socio-demographic questions) had been retained for Version 2 (see Appendix 7). Some of the titles of the sections had been revised to more accurately and clearly describe the phase of care that the questions related to, and some of the questions moved to another section accordingly. Most sections became shorter and the changes made in each section are summarised in Box 5.4

Box 5.4 PCQ-Pv2

Section A: The first time you saw the doctor or nurse about your possible prostate problem (35 questions in v1, reduced to 24 questions in v2)

Section B: Having tests for possible prostate cancer at the hospital (24 questions in v1, reduced to 20 questions in v2)

Section C: Discussing your test results for possible prostate cancer (31 questions in v1, increased to 33 questions in v2)

Section D: Your treatment (28 questions in v1, decreased to 27 questions in v2)

Section E: Monitoring (checking) you (17 questions in v1, increased to 19 questions in v2)

Section F: About you and your health (11 questions in v1, no change for v2)

The same issues were addressed in the construction of this patient sample as in the one for the first pilot (see Table 5.1). One of the hospitals included in pilot one (Hospital 1), was used again as there had been a good response rate and another hospital (Hospital 3) was recruited to replace Hospital 2 where there had been some administrative difficulties in the first pilot and a poor response rate in completing and returning the questionnaire. Hospital 3 was based in the north of England and like Hospital 1 was a teaching hospital in a similar sized city, with a significant ethnic minority population. Questionnaires were posted to 181 patients, 81 in Hospital 1 and 100 in Hospital 3, with one reminder letter. It had been intended to send questionnaires to 100 patients in each hospital but only 81 patients could be identified in Hospital 1 who had not been sent the first questionnaire (PCQ-Pv1).

5.3.3 Results

Characteristics of responders

132 patient questionnaires were returned completed (72.9%), 58 (71.6%) from patients of Hospital 1, and 74 (74% response rate) from Hospital 3. The characteristics of patients are presented in Table 5.4. Eighty (60.6%) responders reported having been actively treated for prostate cancer in the past year.

Table 5.4 Characteristics of responding patients, PCQ-Pv2

Age	**Number of Patients (%)**
<55	2 (1.5%)
55-64	41 (31.1%)
65-74	59 (44.7%)
75+	24 (18.2%)
Ethnic origin	**Number of Patients (%)**
White British	120 (90.9%)
Indian	1 (0.8%)
Pakistani	1 (0.8%)
African/Caribbean	4 (3.0%)
Chinese	1 (0.8%)
Health Status	**Number of Patients (%)**
Very good (9-10)	28 (21.2%)
Good (7-8)	67 (50.8%)
Fair (5-6)	28 (21.2%)
Poor (<5)	3 (2.3%)
Employment status	**Number of Patients (%)**
Employed (full or part time)	30 (22.7%)
Retired	81 (61.4%)
Unable to work due to illness	7 (5.3%)
Other	4 (3.0%)
Type of treatment (some patients reported more than one type of treatment)	**Number of Patients (%)**
Prostatectomy	46 (34.8%)

Radiotherapy	37 (28.0%)
Hormone therapy	33 (25.0%)
Brachytherapy	7 (5.3%)
Active monitoring	42 (31.8%)

N.B. Percentages may not add to 100 due to missing values.

Response patterns

As in pilot 1, the distribution of responses for each question was examined, in order to identify potentially non-discriminatory, confusing, or unnecessary questions. Again, questions for which responses showed little variation across patients, and questions with a high proportion of missing responses, were examined and revised or excluded in the subsequent draft of the questionnaire. Table 5.5 shows the distribution of scores, and missing values, for all questions in each section of the questionnaire. Results are adjusted for filter questions as in pilot 1.

The following tables show the distribution of scores for each question, in all sections of the PCQ-Pv2. See the questionnaire in Appendix 7 for information about response options. Where response options are not numbered on the questionnaire, the first option has been coded as 1, the second as 2 and so on. The 'Error' column shows the number of people completing the question incorrectly (e.g. ticking two boxes where they should only have ticked one).

Table 5.5 PCQ-P Pilotv2: distribution of scores and missing values

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

Question	N ticking each response option					Error	Missing n (%)	Total
	1	2	3	4	5			
A1. Were you taking part in a medical trial?	3	127	.	.	.	0	2 (1.5)	132
A2. Where did you go for the FIRST TIME about your possible prostate problem?	114	1	10	.	.	0	7 (5.3)	132
A3. When you went to the GP's practice/local assessment centre who did you see?	114	6	0	.	.	0	2 (1.6)	122
A4. What was your reason(s) for going to the GP's practice?	72	12	21	14	11	0	23 (18.9)	122
A5. Did the doctor or nurse take your concerns seriously?	106	5	1	7	.	0	3 (2.5)	122
A6. Did the doctor or nurse explain that prostate cancer might be causing your symptoms?	53	12	21	20	4	1 (0.8)	11 (9.0)	122
A7a. Did you have a PSA blood test and/or a DRE before being referred to hospital? PSA	100	11	.	.	.	0	11 (9.0)	122
A7b. Did you have a PSA blood test and/or a DRE before being referred to hospital? DRE	66	20	.	.	.	0	36 (29.5)	122
A8a. Did the doctor or nurse explain beforehand what the tests were trying to find out? PSA	80	8	7	2	0	0	19 (16.4)	116
A8b. Did the doctor or nurse explain beforehand what the tests were trying to find out? DRE	62	7	1	1	4	0	41 (35.3)	116
A9a. Did the doctor or nurse explain beforehand how the tests are carried out? PSA	79	7	8	5	1	0	16 (13.8)	116
A9b. Did the doctor or nurse explain beforehand how the tests are carried out? DRE	63	4	3	2	4	0	40 (34.5)	116
A10a. Did the doctor or nurse explain beforehand that the tests are not always reliable? PSA	66	13	18	2	2	0	15 (12.9)	116
A10b. Did the doctor or nurse explain beforehand that the tests are not always reliable? DRE	50	8	12	2	3	0	41 (35.3)	116
A11a. Did the doctor or nurse explain beforehand what might happen if the tests were abnormal? PSA	62	14	20	3	2	0	15 (12.9)	116

A11b. Did the doctor or nurse explain beforehand what might happen if the tests were abnormal? DRE	50	9	11	2	3	0	41 (35.3)	116
A12a. Did the doctor or nurse offer you any written information about the tests? PSA	29	67	1	.	.	2 (1.7)	17 (14.7)	116
A12b. Did the doctor or nurse offer you any written information about the tests? DRE	20	47	4	.	.	0	45 (38.8)	116
A13a. Did the doctor or nurse involve you as much as you wanted in the decision on whether to have these tests? PSA	93	3	2	2	.	0	16 (13.8)	116
A13b. Did the doctor or nurse involve you as much as you wanted in the decision on whether to have these tests? DRE	71	0	1	3	.	0	41 (35.3)	116
A14a. Did the doctor or nurse explain the results of your tests? PSA	76	18	3	1	.	0	18 (15.5)	116
A14b. Did the doctor or nurse explain the results of your tests? DRE	61	7	2	5	.	0	41 (35.3)	116
A15a. Did the doctor or nurse give you the results of your tests in a considerate way? PSA	84	8	4	2	.	0	18 (15.5)	116
A15b. Did the doctor or nurse give you the results of your tests in a considerate way? DRE	66	2	1	4	.	0	43 (37.1)	116
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?	40	37	14	21	0	0	10 (8.2)	122
A17. How did you feel about the time the GP's practice/local assessment took to refer you to the hospital for further tests?	2	92	13	.	.	0	15 (12.3)	122
A18. Did the doctor or nurse explain why you were being referred to hospital?	90	11	5	4	.	0	12 (9.8)	122
A19a. Did the doctor or nurse give you a choice of which hospital you wanted to go to?	13	97	.	.	.	0	12 (9.8)	122
A19b. Did the doctor or nurse give you a choice of the date you wanted to be seen on?	7	86	.	.	.	0	29 (23.8)	122
A20. Were your needs taken into account when the referral arrangements were made (e.g. transport, time of appointment)?	31	18	58	.	.	4 (3.3)	11 (9.0)	122

A21. Did the doctor or nurse explain how soon you would be seen at the hospital?	43	65	.	.	.	0	14 (11.5)	122
A22. Overall, did you have confidence and trust in the doctor that you saw on this occasion?	94	14	1	0	0	0	13 (10.7)	122
A22. Overall, did you have confidence and trust in the nurse that you saw on this occasion?	49	8	0	0	4	0	61 (50.0)	122
A23. Overall, did the GP practice staff treat you with respect and dignity on this occasion? Doctor	110	4	1	0	0	0	7 (5.7)	122
A23. Overall, did the GP practice staff treat you with respect and dignity on this occasion? Nurse	68	2	0	0	8	0	44 (36.1)	122
A23. Overall, did the GP practice staff treat you with respect and dignity on this occasion? Receptionist	73	5	2	0	7	0	35 (28.7)	122
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?	78	30	7	0	0	1 (0.8)	6 (4.9)	122

SECTION B: Having tests for possible prostate cancer at the hospital.

Question	N ticking each response option								Error	Missing n (%)	Total
	1	2	3	4	5	6	7	8			
B1. Who referred you for tests/further tests at the hospital?	91	13	22	2	2	2	.	.	0	2 (1.5)	132
B2. At which hospital did you have your first appointment for tests?	91	31	.	.	.	.	.	.	0	10 (7.6)	132
B3. Were you an NHS patient or a private patient?	127	4	.	.	.	.	.	.	0	1 (0.8)	132
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?	57	69	.	.	.	.	.	.	0	2 (1.6)	128

B5. How long did you wait between the date you were referred and the date of your first appointment for tests at the hospital?	17	51	27	24	.	.	.	.	1 (0.8)	8 (6.3)	128
B6. How did you feel about the length of time you had to wait for your first appointment for tests at the hospital?	2	87	33	.	.	.	.	.	0	6 (4.7)	128
B7. Did you experience any problems with your hospital visit(s)?	17	5	56	53	3	7	7	3	0	.	128
B8a. How would you rate the hospital facilities? Waiting area	26	46	33	18	1	.	.	.	0	4 (3.1)	128
B8b. How would you rate the hospital facilities? Availability of refreshments	15	38	34	11	15	.	.	.	0	15 (11.7)	128
B8c. How would you rate the hospital facilities? Toilets	29	46	35	6	4	.	.	.	0	8 (6.3)	128
B8d. How would you rate the hospital facilities? Rooms where the tests were carried out	36	43	37	4	0	.	.	.	0	8 (6.3)	128
B9. Did you have enough privacy while the doctor or nurse was examining/testing you?	123	3	.	.	.	.	.	.	0	2 (1.6)	128
B10a. Did the doctor or nurse explain to you the purpose of these tests? TRUS/biopsy	99	10	2	1	.	.	.	.	0	16 (12.5)	128
B10b. Did the doctor or nurse explain to you the purpose of these tests? urine flow	61	11	5	15	.	.	.	.	0	36 (28.1)	128
B10c. Did the doctor or nurse explain to you the purpose of these tests? PSA	87	11	3	4	.	.	.	.	0	23 (18.0)	128
B10d. Did the doctor or nurse explain to you the purpose of these tests? DRE	79	10	4	5	.	.	.	.	0	30 (23.4)	128
B10e. Did the doctor or nurse explain to you the purpose of these tests? Scans	63	11	2	13	.	.	.	.	0	39 (30.5)	128
B11a. Did the doctor or nurse explain to you what each test would involve? TRUS/biopsy	90	13	4	1	.	.	.	.	0	20 (15.6)	128
B11b. Did the doctor or nurse explain to you what each test would involve? urine flow	63	10	3	10	.	.	.	.	0	42 (32.8)	128
B11c. Did the doctor or nurse explain to you what each test would involve? PSA	89	13	3	2	.	.	.	.	0	21 (16.4)	128
B11d. Did the doctor or nurse explain to you what each test would involve? DRE	78	9	4	4	.	.	.	.	0	33 (25.8)	128

B11e. Did the doctor or nurse explain to you what each test would involve? scans	58	13	2	13	.	.	.	.	0	42 (32.8)	128
B12. Did the doctor or nurse explain to you that the biopsy might be painful?	74	20	12	5	.	.	.	.	0	17 (13.3)	128
B13. When you had your biopsy were you offered an anaesthetic?	35	70	.	.	.	.	.	.	1 (0.8)	17 (13.8)	123
B14. Did the doctor or nurse explain that you may need medication (e.g. antibiotics) to control any infections caused by the biopsy?	77	7	23	.	.	.	.	.	0	16 (13.0)	123
B15. Did the doctor or nurse explain to you how long you would have to wait for your test results?	83	13	21	.	.	.	.	.	0	11 (8.6)	128
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)?	54	61	.	.	.	.	.	.	0	13 (10.2)	128
B17. Did the doctor or nurse explain to you what would happen next?	86	17	16	.	.	.	.	.	0	9 (7.0)	128
B18a. Overall, did the hospital staff treat you with respect and dignity? Doctor(s)	111	7	0	0	.	.	.	.	1 (0.8)	9 (7.0)	128
B18b. Overall, did the hospital staff treat you with respect and dignity? Nurse(s)	103	9	0	0	.	.	.	.	0	16 (12.5)	128
B18c. Overall, did the hospital staff treat you with respect and dignity? Receptionist(s)	89	6	1	5	.	.	.	.	0	27 (21.1)	128
B19a. Overall, did you have confidence and trust in the doctor(s) that you saw?	106	10	0	1	.	.	.	.	2 (1.6)	9 (7.0)	128
B19b. Overall, did you have confidence and trust in the nurse(s) that you saw?	98	11	0	2	.	.	.	.	0	17 (13.3)	128
B20. Overall, how would you rate the quality of care provided by your hospital during this stage of testing?	63	49	6	0	1	.	.	.	0	9 (7.0)	128

SECTION C: Discussing your test results for possible prostate cancer

Question	N ticking each response option								Error	Missing n (%)	Total
	1	2	3	4	5	6	7	8			
C1. At which hospital did you discuss your test results?	85	33	.	.	.	.	.	.	0	14 (10.6)	132
C2. Were you an NHS patient or a private patient?	123	2	.	.	.	.	.	.	0	7 (5.3)	132
C3. Which tests did you have at the hospital?	107	63	88	80	67	.	.	.	0	9 (6.9)	130
C4. How were you given your test results?	117	3	0	.	.	.	.	.	0	9 (6.9)	130
C5. Would you have liked to have been given your test results in a different way?	3	121	.	.	.	.	.	.	0	6 (4.6)	130
C6. How long did you have to wait for your test results?	37	51	19	13	.	.	.	.	1 (0.8)	9 (6.9)	130
C7. How did you feel about the length of the time you had to wait for your test results?	0	90	31	.	.	.	.	.	0	9 (6.9)	130
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?	47	76	.	.	.	.	.	.	0	7 (5.4)	130
C9. Did you have enough privacy when you discussed your test results?	119	5	.	.	.	.	.	.	0	6 (4.6)	130
C10. Did the doctor or nurse explain your test results to you?	116	7	1	.	.	.	.	.	0	6 (45.6)	130
C11. Did the doctor or nurse explain your test results in a considerate way?	110	8	4	.	.	.	.	.	0	8 (6.2)	130
C12. Did the test results show that you had prostate cancer?	123	1	.	.	.	.	.	.	0	6 (4.6)	130
C13. Did the doctor or nurse explain your Gleason score to you?	55	27	38	.	.	.	.	.	0	9 (7.0)	129
C14. Did the doctor or nurse offer you any written information about your Gleason score?	37	83	.	.	.	.	.	.	0	9 (7.0)	129
C15. After getting your test results, did the doctor or nurse offer you the chance to talk to a specialist prostate cancer nurse?	106	16	.	.	.	.	.	.	0	7 (5.4)	129
C16. How soon after the doctor or nurse gave you your test results did you discuss them with the specialist prostate cancer nurse?	84	7	7	12	13	.	.	.	0	6 (4.7)	129
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?	5	101	2	11	.	.	.	.	0	10 (7.8)	129

C18a. Were you given enough written or printed information by hospital staff? About the test results	85	29	5	.	.	.	.	.	0	10 (7.8)	129
C18b. Were you given enough written or printed information by hospital staff? About active treatment	76	17	2	.	.	.	.	.	0	34 (26.4)	129
C18c. Were you given enough written or printed information by hospital staff? About watchful waiting/active monitoring	60	13	9	.	.	.	.	.	0	47 (36.4)	129
C19a. Did you have enough time between been given your test results and discussing your treatment options?	113	7	.	.	.	.	.	.	0	9 (7.0)	129
C19b. If no, how much time would you have liked?	1	1	1	1	.	.	.	.	1 (14.3)	2 (28.6)	7
C20. Which treatment options were you offered after you were given your test results?	67	79	49	32	2	44	.	.	0	11 (8.5)	129
C21. Did the doctor or nurse explain what these treatment options would involve?	112	5	2	3	.	.	.	.	0	7 (5.4)	129
C22. Did the doctor or nurse discuss with you the possible side effects or consequences of these treatment options?	102	10	5	4	.	.	.	.	0	8 (6.2)	129
C23. Were you given an explanation of why the other treatment options were not suitable?	76	16	24	.	.	.	.	.	1 (0.8)	12 (9.3)	129
C24. Did the doctor or nurse offer you any written or printed information about any of the following: the treatment options? the side effects or consequences of the treatment options? what could be done about the side effects?	82	78	57	.	.	.	.	.	0	.	129
C25a. Did you have enough time between been given your treatment options and discussing your treatment decision?	106	4	.	.	.	.	.	.	0	19 (14.7)	129
C25b. If no, how much time would you have liked?	0	1	1	1	.	.	.	.	0	1 (25.0)	4
C26. Who decided which type of treatment you were to have?	77	34	64	14	2	.	.	.	0	9 (7.0)	129
C27. Did the doctor or nurse involve you as much as you wanted in the decision about which treatment to have?	2	109	7	.	.	.	.	.	0	11 (8.5)	129
C28. After the treatment decision had been made did the doctor or nurse tell you that you could again discuss your treatment decision?	74	42	.	.	.	.	.	.	0	13 (10.1)	129

C29. Did the doctor or nurse tell you that you could change your mind about which treatment to have?	60	55	.	.	.	.	.	.	0	14 (10.9)	129
C30. Were you satisfied with the way the decision was made about which treatment to have?	111	8	.	.	.	.	.	.	0	10 (7.8)	129
C31. Did the doctor or nurse tell you that you could get help from any of the following (e.g. advice, support)?	101	36	33	25	27	7	3	1	0	14 (10.9)	129
C32a. Overall, did you have confidence and trust in the doctor that you saw on this occasion?	106	11	2	0	1	.	.	.	0	9 (7.0)	129
C32b. Overall, did you have confidence and trust in the nurse that you saw on this occasion?	97	6	2	0	0	.	.	.	0	24 (18.6)	129
C33. Overall, how would you rate the quality of care provided by your hospital when you got your test results?	77	41	3	0	0	.	.	.	0	8 (6.2)	129

SECTION D: Your treatment

Question	**N ticking each response option**									**Error**	**Missing n (%)**	**Total**
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**			
D1. Is your current treatment choice watchful waiting/active monitoring?	42	64	.	.	.	.	.		.	1	24 (18.3)	131
D2. Which treatment have you most recently have?	42	28	25	6	0	0	.		.	0	8 (9.0)	109
D3. Where did you have your most recent treatment?	39	26	8	.	.	.	.		.	3	13 (14.6)	89
D4. Were you an NHS patient or private patient?	74	0	.	.	.	.	.		.	0	7 (8.6)	81
D5. How long did you have to wait from the decision about which treatment to have to the start of the treatment?	7	24	12	10	20	.	.		.	0	8 (9.9)	81
D6. How did you feel about the length of the time you had to wait for your treatment to start?	0	53	20	.	.	.	.		.	0	8 (9.9)	81
D7a. 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)? What your treatment would involve	69	2	1	.	.	.	.		.	0	9 (11.1)	81

D7b. 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)? The possible side effects/consequences of your treatment	66	2	1	.	.	.	.		.	0	12 (14.8)	81
D7c. 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)? Why your treatment was starting on the date arranged	37	8	17	.	.	.	.		.	0	19 (23.5)	81
D7d. 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)? Whether you had a choice about where the treatment took place	13	5	44	.	.	.	.		.	0	19 (23.5)	81
D7e. 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)? What you should do during your treatment	46	9	9	.	.	.	.		.	0	17 (21.0)	81
D7f. 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)? What you should not do during your treatment	45	8	10	.	.	.	.		.	0	18 (22.2)	81
D8. While you were being treated, could you discuss any concerns about your treatment with the doctor or nurse?	63	2	4	.	.	.	.		.	1	11 (13.6)	81
D9. Did you experience problems with your visit(s) for treatment?	20	2	30	22	2	3	3	4	2	0	0	81
D10. Were you told that it might be helpful if someone (e.g. partner, relative) could go with you when you went for treatment?	30	41	.	.	.	.	.	.	.	0	10 (12.3)	81
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?)	59	7	0	6	.	.	.	.	.	0	9 (11.1)	81
D12. Did the doctor or nurse tell you about any of the following sources of help for coping?	56	20	19	14	18	9	10	0	0	0	10 (12.3)	81

D13. Did the doctor or nurse offer you enough information about complementary therapies (e.g. diet/diet supplements/acupuncture/ massage/reflexology)?	18	35	13	.	.	.	.	.	.	0	15 (18.5)	81
D14a. How would you rate the following? Treatment	59	9	3	0	0	.	.	.	.	0	10 (12.3)	81
D14b. How would you rate the following? Nursing	48	10	5	2	0	.	.	.	.	0	16 (19.8)	81
D14c. How would you rate the following? Food/drink	11	13	15	11	6	.	.	.	.	0	25 (30.9)	81
D14d. How would you rate the following? Ward (e.g. privacy, noise, cleanliness)	12	17	17	7	3	.	.	.	.	0	25 (30.9)	81
D15. While you were in the hospital, were your spiritual needs met (e.g. appropriate food, prayer room)? As an inpatient	15	0	3	30	6	.	.	.	.	0	27 (33.3)	81
D15. While you were in the hospital, were your spiritual needs met (e.g. appropriate food, prayer room)? As an outpatient	7	0	1	18	11	.	.	.	.	0	44 (54.3)	81
D16. Did the doctor or nurse explain how well the treatment was going/had gone?	59	8	3	.	.	.	.	.	.	0	11 (13.6)	81
D17. Did the doctor or nurse explain what would happen after your treatment had finished e.g. arrangements for follow-up?	62	4	0	2	.	.	.	.	.	1	12 (14.8)	81
D18. Did the doctor or nurse help you to understand how to care for yourself at home?	53	6	11	.	.	.	.	.	.	0	11 (13.6)	81
D19. Were you given equipment or supplies (e.g. continence pads) to use at home to help you care for yourself?	30	14	8	19	.	.	.	.	.	0	10 (12.3)	81
D20. Did a doctor or nurse organise the aftercare services that you needed (e.g. district nurse, health visitor, physiotherapist)?	34	9	26	.	.	.	.	.	.	1	11 (13.6)	81
D21. Did the doctor or nurse tell you who to contact if you were worried about your treatment or side effects of treatment?	36	47	32	10	2	0	3	.	.	0	13 (16.8)	81
D22. Did the doctor or nurse offer you any financial information on welfare or benefits?	8	23	39	.	.	.	.	.	.	1	10 (12.3)	81
D23. At the end of your treatment in hospital were you contacted by your GP's practice?	8	7	2	43	5	.	.	.	.	4	12 (14.8)	81

D24a. 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)? GP's practice & hospital	46	9	4	3	.	.	.	.	.	1	18 (22.2)	81
D24b. 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)? Between hospitals	34	3	3	8	.	.	.	.	.	0	33 (40.7)	81
D24c. 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)? Between different hospital departments	38	5	1	2	.	.	.	.	.	0	35 (43.2)	81
D25. Overall, did you have confidence and trust in the doctor(s) that treated you?	64	6	0	1	.	.	.	.	.	0	10 (12.3)	81
D25. Overall, did you have confidence and trust in the nurse(s) that treated you?	54	10	0	2	.	.	.	.	.	0	15 (18.5)	81
D26. Overall, did the hospital staff treat you with respect and dignity? Doctor(s)	65	5	0	1	.	.	.	.	.	0	10 (12.3)	81
D26. Overall, did the hospital staff treat you with respect and dignity? Nurse(s)	59	8	0	1	.	.	.	.	.	0	13 (16.0)	81
D26. Overall, did the hospital staff treat you with respect and dignity? Receptionist(s)	46	6	2	7	.	.	.	.	.	0	20 (24.7)	81
D27. Overall, how would you rate the quality of care provided by your hospital when you were treated?	52	17	2	0	0	.	.	.	.	0	10 (12.3)	81

SECTION E: Monitoring (checking) you

Question	**N ticking each response option**						**Error**	**Missing n (%)**	**Total**
	1	**2**	**3**	**4**	**5**	**6**			
E1. Were you offered a "key worker" (the same person to contact throughout your care)?	68	49	.	.	.	.	0	14 (10.7)	131
E2. Have you found it useful to have a "key worker"?	48	13	7	.	.	.	0	14 (17.1)	82
E3. Do you have regular tests for prostate cancer (e.g. PSA blood test, DRE/internal examination)?	111	10	.	.	.	.	0	10 (7.6)	131

E4. Have you experienced any problems with the regular tests you have for prostate cancer.	6	103	.	.	.	.	0	12 (9.9)	121
E5. Where do you discuss the results of your tests (e.g. PSA blood test, DRE)?	61	39	1	.	.	.	2	18 (14.9)	121
E6. Did the doctor or nurse explain why you have these regular tests?	92	7	6	5	.	.	0	11 (9.1)	121
E7. How often are you currently tested for prostate cancer?	0	1	40	5	1	56	1	15 (12.4)	121
E8. Did the doctor or nurse reassure you that the length of the wait between the tests for prostate cancer was appropriate for you?	93	16	.	.	.	.	0	12 (9.9)	121
E9a. Were you offered a choice of where to have these tests (e.g. GP's practice, hospital)?	44	61	.	.	.	.	0	16 (3.2)	121
E9b. If no, would you have liked a choice of where to have these tests?	22	42	.	.	.	.	0	57 (47.1)	121
E10. How were you given your test results?	100	3	5	.	.	.	0	13 (10.7)	121
E11. Would you have liked to have been given your test results in a different way?	1	103	.	.	.	.	0	17 (14.0)	121
E12.Did the doctor or nurse explain your test results to you?	98	6	2	.	.	.	0	15 (12.4)	121
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)?	86	19	.	.	.	.	0	16 (13.2)	121
E14. Did a doctor or nurse discuss with you the possible side effects of your treatment (e.g. incontinence, impotence)?	101	6	8	.	.	.	0	16 (12.2)	131
E15a. Did the doctor or nurse ask you if you had any of the following needs? Emotional (e.g. patient support group)	30	75.	.	.	.	.	1	25 (19.1)	131
E15b. Did the doctor or nurse ask you if you had any of the following needs? Spiritual/ religious (e.g. someone to talk to)	9	86	.	.	.	.	0	36 (27.5)	131
E15c. Did the doctor or nurse ask you if you had any of the following needs? Financial (e.g. benefits available)	12	85	.	.	.	.	0	34 (26.0)	131
E15d. Did the doctor or nurse ask you if you had any of the following needs? Day-to-day (e.g. help with housework)	6	88	.	.	.	.	0	37 (28.7)	131

E16a. 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)? Between GP's practice and hospital	82	16	4	5	.	.	0	24 (18.3)	131
E16b. 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)? Between hospitals	54	12	3	18	.	.	0	44 (33.6)	131
E16c. 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)? Between different departments (e.g. Urology and Oncology)	63	8	2	8	.	.	1	49 (37.4)	131
E17a. Overall, did you have confidence and trust in the doctor(s) that you saw?	107	10	0	1	.	.	0	13 (9.9)	131
E17b. Overall, did you have confidence and trust in the nurse(s) that you saw?	100	8	1	3	.	.	0	19 (14.5)	131
E18a. Overall, did the doctor(s) treat you with respect and dignity?	111	5	0	2	.	.	0	13 (9.9)	131
E18b. Overall, did the nurse(s) treat you with respect and dignity?	103	10	0	3	.	.	0	15 (11.5)	131
E18c. Overall, did the receptionist(s) treat you with respect and dignity?	92	10	1	7	.	.	0	21 (16.0)	131
E19. Overall, how would you rate the quality of care provided by your GP's practice and/or hospital while you are being monitored?	75	38	3	1	0	.	0	14 (10.7)	131

Changes to the questionnaires

Version 2 of the questionnaires was revised on the basis of these results to produce PCQ-Pv3. The changes made to PCQ-Pv2 are summarised in Box 5.5.

Box 5.5 Summary of the changes to PCP-Pv2

Layout/design

Cover: text was revised to include the disclaimer that had been stapled onto the earlier questionnaire in case it went to a person without prostate cancer by mistake or someone who did not know that they had been diagnosed with prostate cancer. The list of the different sections was removed.

The amount of routing was reduced as some respondents had failed to follow it correctly

Sections

Some section descriptions were shortened and clarified, and the number of questions was reduced in all but one section.

Section A: The first time you saw the doctor or nurse about your possible prostate problem (24 questions in v2, reduced to 20 questions in v3)

Section B: Having tests for possible prostate cancer at the hospital (20 questions in v2, reduced to 19 questions in v3)

Section C: Discussing your test results for possible prostate cancer v2, changed to: Getting the diagnosis in v3 (33 questions in v2, reduced to 30 questions in v3).

Section D: Your treatment (27 questions in v2, reduced to 26 questions in v3).

Section E: Monitoring (checking) you (19 questions in v2, reduced to 15 questions in v3)

Section F: About you and your health (11 questions in v2, increased to 12 questions in v3).

Questions

The number of questions was reduced by combining some questions and deleting others so that the questionnaire focused only on identifying problems, and not eliciting respondent preferences. For example, question C19b, *how much time would you have liked?* was not included in PCQ-P v3.

The routing in some sections was shortened or removed so that respondents recorded as much of their experience as possible. For example, question E3 in PCQ-Pv2 routes those who answer *No* to question E14, while the equivalent question (E4) is modified in PCQ-Pv3 and the patient is not routed past any of the following questions

Some questions were modified to enable a Yes/No response format. For example, question A11 in PCQ-Pv2 gave five response options, this was reduced to two (Yes/No) in question A7 in PCQ-Pv3.

The wording of some questions was modified to improve clarity. For example question C13 in PCQ-Pv2 refers to the Gleason score and this is replaced by question C9 that asks about the *aggressiveness of the cancer*.

The format of the overall rating questions used in v1 (numerical scale) was reinstated since this had been more discriminatory than the format adopted from the National Audit Office (2004) questionnaire

Some of the questions in Section F (About you) were modified, in particular, a standard ONS measure of socio-economic class was added which replaced some of the existing questions from v2 (e.g. F10 *Including yourself, how many people live in your household who are aged 18 or over?)*

Questions throughout the questionnaire were revised to ensure greater standardisation of phrasing in questions and responses

The changes made can be seen in version 3 of the questionnaire, PCQ-Pv3 (see Appendix 8).

5.3.4 Discussion

The process of developing the questionnaire required the input of patients as well as health professionals and staff from the voluntary sector. Their willingness to be involved, sometimes in several stages or in lengthy interviews, enabled the drafting and reviews of the questionnaires. It was possible to achieve satisfactory response rates (above 70%) with the use of a single reminder, despite the length of the draft questionnaires used in the pilot tests. However, careful organisation of the surveys by participating hospitals is required to maximise response rates – in one hospital in the first pilot, the organisation of the pilot survey appears to have been defective. The procedure for eliminating patients who were assessed by clinical staff as inappropriate for inclusion appeared effective, as no adverse events occurred, such as the mailing of the questionnaires to someone who had not been told

their diagnosis. The pilots provided reassurance that the questionnaires addressed the issues important to patients, and that the response options and formats were acceptable. Some modifications were required to improve the clarity of the instructions, questions and responses. Ethnic minority patients and carers had been involved in the initial interviews (see Chapter 3), and were included among the respondents to the pilot tests, although the numbers of such patients were relatively small.

The development and review process led to version 3 of the questionnaire (PCQ-Pv3) which was employed in a study of validity and reliability. The process and outcomes of these tests will be explained in the next chapter.

Chapter 6: Testing the prostate cancer care questionnaire: PCQ-Pv3

In this chapter I will describe the testing conducted to ensure that the questionnaire was suitable for use, including the revisions made.

6.1 Introduction

This chapter describes the results of a formal evaluation of the questionnaire according to the standard psychometric criteria of validity and reliability (Streiner and Norman, 1995; Kline, 1990). Users of the measures must have confidence that they provide evidence that can be relied on in planning changes to services. Therefore, having developed instruments following an initial qualitative study and two pilot tests, the psychometric properties of PCQ-P v3 required investigation.

The American Psychological Association, in collaboration with the American Educational Research Association and the National Council on Measurement in Education, have jointly issued an agreed set of standards for psychometric testing, including evaluation of reliability and validity (American Psychological Association, 1999). The standards state

1. A test's validity is the extent to which it measures what it is intended to measure, and hence the degree to which inferences based on test scores are appropriate and meaningful.
2. The reliability of a measuring instrument is the internal consistency and stability of the scores that it generates. This equates to the degree to which it is free of measurement errors.

Validity

Validity may be conceptualised and investigated in different ways, including the following:

1. Face validity – the extent to which an instrument appears to its users to measure what it is supposed to measure. Face validity of the patient questionnaire was assessed through interviews with patients who had responded to the questionnaires and through consultation with the Panel (see Chapter 3).

2. Content validity – the extent to which the items of an instrument sample the relevant and appropriate aspects of what is being measured (in this case patient experience). Content validity was assessed through principal components analysis (PCA), a statistical technique designed to determine the factors underlying the variance in test scores. PCA is a variant of factor analysis suitable for use with non-parametric data. It identifies questions that are answered by individuals in a consistent way, grouping such questions together into factors (also referred to as components). The questions in each factor are used to decide what issue each factor is addressing. This technique was applied to the questionnaire, and the principal factors that emerged were compared to the themes from the interviews and the systematic literature review of studies of patient experience of prostate cancer care (see Chapters 2 and 3). If PCQ-P v3 has content validity, it will contain factors relating to all of the issues identified by the interviews and literature review.

3. Criterion validity – the strength of the relationship between the findings

produced using the instrument and an acceptable independent criterion against which the test instrument may be judged. Criterion validity was assessed, for the patient questionnaire, by correlating the questionnaire's scores with scores obtained with the National Centre for Social Research Short Questionnaire (Department of Health, 2002). If PCQ-P v3 measures what it is supposed to measure, then it should correlate positively with this established questionnaire, but because PCQ-P v3 is focused on the care of one cancer only rather than a group of six cancers, we should not expect the correlation to be very high.

Reliability

One aspect of reliability commonly used in the assessment of questionnaires is internal consistency (or homogeneity) – the degree to which the constituent items of a questionnaire or part of a questionnaire measure the same underlying construct or attribute. The most useful and general index of internal consistency is coefficient alpha (Cronbach, 1951), often called Cronbach's alpha. This is a form of split-half reliability, in which the items in a questionnaire or scale are randomly divided into two sub-scales and correlated with each other (Streiner and Norman, 1995). Alpha is the average of all possible split-half reliabilities of a scale. The standardized version of Cronbach's alpha may be defined by the formula $\alpha = kr/[1 + (k - 1)r]$, where k is the number of items and r is the mean product-moment correlation between the items. It normally ranges from 0 to 1 according to the degree of internal consistency with which the items all measure the same underlying construct. Negative values are mathematically possible but essentially meaningless (i.e.

0.7 is the same as –0.7). In current psychometric practice, a value above either 0.70 (Nunnally, 1978) or 0.60 (Nunnally and Bernstein, 1994) is usually considered satisfactory, depending on the purpose of the testing. Conversely, a high value of alpha (higher than 0.9) may indicate that questions are very similar and therefore several are redundant. Guidelines for best practice in use and interpretation of Cronbach's alpha have been provided by Helms, Henze, Sass, and Mifsud (2006).

Another key aspect of reliability is stability – the degree to which a test or measuring instrument yields approximately the same scores when administered to the same respondents on separate occasions. It indicates the proportion of the total variance in test measurements that is due to 'true' differences between respondents (Streiner and Norman, 1995). It is usually indexed by the test-retest correlation coefficient, assessed by administering the instrument twice, on two separate occasions, to the same group of respondents, and calculating the correlation between the two sets of scores using either the Spearman-Brown prophecy formula or the standard product-moment correlation formula. If a scale is stable, then the correlation should be reasonably high. According to Pasta and Suhr (2004), a correlation of 0.60 or above is considered acceptable for instruments developed for research purposes. The appropriate interval between tests for test-retest studies depends on the stability of the trait or factor being measured. Whilst traits such as personality may remain stable over long periods, patients' experience of care will tend to change as they experience further care, and therefore a relatively short interval between tests would be required. Formal evaluations

of both forms of reliability – internal consistency and stability – were carried out for the questionnaire using the techniques described above.

This Chapter thus describes the methods and results from tests of PCQ-P v3 for validity and reliability. The sections of PCQ-P v3 referred to throughout are as follows:

Section A: GP VISITS & REFERRAL

Section B: TESTS AT THE HOSPITAL

Section C: DIAGNOSIS AND TREATMENT DECISION

Section D: TREATMENT AND DISCHARGE

Section E: MONITORING

6.2 Methods

6.2.1 Introduction

Testing of the properties of PCQ-P v3 took place in a multi-component study involving five hospitals in England. The aims were to:

- enable the derivation of summary scores,
- to empirically test the validity and reliability of PCQ-P v3.

Data collection methods – postal evaluation

We undertook a survey of patients with prostate cancer attending five hospitals that volunteered to take part. The hospitals were identified through consultation with the Cancer Services Collaborative Improvement Partnership

as being potentially willing and capable of taking part in the study, and located in different settings in England. Of the five that initially agreed to take part, one in the north of England dropped out, and was replaced by another, although this hospital was in southern England which reduced the geographical diversity of the sample.

The features of the five participating hospitals are shown in Table 6.1

Table 6.1 Features of hospitals involved in the testing of the questionnaires

	1	**2**	**3**	**4**	**5**
Foundation Trust	No	No	No	Yes	Yes
Teaching Hospital	No	No	Yes	Yes	Yes
Population served	Mainly Urban	Mainly Rural	Mainly Urban	Mainly Urban	Mainly Rural
Location in England	South	South West	South West	South	East Anglia

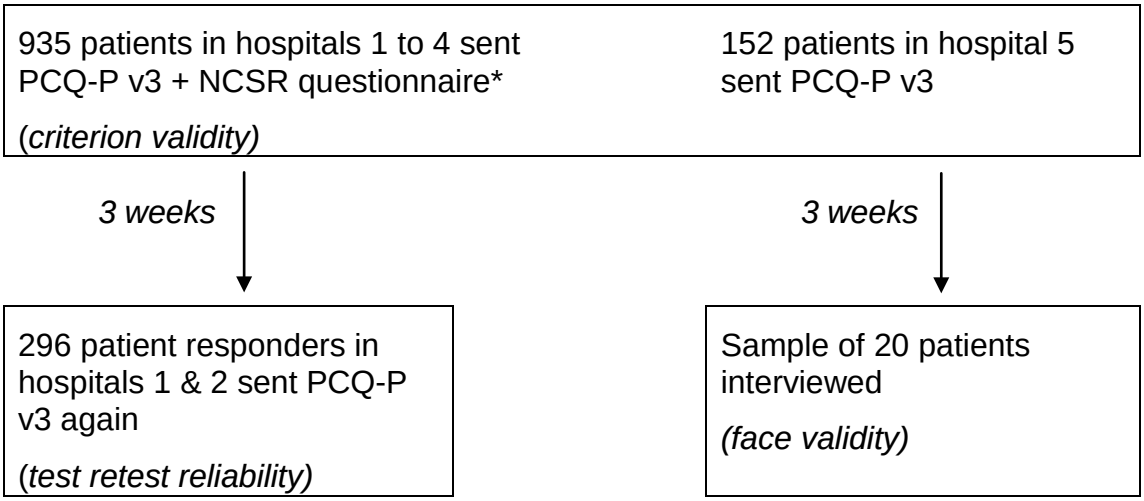
In each hospital, clinic staff identified patients from clinic lists. The lists were checked by clinical staff (usually specialist nurses) to remove patients who were known to have died, or who for other reasons (such not being aware of their diagnosis) should not be sent a questionnaire. Questionnaires were sent to patients by the hospitals and non-responders were sent one reminder. It was difficult to obtain information about non-responders because patient lists were held by the hospital to maintain patient confidentiality. Consequently, any investigation of non-responders would have required further research by the hospitals to review hospital clinical records to identify the characteristics of non-responders. This was not practicable.

To reduce respondent burden, the PCQ-P v3 was split into two parts. The first part comprised Sections A, B and C (GP visit and referral, testing, diagnosis and treatment decision) and was named PCQ-P Version 3.2. The second part comprised Sections D and E (treatment and monitoring) and was named PCQ-P Version 3.3. Both parts also included Section F (About You).

Although accepted methods for estimating sample sizes for psychometric studies are not well developed, guidance on desirable sample sizes is available. The larger the sample used, the smaller the confidence interval. Streiner and Norman (1995, p. 87) report that "Nunnally (1978) recommends at least 300 subjects and Guilford (1956) and Kline (1986) are a little less demanding and recommend 200." The sample size for testing the PCQ-P v3 was chosen to ensure adequate numbers for undertaking psychometric tests. It was originally aimed to include 400 responses for the tests of internal consistency and principal components analysis, and around half this number for the test-retest study of reliability. It was intended to invite up to 750 patients to take part in the test of criterion validity, anticipating around 600 respondents. The participating hospitals were asked to invite between 150-250 patients each, depending on the numbers of patients with prostate cancer under their care. At each hospital, the samples included all patients in whom a new diagnosis of prostate cancer had been made in the previous two years.

The process of this testing phase is outlined in the flow diagram (Figure 6.1) below)

Figure 6.1 Flow diagram of testing phases



* The National Centre for Social Research designed this questionnaire for the 1999/2000 national survey of cancer patients.

Four hundred and thirty-one patients were sent Version 3.2 (253 in hospital 1 and 178 in hospital 3), and 504 patients were sent Version 3.3 (253 in hospital 2 and 251 in hospital 4). For the study of criterion validity, patients in all four of these hospitals (n = 935) were also sent the corresponding sections of the short NCSR questionnaire to be filled in at the same time as the prostate experience questionnaire, to provide data to assess criterion validity. Responders in hospitals 1 and 2 (n = 296) were included in the test of test-retest reliability; in these two hospitals patient respondents were re-sent the same version of the questionnaire a second time after an interval of approximately three weeks. One hundred and fifty-two patients in Hospital 5 received the full questionnaire (PCQ-P v3), and a reply slip to complete and return if they were interested in being interviewed in order to check the face validity of the questionnaire. From the 28 replies received we selected 20 patients for interview, selecting patients to ensure that the sample included a wide a range of treatments as possible.

Analysis of data – postal evaluation (deriving scores for each section of PCQ-Pv3)

A key aim of this stage of the study was to produce overall scores for each section of PCQ-Pv3 that would facilitate comparisons between different hospitals. The presentation of the results from each question individually constitutes a significant amount of information. A summary score that simplifies comparisons yet draws attention to aspects of care where there are differences would aid interpretation. Data from the full data set including patients from all five hospitals were used in developing these section scores for the patient questionnaire. Scores for each section were produced based on responses to selected questions. All questions in each section that reported on experience (rather than merely addressing factual issues, such as whether or not the patient had been diagnosed with prostate cancer) were initially included in the overall score for the section. Some recoding and calculation was required to produce the overall section scores. First, questions were recoded so that scores on each question ranged from 0 to 1, with 1 indicating the most positive score. Second, to avoid questions with multiple sub-questions being overly weighted in the section score, a single score for each relevant question was produced by calculating the mean score across the sub-questions. Section scores were then calculated in the following way. For each respondent a mean score for each section was produced by summing the recoded scores on the relevant questions and dividing this by the number of questions completed in the section, then multiplying this figure by 100 to produce a score for the section on a 0-100 scale:

$$\frac{\text{Sum of scores}}{\text{Number of questions completed}} \times 100$$

Section scores were only calculated for respondents who had completed at least 50% of the questions in the respective section. Decisions about which questions to include in the overall scores for each section were informed by the results of a Principal Components Analysis of the full patient data set from the 5 hospitals (see section 5.3.2.2). This analysis checked whether the questions in each section produced coherent and meaningful factors, and whether any questions did not load onto any of the factors and hence might be better excluded from the overall section scores. Also, Cronbach's alpha scores (Cronbach, 1951) were inspected along with predicted alpha for the section if particular questions were removed. After inspection of these data a small number of questions were removed from the calculation of final scores to improve the internal consistency and produce a meaningful factor structure. The factor structure underlying these scores, and the internal consistency of the scores, are described in the sections below. The final set of questions included in the overall section scores are listed in Table 6.2 for the PCQ-Pv3.

Table 6.2 Composition of section scores– PCQ-Pv3

Questions included in the calculation of the overall score for SECTION A: GP VISITS & REFERRAL
A3. Did the doctor or nurse take your concerns seriously?
A5. Did the doctor or nurse explain that the tests were trying to find out whether you might have prostate cancer?
A6. Did the doctor or nurse explain how the DRE test would be carried out / that the PSA test is not always reliable?
A7. Did the doctor or nurse explain what would happen if the results were abnormal?
A8. Did the doctor or nurse offer you any written information about the test(s)?
A9. Were you given a choice about whether you wanted to be tested for prostate cancer?
A10. Did the doctor or nurse clearly explain your test results?
A11. Did the doctor or nurse give you your test results in a considerate way?

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

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

A15. 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?

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

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

Questions included in the calculation of the overall score for SECTION B: TESTS AT THE HOSPITAL

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?

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

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

B7. How would you rate: Waiting area; Availability of refreshments; Toilets; Rooms where the tests were carried out

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

B9. Did the doctor or nurse explain that these test results were to find out if you had prostate cancer?

B10a. Explanation of what test would involve: TRUS/biopsy; urine flow; PSA; DRE; Scans (MRI, CT)

B11. Did the doctor or nurse explain to you that the biopsy might be painful?

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

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

B14. Did the doctor or nurse clearly explain to you how long you would have to wait for your test results?

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)?

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

Questions included in the calculation of the overall score for SECTION C: DIAGNOSIS AND TREATMENT DECISION

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

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?

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

C6. Did the doctor or nurse clearly explain your diagnosis?

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

C9. Did the doctor or nurse clearly explain how aggressive the cancer was likely to be?

C12. How did you feel about the length of time you had to wait to discuss your diagnosis with the specialist nurse?

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

C15.How did you feel about the length of time between being given your diagnosis and discussing your treatment options?

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

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

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

C19. Did the doctor or nurse clearly explain why the other treatment options were not suitable for you?

C20. Did the doctor or nurse give you any written information about the treatment options / the possible side effects or consequences of the treatment options?

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

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

C24. Did the doctor or nurse involve you as much as you wanted in the decision about which treatment to have?

C25. Were you confident that the treatment decision was the best one for you?

C26. After the treatment decision had been made did the doctor or nurse tell you that you could discuss your treatment decision again?

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

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

Questions included in the calculation of the overall score for SECTION D: TREATMENT AND DISCHARGE

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

D6. 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)?

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

D8. While you were receiving treatment were you able to discuss any concerns about your treatment with the doctor or nurse?

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

D10. How would you rate: the treatment; the nursing; the food/drink; the ward (e.g. privacy, noise, cleanliness)?

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)?

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

D14. Did the doctor or nurse explain how well the treatment was going/had gone?

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)?

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)?

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)?

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

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

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

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

D23. Have staff in different places worked well together when caring for you for this condition: between GP's practice and hospital; between hospital and hospital; between different departments (e.g. Urology and Oncology)?

Questions included in the calculation of the overall score for SECTION E: MONITORING

E3. Did the doctor or nurse explain why you have these regular tests?

E5. Has a doctor or nurse reassured you that the length of the wait between these tests for prostate cancer is appropriate for you?

E6. Have you been offered a choice of where to have these tests (e.g. GP's practice, hospital)?

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

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

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

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)?

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

E12. Are staff in different places working well together when monitoring you for this condition: between GP's practice and hospital; between hospital and hospital; between different departments (e.g. Urology and Oncology)?

6.2.2. Validity

6.2.2.1 Face validity

Face validity was investigated in interviews of a sample of patients in hospital 5 who had completed PCQ-Pv3 to discover whether they had understood the questions and whether all the issues important to them had been addressed. The sampling frame was devised to ensure that patients at different stages of care, and who had experienced different types of treatment (including active monitoring) were included. A combination of telephone and face-to-face interviews were conducted, the majority of which took place within one month of completion of the questionnaire. The interview schedule followed the structure of the questionnaire. For each section of the questionnaire, patients were asked to describe; how good they felt their experience had been and why; whether there was anything that went particularly well or could have been better; and whether there were any issues that were important to them which had not been covered by the questionnaire. Interviews were not recorded, but detailed notes were taken. The issues arising in each interview were compared and contrasted with responses to the previously completed questionnaire to identify whether issues raised in the interviews were adequately covered by the questionnaire, and to highlight any discrepancies in responses. To supplement these interviews, the Panel was also asked to study the measures for a final time and judge whether it contained questions on all the important issues.

6.2.2.2 Content validity

Principal Components Analysis was carried out on the patient data from 5 hospitals, to identify the factors in each section of the questionnaire. This analysis checked whether the questions in each section produced coherent and meaningful factors. The following types of questions were not included in the factor analysis: all non-evaluative questions (e.g. 'were you diagnosed with prostate cancer'); 'overall' questions in which patients were asked to rate their care overall on a scale from 0-10 (e.g. Section A question 20); patient ratings of their confidence in doctors, nurses and receptionists, and of whether these members of staff treated them with respect and dignity (e.g. Section A questions 18 and 19); the questions which asked patients to report how long they had to wait (e.g. Section A question 12).

The number of factors in each Section was decided by firstly using a threshold of eigenvalue >1 to select factors. However, in the analysis of the data for most of the sections of the questionnaire, this produced 3 to 4 factors with relatively high eigenvalues, then 2 or 3 more factors with eigenvalues just above 1. In these cases a cut-off threshold was chosen based on inspection of the scree plot, and this produced a meaningful and comprehensive set of factors. The questions included in each factor were inspected in order to identify the theme or aspect of care that was represented. The themes derived from the factor analysis were compared qualitatively with themes identified from the interviews and the literature review undertaken in the early stages of the study (see Chapters 2 and 3).

6.2.2.3 Criterion validity

Assessing criterion validity involves comparing responses to a new instrument to those given by the same participant to an existing questionnaire that is accepted as valid. The first stage in assessing criterion validity for this study was the selection of a suitable existing patient experience measure against which to compare the PCQ-Pv3. The aim was to identify tools that had been designed (or used) to measure patient experience of prostate cancer care. Potential tools were identified from the initial literature review and the survey of Cancer Networks (see Chapter 2). This was supplemented by an internet search to identify any other potentially relevant tools. Thirteen potentially relevant questionnaires were identified. These are listed in Table 6.3.

Table 6.3 Questionnaires evaluated for use in assessing criterion validity

Questionnaire name	**Developed by:**	**Details (reference /Link or information about where developed)**
1. NCSR National Patient Survey: cancer 1999 /2000 Full & Short versions (NCSR questionnaire)	National Centre for Social Research, London	http://www.dh.gov.uk/prod_consum_dh/idcplg?IdcService=GET_FILE&dID=4809&Rendition=Web http://www.dh.gov.uk/prod_consum_dh/idcplg?IdcService=GET_FILE&dID=17047&Rendition=Web
2. NAO National Patient Survey (cancer) 2004	Picker Institute	http://www.nao.org.uk/publications/nao_reports/04-05/0405288_patientsurvey.pdf
3. Satisfaction with Care	Stanford University, USA	Lubeck DP, Litwin MS, Henning JM, Mathias SD, Bloor L, Carroll PR. (2000) An instrument to measure satisfaction with healthcare in an observational database: Results of a validation study using data from CaPSURE. The American Journal of Managed Care, 6(1) 70-76.

4. Patient Career Diary (cancer)	Department of Health Sciences, University of Leicester	Cheater F, Preston C, Wynn A, Hearnshaw H, Baker R. (1999) Patients' views of cancer services: development of a questionnaire for accreditation. European Journal of Oncology Nursing, 3(2) 72-82.
5. Picker Patient Experience questionnaire	Picker Institute	Jenkinson C, Coulter A, Bruster S. (2002) The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. International Journal for Quality in Health Care, 14(5), 353-8.
6. Cancer Services Evaluation of care and support	Clinical Effectiveness, Torbay Hospital	Developed within Peninsular Cancer Network (not publicly available)
7. Improving nursing services for patients with prostate cancer. KCL Patient Outcome Scale	Florence Nightingale School of Nursing & Midwifery, Kings College London	www.**kcl**.ac.uk/content/1/c6/01/29/24/Pt_q_v2.pdf
8. Cancer patients' experience survey	Sussex Cancer Network	Developed within Sussex Cancer Network (not publicly available)
9. LNR Prostate cancer patient questionnaire	LNR Cancer Network	Developed within Leicestershire, Northamptonshire & Rutland Cancer Network (not publicly available)
10. Informational Needs Assessment Questionnaire	Department of Nursing, University of Ulster	Templeton HRM, Coates VE. (2001) Adaptation of an instrument to measure the informational needs of men with prostate cancer. Journal of Advanced Nursing,35(3), 357-364.
12. Palliative care outcome scale	Palliative Care Core Audit Project, Kings College London	Hearn J, Higginson IJ. (1999) Development and validation of core outcome measure for palliative care: the palliative care outcome scale. Quality in Health Care, 8, 219-227.
13. Prostate cancer charity survey (The Experiences of Men with Prostate Cancer: The first national survey)	The Prostate Cancer Charity	http://www.prostate-cancer.org.uk/news/features/survey_1.asp

Each identified tool was evaluated for quality and relevance independently by myself and another researcher (CT) using a structured evaluation form (see

Appendix 9). The form was devised through discussion (myself and CT) to check the appropriateness and relevance of each questionnaire via a range of questions (e.g. relevance to prostate cancer, the stages of care it measured, whether it measured patient experience or satisfaction or something else) and its reliability and validity. A shortlist was compiled based on the evaluation, and, following discussion involving myself and two other researchers who completed the form, the short version of the NCSR questionnaire (Department of Health, 2002) was selected as the most appropriate tool (see Appendix 10). The NAO and NCSR questionnaires were very similar, the NAO questionnaire being designed to monitor progress in patient experience since the NCSR survey had been undertaken in 2000. Of the other surveys, they either did not cover the issues salient to prostate cancer care (e.g. the Patient Career Diary (cancer)) or had not been developed with sufficient rigour to justify acceptance of validity.

The analysis for criterion validity involved calculation of Pearson's correlations between an overall score for Version 3.2 patient questionnaire (derived by adding the scores of sections B and C together), or Version 3.3 (adding the scores of sections D and E together), and a similar single score derived from the corresponding parts of the NCSR questionnaire. A negative correlation would be expected as a larger score on the prostate care questionnaire represents a more positive experience, whereas a larger NCSR score represents a greater number of problems with care.

6.2.3 Reliability

6.2.3.1 Test-retest reliability

Data from the two hospitals in which patients filled in a second copy of the questionnaire (Hospitals 1 and 2; see Figure 6.1) after a time interval of approximately three weeks were analysed to assess test-retest reliability of the questionnaire. Two approaches were used. Firstly, the percentage agreement between individuals' responses to each experience question on the first mailing, and their responses to each of the same questions on the second mailing was calculated to check whether respondents answered consistently. Percentage agreement was calculated by counting the number of questions within each section which were answered in the same way on the first and the second occasion by each respondent, dividing this by the number of questions completed by the respondent.

Secondly, test-retest reliability of the overall section scores was assessed by calculation of Pearson correlations between the overall section scores (calculated as described above) on the first compared with the second mailing (Aiken, 1997).

6.2.3.2 Internal consistency

Internal consistency of the final set of questions included in the overall section scores was checked using Cronbach's alpha (Cronbach, 1951). This analysis normally produces a figure between 0 and 1, where higher values indicate a higher degree of internal consistency within the question set.

6.3 Results – evaluation of PCQ-Pv3

6.3.1 Response rates

Table 6.4 summarises the empirical testing of the questionnaire, and shows the number of respondents and response rates for each participating hospital.

Table 6.4 Testing the Questionnaires: overview and response rates

Hospital	Questionnaires	Tests	Response rate mailing 1	Response rate mailing 2
1	PCQP v3.2; NCSR short questionnaire version 3.2	Test-retest reliability (PCQP v3.2 sent again after 3 weeks) Criterion validity	Patients: 149/253 (58.9%)	Patients: 79/125 (63.2%)
2	PCQP v3.3; NCSR short questionnaire version 3.3	Test-retest reliability (PCQP v3.3 sent again after 3 weeks) Criterion validity	Patients: 193/253 (76.3%)	Patients: 69/171 (40.4%)
3	PCQP v3.2; NCSR short questionnaire version 3.2	Criterion validity	Patients: 93/178 (52.1%)	
4	PCQP v3.3; NCSR short questionnaire version 3.3	Criterion validity	Patients: 203/251 (80.9%)	
5	PCQ-P v3	Content validity (interviews with patients/carers compared with questionnaire responses)	Patients: 114/152 (75.0%)	Interviews with 20 patients

PCQP v3.2 comprised questions on visit to GP, referral, tests at the hospital, diagnosis and treatment decision

PCQP v3.3 comprised questions on treatment and monitoring

6.3.2. Validity

6.3.2.1 Face validity

Patient interviews

Face validity had been investigated by asking patients who had completed PCQ-P v3 to take part in interviews. Twenty patients were interviewed in total, 11 face-to-face and nine via telephone. The numbers for each type of treatment received by patients are recorded below (see Table 6.5).

Table 6.5 Patients interviewed in study of face validity

Type of treatment	**Number of patients**
Prostatectomy	5
Hormone therapy	7
Radiotherapy & Hormone therapy	1
No active treatment	7
Total	**20**

All participants agreed that the questionnaires covered important aspects of care. However, some patients highlighted the importance of a well organised discharge procedure, and reported having experienced significant problems at this phase of care. This indicated that there was a need for more detailed questions on discharge in the PCQ-P v3. The particular issues identified as needing to be addressed were: knowing what to expect in terms of recovery time and side effects; and knowing how to get hold of appropriate supplies after discharge (such as continence pads). Additional questions on these issues were added to the final version of the questionnaire.

When discrepancies were identified between patient reports of their experience and their responses to the questionnaires, or when misunderstandings of questions were highlighted in interviews, questions were inspected and minor rewording undertaken to improve clarity for the final versions of the questionnaires.

The Panel

Face validity was also assessed by the Panel. The members were each sent copies of the PCQ-P v3 along with summaries of the issues found to be important to patients and carers from the findings of the initial literature review and patient and carer interviews. They were asked to judge the extent to which the questionnaires addressed the identified issues. Feedback from the Panel highlighted minor changes in wording needed, but otherwise members of the Panel agreed that the questionnaire had high face validity.

6.3.2.2 Content validity

Principal Components Analysis

Principal Components Analysis was carried out using the data from the first mailing in all 5 hospitals, from 865 responders (data were available from 355 responders for Sections A, B and C, and 510 responders for Sections D and E). Characteristics of responders are in Table 6.6 below.

Table 6.6 Patient characteristics (content validity study)

Characteristics	N (%)
Age (years)	
<55	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)

The questions included in this analysis were all those selected for inclusion in the overall score for each section. These were the majority of the evaluative questions in each section. This analysis investigates whether each section comprises questions about coherent and meaningful aspects of care, and reflects the salient issues identified as important to patients and carers in

earlier stages of the study. Once the results of the Principal Components Analysis had been inspected, and the factors allocated titles indicating the focus of the questions included in the factor, the factors for each section were compared qualitatively to the issues identified in the patient and carer interviews, and to the results of the systematic literature review.

The results of the Principal Components Analysis for each section are presented in Table 6.7. Questions are arranged in order of the magnitude of their loading on the principal factor. Only loadings of over 0.3 are shown. In each section it was possible to identify three or four meaningful factors. Table 6.8 lists the questions that were not included in any of the factors.

Table 6.7 Principal Components Analysis with Varimax rotation for each section of the patient questionnaire

SECTION A: GP VISITS & REFERRAL (N=204)

	Factor 1: Explanation	**Factor 2: Referral**	**Factor 3: Taking the problem seriously**
A5. Did the doctor or nurse explain that the tests were trying to find out whether you might have prostate cancer?	.791		
A10. Did the doctor or nurse clearly explain your test results?	.737		.344
A7. Did the doctor or nurse explain what would happen if the results were abnormal?	.730		
A14. Did the doctor or nurse explain that you were being referred to hospital to find out if you had prostate cancer?	.697		
A6. Did the doctor or nurse explain how the DRE test would be carried out / that the PSA test is not always reliable?	.645		
A9. Were you given a choice about whether you wanted to be tested for prostate cancer?	.597	.323	
A11. Did the doctor or nurse give you your test results in a considerate way?	.571		.507
A15. 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?		.718	
A16. Were you asked if you had any needs when the referral arrangements were made (e.g. transport needs, time of appointment)?		.718	
A17. Did the doctor or nurse tell you how soon you would be seen at the hospital?		.605	
A8. Did the doctor or nurse offer you any written information about the test(s)?		.588	
A3. Did the doctor or nurse take your concerns seriously?			.704
A13. How did you feel about the time the GP's practice/local assessment centre took to refer you to hospital?			.701

Rotation converged in 5 iterations.

Set criteria: eigenvalue>1

SECTION B: TESTS AT THE HOSPITAL (N=240)

	Factor 1: Explanation & support	**Factor 2: Quality of care**	**Factor 3: Appointment**
B14. Did the doctor or nurse clearly explain to you how long you would have to wait for your test results?	.664		
B13. Did the doctor or nurse explain that you may need medication (e.g. antibiotics) to control any infections caused by the biopsy?	.648		
B16. Did the doctor or nurse clearly explain to you what would happen next?	.628		
B9. Did the doctor or nurse explain that these test results were to find out if you had prostate cancer?	.531		
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)?	.505		
B12. When you had your biopsy were you offered a local anaesthetic?	.434		.340
B7. How would you rate: Waiting area; Availability of refreshments; Toilets; Rooms where the tests were carried out		.833	
B10a. Explanation of what test would involve: TRUS/biopsy; urine flow; PSA; DRE; Scans (MRI, CT)		.722	
B6. Did you experience any problems with your hospital visit(s)?		.483	
B11. Did the doctor or nurse explain to you that the biopsy might be painful?		.386	
B8. Did you have enough privacy while the doctor or nurse was examining/testing you?			.783
B5. How did you feel about the length of time you had to wait for your first appointment for tests at the hospital?			.440
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?	.333	.396	-.404

Rotation converged in 7 iterations.

Set criteria: limited to 3 Factors (after inspecting scree plot)

SECTION C: DIAGNOSIS AND TREATMENT DECISION (N=134)

	Factor 1 Explana-tion & support	Factor 2 Making treatm-ent decision	Factor 3 Getting the diagno-sis	Factor 4 Length of wait
C16. Did the doctor or nurse clearly explain what these treatment options would involve?	.817			
C17. Did the doctor or nurse explain the possible side effects or consequences of these treatment options?	.795			
C18. Did the doctor or nurse clearly explain what could be done about the side effects?	.641	.318		
C28. Did the doctor or nurse give you the information about who to contact for advice or support (e.g. specialist nurse, patient support group, charity)?	.636			
C19. Did the doctor or nurse clearly explain why the other treatment options were not suitable for you?	.608	.358		
C24. Did the doctor or nurse involve you as much as you wanted in the decision about which treatment to have?	.591			
C6. Did the doctor or nurse clearly explain your diagnosis?	.511			
C25. Were you confident that the treatment decision was the best for you?	.475			
C27. Did the doctor or nurse tell you that you could change your mind about which treatment to have?		.826		
C26. After the treatment decision had been made did the doctor or nurse tell you that you could discuss your treatment decision again?		.803		
C22. Did the doctor or nurse encourage you to take your time before making a decision about which treatment to have?	.415	.520		
C13. Were you given any written information about your diagnosis?		.517		
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?		.473		
C9. Did the doctor or nurse clearly explain how aggressive the cancer was likely to be?	.349	.367		

C20. Did the doctor or nurse give you any written information about the treatment options / the possible side effects or consequences of the treatment options?		.360		
C7. Were you given your diagnosis in a considerate way?			.835	
C5. Did you have enough privacy when you discussed your diagnosis?			.809	
C3. How did you feel about the length of the time you had to wait to get your diagnosis?			.483	
C15.How did you feel about the length of time between being given your diagnosis and discussing your treatment options?				.754
C21. How do you feel about the length of time between being given your treatment options and discussing your treatment decision?				.697
C12. How did you feel about the length of time you had to wait to discuss your diagnosis with the specialist nurse?				.694

Rotation converged in 5 iterations

Set criteria, limited to 4 Factors (after inspecting scree plot)

SECTION D: TREATMENT AND DISCHARGE (N=50 TO 510)

	Factor 1: Preparation for discharge	**Factor 2: Treatment**	**Factor 3: Information**
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)?	.730		
D18. Were you given equipment or supplies (e.g. continence pads) to use at home to help you care for yourself?	.698		
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)?	.674		

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)?	.647		
D14. Did the doctor or nurse explain how well the treatment was going/had gone?	.606		
D20. Did a doctor or nurse organise the aftercare services that you needed (e.g. district nurse, physiotherapist)?	.605		.333
D9. Did you experience any problems with your hospital visit(s)?	.359		
D10.How would you rate: the treatment; the nursing; the food/drink; the ward (e.g. privacy, noise, cleanliness)?		.730	
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)?		.638	
D6. 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 treatment)?	.335	.526	
D23. Have staff in different places worked well together when caring for you for this condition: between GP's practice and hospital; between hospital and hospital; between different departments (e.g. Urology & Oncology)?		.505	
D5. How did you feel about the length of time you had to wait for your treatment to start?		.462	
D8. While you were receiving treatment were you able to discuss any concerns about your treatment with the doctor or nurse?	.314	.324	
D21. Did the doctor or nurse offer you any financial information on welfare or benefits?			.673
D19. Did a doctor or nurse discuss whether you might need any extra day to day help (e.g. help with housework)?			.660
D13. Did the doctor or nurse give you any information about complementary therapies (e.g. diet/diet supplements, acupuncture, massage, reflexology)?		.345	.571

D7.Were you advised that it might be helpful if someone (e.g. partner, relative) could go with you when you went for treatment?			.487

Rotation converged in 6 iterations.

Missing = pairwise

Set criteria: limited to 3 Factors (after inspecting scree plot)

SECTION E: MONITORING (N=280)

	Factor 1: Explanation & reassurance	**Factor 2: Advice**	**Factor 3: Choice**
E9. Does the doctor clearly explain what the test results mean?	.769		
E3. Did the doctor or nurse explain why you have these regular tests?	.706		
E8. Has the doctor or nurse clearly explained what can affect your PSA levels (e.g. exercise, ejaculation)?	.552	.338	
E5. Has a doctor or nurse reassured you that the length of the wait between these tests for prostate cancer is appropriate for you?	.528		
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)?		.860	
E11. Do you know how to get advice and help in managing symptoms or side effects of treatment (e.g. continence, problems with sex, pain)?		.785	
E12. Are staff in different places working well together when monitoring you for this condition: between GP's practice and hospital; between hospital and hospital; between different departments (e.g. Urology and Oncology)?	.403	.416	
E6. Have you been offered a choice of where to have these tests (e.g. GP's practice, hospital)?			.800
E7. Were you offered a choice of how to be given your test results (e.g. face-to-face, by telephone)?			.761

Rotation converged in 9 iterations.

Set criteria: eigenvalue>1

Table 6.8 Questions *not* included in any of the factors – PCQ-Pv3

C10. Did the doctor or nurse clearly explain whether or not the cancer had spread outside the prostate? *C11. After getting your diagnosis, did the doctor or nurse offer you the chance to talk to a specialist nurse?* *D11. At the hospital, were your spiritual needs met (e.g. appropriate food, prayer room)?* *D22. At the end of your treatment in hospital were you contacted by your GP's practice?*

Content validity was assessed qualitatively by comparing the factors that emerged from the Principal Components Analysis with the key themes identified in the literature review and interviews conducted at an earlier stage of the study (see Chapters 2 and 3 respectively). Table 6.9 shows the factors along with identified themes from the interviews and literature review.

Table 6.9 Content validity: Factors from Principal Components Analysis (PCA) of the patient questionnaire, and themes from interviews and literature review

Factors from PCA of patient questionnaire	Themes from interviews	Themes from literature review
Section A: GP VISITS & REFERRAL		
Factor 1: Explanation	Explanation of purposes of tests Awareness of being tested for prostate cancer Involvement in decision to be tested Informed of results Written information about results Informed of reason for referral	Knowledge/information/ communication
Factor 2: Referral	Explanation of reason they are being referred and for waiting time	-
Factor 3: Taking the problem seriously	Patient symptoms taken seriously by GP	-

Section B: TESTS AT THE HOSPITAL		
Factor 1: Explanation & support	Explanation of tests Care at biopsy	Knowledge/information/ communication Pain Support
Factor 2: Quality of care	Parking, appropriate rooms for tests, problems	Satisfaction with care
Factor 3: Appointment	Appointment times Invitation to carers to attend	Role of carer
Section C: DIAGNOSIS AND TREATMENT DECISION		
Factor 1: Explanation & support	Discussion of treatment options Support	Knowledge/information/ communication Treatment side effects Support
Factor 2: Making treatment decision	Involvement in the treatment decision Information and explanation about treatment decision Invitation to carers to attend	Knowledge/information/ communication Decision making Role of carer Relationship with healthcare professionals
Factor 3: Getting diagnosis	Diagnosis given considerately Sensitive communication Privacy	Knowledge/information/ communication Relationship with healthcare professionals
Factor 4: Length of wait	Anxiety while waiting for treatment to start	-
Section D: TREATMENT AND DISCHARGE		
Factor 1: Preparation for discharge	Explanation of success of treatment Arrangements for follow-up Follow-up care Information about where to get advice and support	Knowledge/information/ communication Self care; self help Support
Factor 2: Treatment	Wait to start treatment Being prepared for treatment and how it would be organised Practical issues, attending appointments, parking Coordination of care	Pain Satisfaction with care
Factor 3: Information	Invitation to carers to attend	Self care; self help Role of carer

	Practical information e.g. continence supplies	Complementary therapies
Section E: MONITORING		
Factor 1: Explanation & reassurance	Explanation of time period between monitoring visits Explanation of test results	Knowledge/information
Factor 2:Advice	Information about sources of advice and support Advice on managing side effects	Knowledge/information Treatment side effects Support
Factor 3: Choice	Choice of where to have tests and how to receive results of test(s)	-
THEMES NOT COVERED IN THE QUESTIONNAIRE		Coping/adjustment/ emotional reactions/ psychological distress/anxiety

It is evident that the aspects of care identified in the interviews and literature review are covered by questions in the PCQ-P v3, suggesting that the questionnaire has sound content validity. Only one issue identified in the literature review was not directly covered by the questionnaire – that of 'coping/adjustment/ emotional reactions/ psychological distress/anxiety'. However, this does not relate directly to patient experience of care, rather it is an outcome that could be influenced by experience of care along with a range of other factors, and would be expected to be included in a quality of life instrument for prostate cancer.

6.3.2.3 Criterion validity

A total of 592 patients returned both a completed prostate experience questionnaire and a completed NCSR questionnaire. Data were available

from 224 patients from hospitals 1 and 3 who completed sections A, B and C, and 368 patients from hospitals 2 and 4 who completed sections D and E. Characteristics of the responders are described in Table 6.10.

Table 6.10 Criterion validity - characteristics of patient responders

Age	**Number of patients (%)**
<55	12 (2.0)
55-64	142 (24.0)
65-74	245 (41.4)
75+	169 (28.5)
Overall health	**Number of patients (%)**
Very good	164 (27.7)
Good	267 (45.1)
Fair	123 (20.8)
Poor	15 (3.0)
Very poor	7 (1.0)
Ethnicity	**Number of patients (%)**
White British / Irish	551 (93.1)
South Asian	8 (1.0)
African / Caribbean	13 (2.2)
Other	0
Current situation	**Number of patients (%)**
Employed	120 (20.3)
Retired	430 (72.6)
Other	18 (3.0)
Current or most recent occupation	**Number of patients (%)**
Professional	150 (25.3)
Managerial	124 (20.1)
Clerical	25 (4.0)
Technical / craft	109 (18.4)
Manual / service	114 (19.3)

Criterion validity was assessed through comparing section scores of PCQ-Pv3, with scores derived from the NCSR short questionnaire. It was not possible to check the criterion validity of Section A of the prostate experience questionnaire as the short NCSR questionnaire did not include evaluative questions about the aspects of care relating to GP consultation and referral included in the PCQ-Pv3. Section scores for the PCQ-Pv3 were calculated as described above. Scores for the NSCR were calculated by recoding to produce binary responses indicating whether the respondent experienced a problem with each aspect of care (Prescott, 2004), then summing the number of 'problems' reported. Scores for each questionnaire were only calculated for respondents who had completed at least 50% of the questions. Criterion validity is reported as the Pearson correlation between the score derived across the first half of the PCQ-Pv3 (combining the scores of sections B and C), or the second half (combining the scores of D and E), and a similar single score derived from across the corresponding NCSR questionnaire (adding up the number of problems reported). A negative correlation is expected as a larger PCQ-Pv3 score represents a more positive experience, whereas a larger NCSR score represents a greater number of problems.

Table 6.11 Criterion validity: - Correlation between scores obtained by the PCQ-Pv3 and scores of the short NCSR questionnaire

	Correlation: Pearson's r; *p value* (N)
Combined score Sections B&C *by* 1st half NCSR	-0.23 p=0.002 (175)
Combined score Sections D&E *by* 2nd half NCSR	-0.46 p<0.001 (201)

Table 6.11 shows a small but significant negative correlation between the scores from the first half of PCQ-Pv3 and the scores from the first half of the NCSR questionnaire. There is a moderate negative correlation, which is also significant, between scores from the second half of PCQ-Pv3 (sections D and E) and scores from the second half of the NCSR questionnaire. Correlations between the scores on each instrument are not high, but this is likely to reflect the fact that, although the two questionnaires aim to measure patient experience, they include questions on different issues. In particular, some of the issues included in PCQ-Pv3 are not addressed in the short NCSR questionnaire. Hence, correlations would not be expected to be large. However the correlations indicate that scores obtained by the two instruments tend to be in the predicted direction, and of similar magnitude, which supports the argument that the questionnaires are measuring broadly the same issue: that of patient experience of care. These findings provide some support for the validity of the prostate experience questionnaire.

6.3 3 Reliability

6.3.3.1 Internal consistency

Internal consistency reliability was assessed using the data from the first mailing in all 5 hospitals, including 865 responders (data were available from 355 responders for Sections A, B and C, and 510 responders for Sections D and E). Characteristics of the responders are described in Table 6.10 (above). Alpha was calculated for the final set of questions used in calculating the overall section score for each section. Due to missing values in section D, the number of cases included in the calculation of the

Cronbach's alpha was small.

Table 6.12 shows Cronbach's alpha for each section of the questionnaire. Alpha scores for each section are all above 0.6, indicating that each section has satisfactory internal consistency, and this supports the use of overall section scores as a summary measure of responses in each section.

Table 6.12 Internal consistency reliability: Cronbach's alpha for each section of the patient questionnaire

	Cronbach's alpha *(N)*
Section A	0.80 *(204)*
Section B	0.63 *(240)*
Section C	0.77 *(134)*
Section D	0.65 *(34)*
Section E	0.68 *(280)*

6.3.3.2 Test-retest reliability

A total of 148 patients returned completed questionnaires on both the first and second occasion. Seventy-nine patients from hospital 1 returned Version 3.2 on both occasions, and 69 from hospital 2 returned Version 3.3 on both occasions. The characteristics of responders are given in Table 6.13 below.

Table 6.13 Test retest reliability - characteristics of patient responders

Age (years)	**Number of patients (%)**
<55	2 (1.3)
55-64	36 (24.3)
65-74	61 (41.2)
75+	45 (30.4)
Overall health	**Number of patients (%)**
Very good	46 (31.1)
Good	63 (42.6)
Fair	32 (21.6)
Poor	2 (1.3)
Very poor	0
Ethnicity	**Number of patients (%)**
White British / Irish	137 (92.6)
South Asian	1 (1.3)
African / Caribbean	3 (2.0)
Current situation	**Number of patients (%)**
Employed	23 (15.5)
Retired	110 (75.3)
Other	8 (5.4)
Current or most recent occupation	**Number of patients (%)**
Professional	35 (23.6)
Managerial	26 (17.6)
Clerical	5 (3.4)
Technical / craft	29 (19.6)
Manual / service	28 (18.9)

Test-retest reliability was assessed using two measures: firstly, percentage agreement, i.e. the extent to which individual questions were answered in the same way on the first and second mailing; and secondly, correlation between overall section scores on the first and second mailing.

The mean (and median) percentage agreement for the whole sample (considering the questions with an experience element within each section), for the whole sample, is reported in Table 5.14. Sixty % of the questions of Section A, 76.9% of Section B, 86.9% of Section C, 87.1% of Section D and 50% of Section E achieved levels of agreement of 80% or higher. The mean percentage agreement for each section is over 80% for all sections, and over 90% for section D (treatment and discharge). This means that, on average, respondents gave exactly the same response on the first and second mailing for over 80% of the questions in each section.

Table 6.14: Test-retest reliability: Mean percentage agreement scores for each section of the PCQ-Pv3

	Mean percentage agreement, *st dev, min- max (N)* *median*
Section A	83.69 *12.11, 53.85-100.00 (64)* *85.71*
Section B	84.16 *10.82, 54.17-100.00 (78)* *85.19*
Section C	86.79 *15.25, 33.33-100.00 (63)* *90.91*
Section D	90.70 *9.77, 55.56-100.00 (69)* *93.75*
Section E	81.20 *16.80, 37.50-100.00 (58)* *85.71*

The second approach to assessing test-retest reliability involved calculating the correlation between respondents' overall sections scores on the first and second mailing. Table 6.15 shows the mean score for each section on the

first and second mailing, and the Pearson correlations and Intraclass correlations (ICCs) between respondents' scores for each section on the first and second mailing. Pearson correlation coefficients and ICCs were similar, and all relatively large, between 0.57 and 0.74, falling within the acceptable range identified by Pasta and Suhr (2004). The correlations were significant for all 5 sections of the questionnaire. This finding indicates satisfactory test-retest reliability.

Table 6.15 Test-retest reliability: Mean section scores on the first and second mailing, and correlation between section scores for each section of the PCQ-Pv3

	1st mailing mean score, *st dev, min, max (N)*	**2nd mailing** mean score, *st dev, min, max (N)*	**Correlation** Pearson's r, *p value* (N)	**Intra Class Correlation Coefficient (ICC)** (95% C.I.)
Section A	69.14 *19.57, 11.54-100 (60)*	68.50 *18.65, 16.67-100 (62)*	0.68 *p<0.001 (58)*	0.68 (0.52-0.80)
Section B	84.43 *15.31, 28.48-100 (73)*	81.27 *10.58, 39.74-99.37 (72)*	0.61 *p<0.001 (69)*	0.57 (0.39-0.71)
Section C	88.43 *11.97, 55.00-100 (62)*	87.62 *13.10, 31.25-100 (63)*	0.61 *P<0.001 (53)*	0.61 (0.40-75)
Section D	73.21 *17.13,27.68-99.26 (48)*	74.80 *14.46, 41.35-100 (49)*	0.74 *p<0.0001 (44)*	0.73 (0.56-0.84)
Section E	74.33 *21.92, 16.67-100 (61)*	74.88 *19.71, 18.75-100 (60)*	0.71 *p<0.001 (58)*	0.70 (0.54-0.81)

6.3.5 Section scores: results from the 5 hospitals

Section scores of PCQ-Pv3 were calculated for each participating hospital, and are presented here in Table 6.16. The section scores were calculated based on all the questions which had been retained in the factor analysis (these are listed in table 6.2). In addition, scores have been calculated for each factor within each section, using the questions retained in the principal components analysis (see table 6.7) with the exception that in calculating the score for Factor 3 of section B, question B3 was omitted as this question was found to have a negative loading on the factor. Factor scores were produced simply by adding scores on each question in the factor, and did not incorporate the item loadings. Table 6.16 shows the mean score for each section, and each factor within sections, by hospitals. Significant differences between hospitals' scores are indicated (based on results of one-way ANOVA and Tukey's HSD tests). If the questionnaire is to be used for quality improvement, hospitals may find it useful to have these summary scores, as well as having simple frequency data indicating the number of patients who have answered each question in a positive or negative way.

Table 6.16 Summary section scores on the PCQ-Pv3, by hospital

Section and scales within sections		N	Mean score	Standard deviation	F value for difference between means for individual hospitals (p value)
score for Section A	Hospital 3	83	63.3	19.9	1.71 (0.18)
	Hospital 5	98	68.9	22.4	
	Hospital 1	126	65.2	20.7	
	Total	*307*	*65.9*	*21.1*	
Section A factor 1 explanation	Hospital 3	78	80.0	24.6	0.85 (0.56)
	Hospital 5	88	83.9	23.0	
	Hospital 1	113	81.1	24.6	
	Total	*279*	*81.7*	*24.1*	
Section A factor 2 referral	Hospital 3	84	24.0[a]	25.8	4.79 (0.009)
	Hospital 5	96	37.5[a]	32.9	
	Hospital 1	127	28.8	30.5	
	Total	*307*	*30.2*	*30.4*	
Section A factor 3 picking up problem	Hospital 3	86	88.1	25.7	1.23 (0.29)
	Hospital 5	98	92.6	19.1	
	Hospital 1	134	92.2	20.7	
	Total	*318*	*91.2*	*21.7*	
score for Section B	Hospital 3	85	79.9	14.3	1.86
	Hospital 5	103	83.8	13.0	(0.16)
	Hospital 1	140	82.6	14.5	
	Total	*328*	*82.3*	*14.0*	
Section B factor 1 explanation	Hospital 3	83	78.4	23.1	2.49 (0.08)
	Hospital 5	97	83.9	19.4	
	Hospital 1	134	84.6	19.8	
	Total	*314*	*82.7*	*20.7*	

Section B factor 2 quality of care	Hospital 3	84	79.5[a]	13.1	5.77 (0.003)
	Hospital 5	103	85.8[a,b]	12.0	
	Hospital 1	140	83.0 [b]	12.6	
	Total	*327*	*83.0*	*12.7*	
Section B factor 3 appointment	Hospital 3	84	89.3	20.6	6.06 (0.003)
	Hospital 5	103	94.7	17.0	
	Hospital 1	140	85.4	22.8	
	Total	*327*	*89.3*	*20.9*	
score for Section C	Hospital 3	80	83.8	13.7	2.01
	Hospital 5	95	87.1	13.4	(0.14)
	Hospital 1	117	87.5	13.2	
	Total	*292*	*86.4*	*13.4*	
Section C factor 1 explain/involve	Hospital 3	79	89.4	15.1	1.54 (0.22)
	Hospital 5	93	89.6	16.8	
	Hospital 1	118	92.6	12.4	
	Total	*290*	*90.8*	*14.7*	
Section C factor 2 treatment decision	Hospital 3	80	69.8	27.0	2.48 (0.09)
	Hospital 5	96	77.1	22.9	
	Hospital 1	121	77.1	25.8	
	Total	*297*	*75.1*	*25.4*	
Section C factor 3 diagnosis	Hospital 3	80	89.4[a]	21.3	5.88 (0.003)
	Hospital 5	98	96.3[a,b]	10.4	
	Hospital 1	125	89.5 [b]	16.7	
	Total	*303*	*91.7*	*16.7*	

Section C factor 4 length of wait	Hospital 3	80	93.5	18.8	0.68 (0.51)
	Hospital 5	95	94.9	19.2	
	Hospital 1	122	96.5	15.3	
	Total	*297*	*95.2*	*17.6*	
score for Section D	Hospital 5	61	71.6	14.0	4.72
	Hospital 2	127	73.8[a]	14.8	(0.01)
	Hospital 4	116	67.6[a]	18.1	
	Total	*304*	*71.0*	*16.2*	
Section D factor 1 discharge	Hospital 5	63	83.5[a]	17.6	4.27 (0.02)
	Hospital 2	126	83.5[b]	19.8	
	Hospital 4	115	76.0[a,b]	25.2	
	Total	*304*	*80.7*	*21.8*	
Section D factor 2 treatment	Hospital 5	65	90.1	11.2	0.28 (0.76)
	Hospital 2	133	90.8	12.9	
	Hospital 4	122	89.5	15.1	
	Total	*320*	*90.2*	*13.4*	
Section D factor 3 practical information	Hospital 5	61	26.8 [a]	25.3	4.73 (0.01)
	Hospital 2	126	36.8 [a,b]	26.9	
	Hospital 4	116	27.0 [b]	29.0	
	Total	*303*	*31.0*	*27.8*	
score for Section E	Hospital 5	93	75.1[a]	20.2	7.84
	Hospital 2	171	74.3 [b]	20.4	(0.000)
	Hospital 4	195	66.9 [a,b]	20.6	
	Total	*459*	*71.3*	*20.8*	

Section E factor 1explanation	Hospital 5	93	80.5	21.8	0.81 (0.44)
	Hospital 2	171	77.6	22.0	
	Hospital 4	197	77.1	22.3	
	Total	*461*	*77.9*	*22.1*	
Section E factor 2 advice	Hospital 5	91	91.0[a]	20.0	20.68 (0.000)
	Hospital 2	165	89.5[b]	20.4	
	Hospital 4	184	74.6[a,b]	30.3	
	Total	*440*	*83.6*	*26.1*	
Section E factor 3 choice	Hospital 5	93	42.5	39.7	3.59 (0.03)
	Hospital 2	166	47.3 [a]	41.7	
	Hospital 4	195	35.9 [a]	39.9	
	Total	*454*	*41.4*	*40.7*	

a,b Means with the same superscript differ significantly from each other at $p<0.05$. Other differences are not significant

It is notable that certain factors in sections tended to have higher mean scores than others (e.g. Section C factor 4 compared to Section A factor 2). This makes it more difficult to compare performance across factors or sections. The results in table 6.16 provide a guide for hospitals in assessing their performance against expected scores. As an example of how these results could be displayed in a comparison between hospitals, Figures 6.2 to 6.5 show scores for each hospital on Section D, and each factor within section D. For the purposes of this thesis these charts are shown with the full y axis (on a scale of 0-100), however this makes small differences between hospitals difficult to identify. For reporting purposes, hospitals may prefer to use a truncated axis (for example with a scale of 50-100).

Figure 6.2 Mean score for Section D by hospital

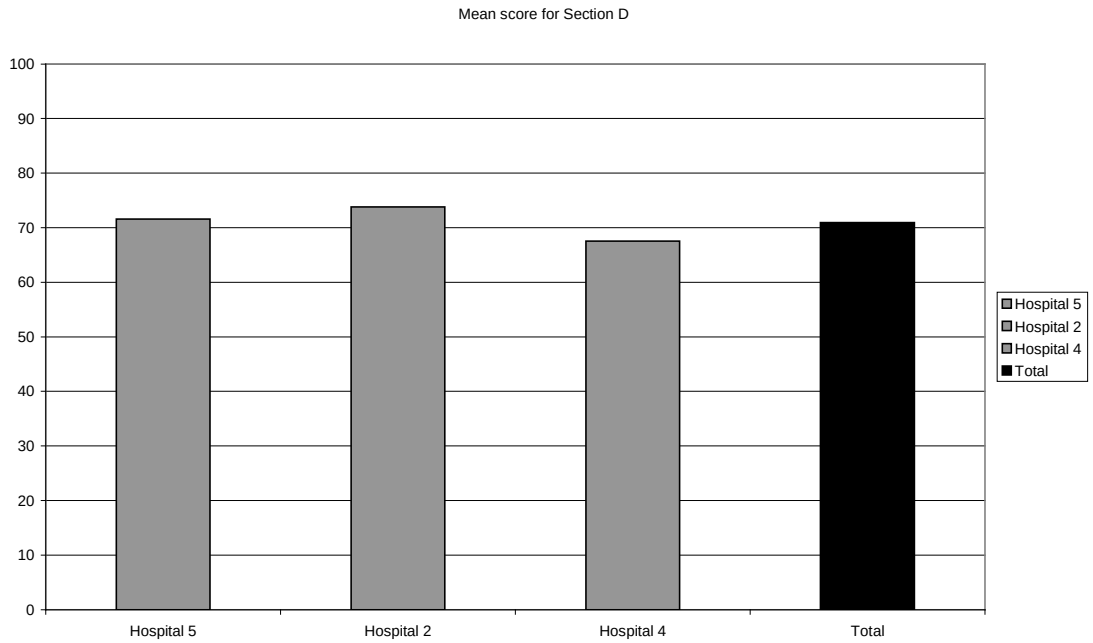


Figure 6.3 Mean score for factor 1(discharge), by hospital

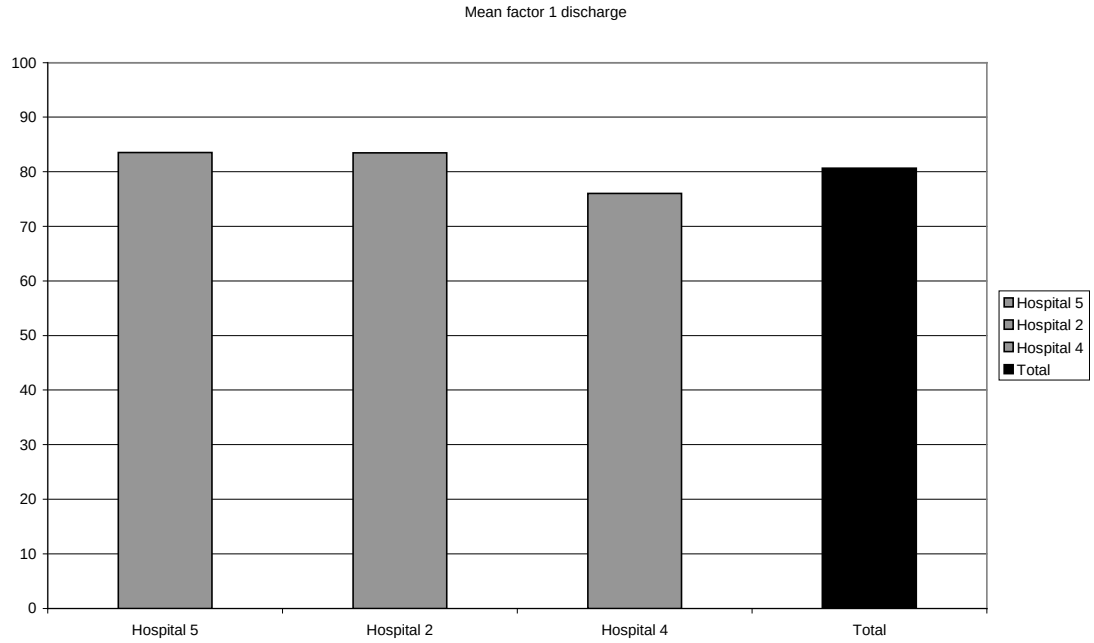


Figure 6.4 Mean score for factor 2 (treatment), by hospital

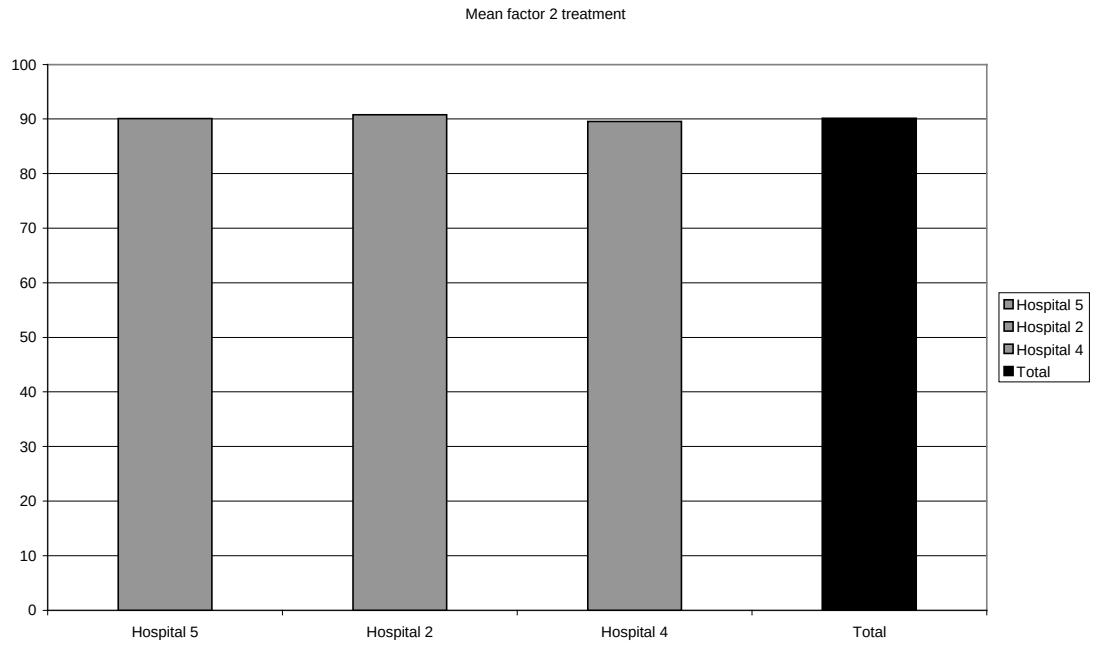
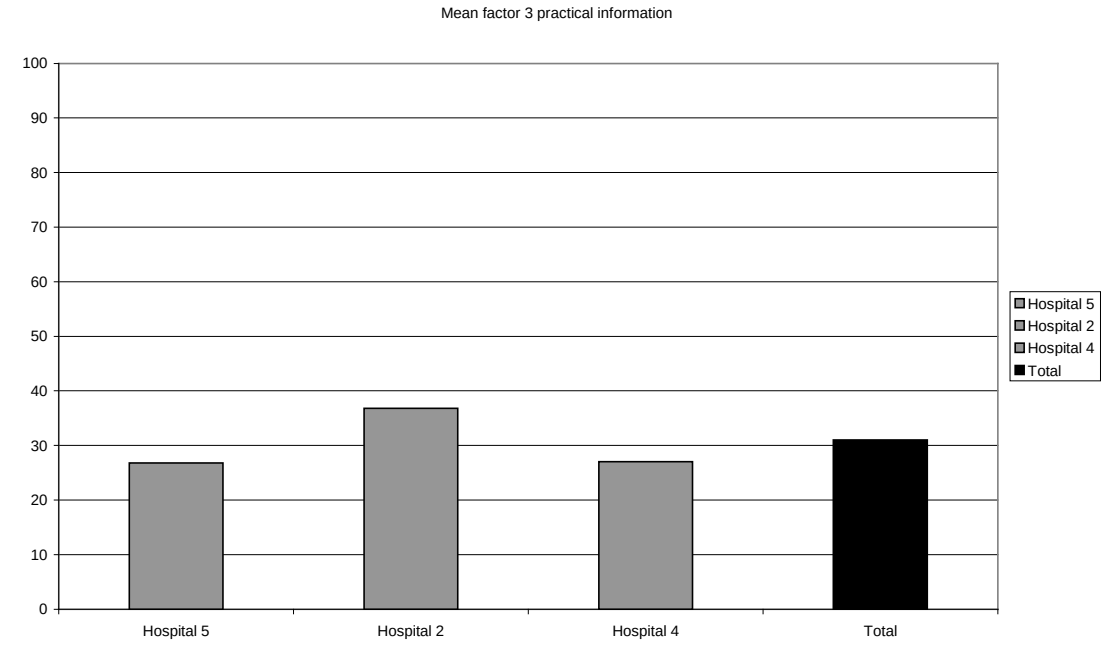


Figure 6.5 Mean score for factor 3 (practical information), by hospital



6.4 Discussion

In this Chapter a series of inter-related studies that have sought to investigate the psychometric properties of the questionnaire (PCQ-Pv3) have been presented. Users of the questionnaire need confidence that the findings they obtain can be relied on to draw attention to aspects of patient experience that need improvement and to accurately assess the impact of initiatives to improve patient experience. The findings are reassuring in this respect. The PCQ-Pv3 has satisfactory reliability. Tests of validity likewise produced positive findings.

It should be noted that in Section D of PCQ-Pv3, several of the questions about provision of equipment and supplies, the organisation of aftercare services, and contact by GP, were answered as 'not applicable' by many responders. This resulted in the number of cases included in the calculation of Cronbach's alpha to be low (34). These are important issues and should be retained in the full questionnaire. However, the calculation of overall section scores allows for some missing data, and statistical analysis shows the score for Section D to have good reliability and validity.

Response rates to the questionnaire were generally satisfactory. Because hospitals do not consistently retain demographic details of patients, information on non-responders was not available.

The calculation of section and sub-section scores was relatively straightforward and could readily be included in any software package

developed to accompany the measure. The scores provide a summary estimate of experience that could be useful in comparing hospitals. When scores are low, detailed review of responses to individual questions should guide the hospital to aspects of care that need improvement. The components identified by Principal Components Analysis matched very closely the issues identified in our preliminary studies (see Chapter 2) as important to patients and their carers. It is important to emphasise that a consistent theme runs through the components, and is highlighted by the titles assigned to them. Each section of the measure contains factors or components relating to the inter-related concerns of information, explanation and involvement. This finding may suggest what the principal focus of efforts to improve patient experience of prostate cancer care should be.
Because no other measure existed of patients' experiences of prostate cancer care it was difficult to identify a suitable questionnaire to test the construct validity of the draft questionnaire. The NCSR questionnaire we selected did cover some of the same care domains but was a generic cancer questionnaire rather than one specifically designed for patients with prostate cancer.

However, there are some limitations to the testing reported in this chapter. Because no other measure existed of patients' experiences of prostate cancer care it was difficult to identify a suitable questionnaire to test the construct validity of the draft questionnaire. The NCSR questionnaire we selected did cover some of the same care domains but was a generic cancer

questionnaire rather than one specifically designed for patients with prostate cancer.

Questionnaires may also be tested for sensitivity to change. Sensitivity refers to “the proportion of actual cases who score as positive cases on a measurement tool” and sensitivity to change is “the ability of the gradations in the scale’s scores adequately to reflect actual changes“ (Bowling 2002). Testing PCQ-Pv3 for sensitivity to change would measure the extent to which scores on sections of the questionnaire are responsive to changes in care. However, it is not clear if changes in care (such as a change in type of treatment, or a change of staff caring for the patient) would have an impact on reported patient experience scores (i.e. for there to be a corresponding change in the score when there is a new experience of care). Furthermore, there are parts of the questionnaire where it would not be possible to test for sensitivity, for example the initial visit to the GP is not a phase of care that can be repeated. Consequently, PCQ-P was not tested for sensitivity to change.

Chapter 7: Preparing the final version of the questionnaire

In this chapter I will describe the piloting of the questionnaire and the final revisions made.

7.1. Redrafting the questionnaire: from PCQ-Pv3 to PCQ-Pv4

7.1.1 Introduction

The questionnaire used in the testing phase described in Chapter 6 was redrafted to ensure that any potentially poorly discriminating, confusing, or unnecessary questions were removed. The questionnaire was revised so that it would be suitable for use with a range of sub-groups of patients with prostate cancer and within local settings.

7.1.2 Methods

The questionnaire was reviewed and changes made as a result of testing the questionnaire for reliability, validity and sensitivity in the five hospitals as described in Chapter 6. The distribution of responses for each question was examined from all five of the hospitals and those responses that showed little variation were revised or eliminated. The comments that were made by patients during interviews to check the validity of the questionnaire were used to review and inform the questionnaire. Any questions that required clinical knowledge were referred to the three clinicians on the research team for their advice.

7.1.3 Results

The questions in PCQ-Pv3 were revised and the changes are summarised in Box 7.1 and Box 7.2 below:

Box 7.1: Changes made to the number of questions in PCQ-Pv3

Section A: The first time you saw the doctor or nurse about your possible prostate problem (20 questions in v3, reduced to 17 questions in v4)

Section B: Having tests for possible prostate cancer at the hospital (19 questions in v3, increased to 20 questions in v4)

Section C: Getting the diagnosis and making the treatment decision (30 questions in v3 stayed as 30 questions in v4)

Section D: Your treatment (26 questions in v3, reduced to 25 questions in v4)

Section E: Monitoring (checking) you (15 questions in v3 stayed as 15 questions in v4)

Section F: About you and your health (12 questions in v3, reduced to 10 questions in v4)

Box 7.2: Summary of changes made to the questions in PCQ-Pv3

1. The order of the questions was changed to improve the flow of the questionnaire and to reflect how patients would move through the system (e.g. question C8 “Were you diagnosed with prostate cancer?” was moved to follow the question “Did you have enough privacy when you discussed your diagnosis?” and before the question on “Were you given your diagnosis in a considerate way?”

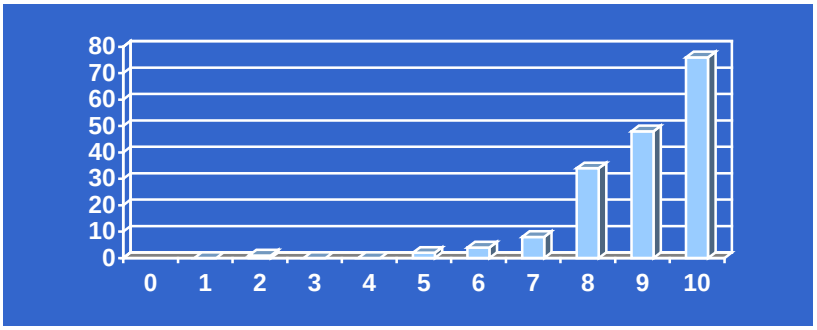
2. Some of the questions that had sub-sections were revised into one question to ensure that they were easier to understand (e.g. question A6 “Did the doctor or nurse explain: a) how the DRE test would be carried out?; b) that the PSA test is not always reliable?” was changed to “Were you given information about being tested for prostate cancer (e.g. what the tests would involve)?”

3. The overall care questions at the end of each of the sections were deleted (e.g. “How would you rate the quality of care provided by your hospital when you got your diagnosis?”) as they did not produce useful data (little or no discrimination in responses given).

The possibility of providing 'overall' scores was explored to enable hospitals to readily compare their results with others. However, the 'overall' questions on the quality of care attracted uniformly positive responses and were insensitive to variations in care. For example:

B19. Overall, how would you rate the quality of care provided by your hospital during this stage of testing?

The frequency of responses for each number on 0-10 scale (n=173) is shown in the bar chart that follows:



The notes taken in validity interviews confirmed that patients gave high scores in spite of reporting negative experiences (e.g. score of 10 given by patient on B19 who reported "…too much delay in picking up prostate cancer". ". This finding reflects the tendency of simple satisfaction questions to attract uniformly positive responses.

In addition to the change in the questions, the sections themselves were reconfigured to allow them to be tested at three different hospitals. The PCQ-Pv3 consisted of six sections that had been organised into three separate questionnaires for testing purposes (Version 3.1 consisting of all six sections, Version 3.2 consisting of sections A, B, C and F and Version 3.3 consisting of sections D, E and F). For the purpose of testing all the sections of the new version of the questionnaire, PCQ-Pv4, (see Appendix 11), the sections were reconfigured into three new questionnaires, called 4.1, 4.2 and 4.3. This kept the questionnaires to a length (24 -40 questions) that patients would be able

to complete and focused on two consecutive phases of the care pathway. The three new questionnaires are outlined in Table 7.1 below.

Table 7.1 The new PCQ-Pv4 questionnaires

PCQ-Pv4
Questionnaire 4.1 Section A: initial presentation/investigation Section B: tests at the hospital Section F: about the patient
Questionnaire 4.2 Section C: diagnosis and making the treatment decision Section F: about the patient
Questionnaire 4.3 Section D: treatment Section E: monitoring Section F: about the patient

7.1.4 Discussion

The tests for validity, reliability and sensitivity to change that were carried out and described in Chapter 5 demonstrated that the questionnaire (PCQ-Pv3) displayed many of the qualities necessary for an instrument designed to capture the experiences of care of men with prostate cancer. However, the tests also showed that there was a need to redraft parts of the questionnaire to produce a version ready for a final round of piloting. This version, PCQ-Pv4, was slightly shorter than its predecessor, with five fewer questions, and had some changes to the order of the questions to improve the flow. A significant change was the removal of the overall quality of care questions that had failed to produce any useful data because of little or no discrimination in

the responses given. These questions were replaced with an open question inviting patients to make any positive or negative comments they wished about the care received.

The new questionnaire was divided into three sections as described above and was now ready for piloting.

7.2 Final piloting of the questionnaire

7.2.1 Introduction

This section will describe how the questionnaire was prepared for use in local service settings, based on the principle that the questionnaire should be usable and provide meaningful findings without researcher support. The work already undertaken in the piloting of the questionnaires (see Chapter 5) and the testing of the questionnaire for validity and reliability (see Chapter 6) will form the foundation for this stage.

7.2.2 Methods

For this stage of the study we recruited urology or oncology consultants in three hospitals who were willing to independently undertake a survey of around 100 prostate cancer patients from their hospital, using the PCQ-Pv4 questionnaire. The three hospitals were recruited via the Service Improvement Leads (SILs) at the Cancer Networks. The National Manager for Urology contacted the SILs at all the Cancer Networks to ask them to identify hospitals within their network that would be willing to take part in this

stage of the study. A list of interested hospitals with their specific contact details was collated, and the three hospitals were identified and chosen from the list for their geographical diversity and differing patient populations (one hospital in the east of England withdrew and was replaced by one from the West Midlands which reduced the geographical diversity). The questionnaire was split into three sections (see Table 7.1), and the hospitals were asked to each choose a different section to administer. It was suggested to each hospital that they surveyed 100 patients, but that they could increase or decrease this number depending on their situation.

A preliminary visit was made to each hospital to explain the process of carrying out the survey. Hospitals requested that the questionnaires already be placed in envelopes ready to be posted to patients or handed out in clinics. Research governance approval was applied for and given at each of the hospitals. After the survey had been completed at each hospital, members of staff were interviewed who had been involved in piloting the questionnaire. An interview topic guide was developed which drew on the earlier experience of piloting the questionnaire in hospitals and is summarised in Box 7.3 below.

During the interviews the interviewer took notes of the interviewee's comments and made the suggested amendments to a copy of the questionnaire.

Box 7.3 Summary of the interview schedule for interviews with hospital staff

Reviewing their experience of administering the questionnaire and discussing ideas for improvement

1. Questionnaire: are there any comments you would like to make about the content and format of the questionnaire (e.g. questions that were not clear, length of the questionnaire)?

2. Administration of the questionnaire: how did you distribute the questionnaire; what do you think of the response rate; did you have any difficulties administering the questionnaire; would you rather it be administered by an independent body; what are staff's attitude to questionnaires about patient experience; would the findings be used to review and change practice?

3. Additional comments: is there anything else you would like to add regarding any aspect of the questionnaire/administration*?

*Feedback was also sought on a User Guide and software developed to aid the use of the questionnaire and enter data respectively. However, this thesis reports solely on the development of the questionnaire and so the development and review of these tools are outside its remit.

7.2.3 Results

The three hospitals administered the version of the questionnaire that they were provided with to patients who had been tested or diagnosed with prostate cancer. All the hospitals posted the questionnaires to patients from their current lists, going back up to one year from time of diagnosis. One of the hospitals also handed questionnaires to patients attending Urology Clinics. Hospitals were encouraged to send a reminder letter to non-responders, and Hospitals 2 and 3 did so. The number of questionnaires distributed and returned is summarised in Table 7.2.

Table 7.2 Numbers of questionnaires distributed by hospitals and completed and returned

	Questionnaire	Number of questionnaires distributed	Number of questionnaires completed and returned (%)
Hospital 1: South West England	4.1	100	65 (65)
Hospital 2: South of England	4.2	82	40 (49)
Hospital 3: West Midlands	4.3	100	52 (52)

The piloting was undertaken to gain feedback from staff administering the questionnaire. Consequently, while the response rates and results of the questionnaires were of interest to the hospitals they fell outside the purpose of the piloting and so are not reported on here.

Five interviews were conducted with both clinical and administrative staff from the three hospitals, and their comments and suggestions are summarised below.

Content

a) Some of the questions should have words added or removed from them to make them clearer. For example, in question B4 it was suggested that the phrase “by your GP” be added to clarify who the question was referring to.

b) The language in some of the questions could be modified to make them clearer. For example, in question B7 it was suggested that it

would be clearer if the answer option was changed from “cost” to “too expensive”. This would be make it clear that the problem with parking at the hospital was the tariff charged for visitors.

c) Those questions that had several parts to them should be made clearer by labelling the parts a, b, c etc. For example, in question B8 “How would you rate the hospital facilities?” the facilities listed (waiting room, availability of refreshments, toilets, rooms where the tests were carried out) had letters a, b, c, d inserted in front of them to make it clearer that each one should be answered.

Format

a) The title of the questionnaire on the cover used the word cancer which was inappropriate for those patients who had only been tested for prostate cancer. The suggestion was to remove the word “cancer” and replace it with “care”.

b) The sections were identified as A, B, C etc. which did not help the responder to know what the questions were about. It was suggested that putting the titles in the section headings so that Section B would be supplemented with “Having tests for possible prostate cancer at the hospital” would make it clearer and help to prevent patients from completing sections in error.

c) Filter questions that routed respondents from a question in one section to the start of a new section denied them the opportunity to record any of their health care experiences in the open text question at the end of each section. It was suggested that in order to capture

this potentially valuable information they be routed to that question at the end of the section.

Administration: distribution of the questionnaire and response rate

a) Two methods of distributing the questionnaire packs, by post and by hand in Urology Clinics, were used and no problems were reported.

b) It was suggested that before administering the questionnaire, there is a need for a group meeting of all healthcare professionals involved to discuss and to ensure that administration staff are informed in advance.

c) It was reported that compiling a list of patients who have been diagnosed with prostate cancer and have not died recently is time consuming, unless there is a database that contains all of this information.

d) There were different opinions about the best method of distributing the questionnaire. Some staff felt that handing out the questionnaires in clinic and also possibly having someone help the patients fill in the questionnaire would improve the response rate. Others felt that a postal distribution of the questionnaire would work better as it is easier to control and manage, ensuring that the questionnaire is going to the right person at the most appropriate time.

Administration: practical issues when administering the questionnaire

a) Providing support for hospitals to carry out the questionnaire survey was suggested as a more effective way of ensuring its successful administration than financial incentives.

b) Some felt that having the questionnaire administered by an independent body would be helpful, others were not sure whether this would help as they felt that the independent body would find it hard to access patient details to compile lists of patients.

Administration: implementation of the findings

a) Some staff were reported as being indifferent to the findings of questionnaires on patient experiences. Others stated that staff attitudes were quite positive and they (particularly the doctors) are keen to use them and were interested in the results.

b) The way in which the proposal to undertake a patient survey is presented to staff can influence their attitude. There may be some scepticism if it is seen as imposed and compulsory, and will not be welcomed.

c) The questionnaires were useful tools that can be used alongside other data when considering service re-design and possibly linked in with other cancer measures.

d) Support will be needed to implement the changes planned in response to the findings of the questionnaire.

7.2.4 Discussion

Piloting the questionnaire in the three hospitals proved a valuable stage in the development of the questionnaire. Hospital staff were able to use the questionnaire with their patients independently, and so were then in a position to provide feedback from first-hand experience. The staff involved highlighted a number of issues to address, particularly concerning the administration of the questionnaire. The process of revising the questionnaire is described in Chapter 7.3 below.

7.3 Final revision of the questionnaire

7.3.1 Introduction

This section describes the process of revising the questionnaire for the final time to produce PCQ-P. The revisions are based on the piloting carried out by the three hospitals described in Chapter 7.2.

7.3.2 Methods

The questionnaire was reviewed in the light of the queries from the hospitals while they were using the questionnaire and the interviews of hospital staff after they had completed its administration. The comments and suggested changes to the layout, instructions, headings and questions in the questionnaire were noted during the interview, and then discussed by the research team until consensus was reached.

7.3.3 Results

The questionnaire was modified, and the types of changes made are summarised below (see Box 7.4).

Box 7.4 Changes made to the PCQ-Pv4

1. Making the purpose of the questionnaire clearer (e.g. simplifying the title of the questionnaire, making the instructions clearer)

Title of PCQ-Pv4 of questionnaire:

MEASURING PROSTATE CANCER EXPERIENCE

YOUR VIEWS ABOUT YOUR HEALTH CARE

Title of final version of the questionnaire:

THE PROSTATE CARE QUESTIONNAIRE FOR PATIENTS (PCQ-P)

2. Clarifying the questions (e.g. being more precise about which care episode is being referred to)

PCQ-Pv4 Section B Question 4

How long did you wait between the date you were referred and the date of your first appointment for tests at the hospital?

Changed to:

How long did you wait between the date you were referred by your GP/Assessment Centre and the date of your first appointment at the hospital?

3. Making the response options clearer (e.g. adding response options to capture patients' experiences more accurately, putting questions with subsections in tables and labelling them)

PCQ-Pv4 Section D Question 19

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 care for yourself?

Yes □ No □

Changed to:

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 care for yourself?

Yes □ No □ I did not need any □

4. Making the questionnaire easier to use (e.g. changing the order of the questions to better reflect the events in the patient pathway, using the same wording for all questions covering the same issue across different sections)

Question A4 (in PCQ-Pv4) moved to become Question 8 (in PCQ-P), to allow patients to answer questions about information and explanation of PSA and DRE tests before answering whether they had the test.

7.3.4 Discussion

The purpose of the piloting of the questionnaire PCQ-Pv4 described above was to prepare it for use in the NHS. The questionnaire was revised as result of its use in the three local service settings and the changes made reflect the lessons learnt. This was the final stage in the thorough and lengthy development of the questionnaire and has resulted in a final version users may be confident reliably measures the important aspects of patients' experience of prostate cancer care. It is ready for use with patients tested for, or diagnosed with, prostate cancer. To reflect this, the questionnaire is called:

The Prostate Care Questionnaire – Patients and abbreviated to **PCQ-P**

A copy of the questionnaire can be found in Appendix 12.

In terms of reporting the results of the questionnaire for quality improvement purposes, overall summary scores can be produced as well as detailed frequency counts for each individual question. Scores for each of the sub-

factors identified for each section can also be produced. These summary scores, accompanied by the detailed frequency data should make it easy to identify specific problem areas. The process of scoring the questionnaire is explained in full in Appendix 13.

Considerable flexibility on using the questionnaire has been built in for users. The questionnaire can be used in its entirety to measure patients' experience of prostate cancer care from initial consultation to monitoring post treatment. However, as this may involve patients recalling experiences over many months or even years this may be problematic. Users of the questionnaire may therefore choose to focus on specific phases of care that they wish to investigate by selecting the appropriate sections from the questionnaire (i.e. initial consultation; tests at the hospital; diagnosis and treatment decision; treatment; monitoring). These sections can be used individually or together in combinations, but should always include Section F, About You which provides valuable demographic data. The measure can also be used in a variety of ways, for example as a tool for reviewing service delivery in a hospital, or to conduct regional or national surveys for comparisons between hospitals or to establish benchmarks for prostate care.

Chapter 8: Discussion

This study was designed to develop a measure of patient experience of prostate cancer care. In this chapter I will discuss the study design, the use of the questionnaire, and issues for further research.

8.1 Introduction

It is clear from a number of NHS documents (NHS Cancer Plan 2000, Cancer Reform Strategy (Department of Health, 2007) Prostate Cancer Risk Management Programme (PCRMP) (Department of Health, 2009b) that the policy direction of NHS cancer care has, for some time, been firmly towards the establishment of patient-centred care. This has also been reflected in the recent NICE guidelines on the diagnosis and treatment of prostate cancer, where page 2 is headed "Patient-centred care" and says

"Treatment and care should take into account the man's needs and preferences. Men with prostate cancer should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals."

(NICE, 2008)

As the NHS continues to reform its services to make care more patient-centred it will need to check the progress it is making. One important source of information is the reported experience of the patients themselves. This is recognised by the Department of Health which has recently announced the

introduction of Patient-reported outcome measures (PROMS) from 1st April 2009. PROMs are "measures of a patient's health status or health-related quality of life. They are typically short, self-completed questionnaires, which measure the patients' health status or health related quality of life at a single point in time" (Department of Health, 2009a). They are designed to provide a measure of the effectiveness of clinical procedures and can be used to benchmark performance and to provide information that GPs and patients can use to inform their choices. The use of patient experience measures of course is not a completely new approach and some tools already exist. However, development has been patchy and there are diseases for which no suitable tool exists for measuring patients' experiences of care. This thesis has established that one such area is prostate cancer and has described the development of a questionnaire to capture the experiences of care of those patients.

Patients have information needs and are faced with choices at different phases of their healthcare journey. For those who may have prostate cancer there are particular concerns. The condition and possible symptoms are still not widely known or understood, the testing can be particularly unpleasant, the available treatment choices are increasing and are associated with significant risks of severe side-effects, and the benefits of treatment on length of life are still uncertain.

The diagnosis and treatment issues are covered by the NICE guidelines for prostate cancer and this guidance would be expected to inform professional

practice, so leading to improvements in prostate cancer care. The measure developed and described here could be used to monitor the adherence to aspects of these guidelines.

8.2 The development and testing of the questionnaire: the strengths and weaknesses of the methods used

The discussion in Chapter 1 of the respective merits of patient satisfaction and patient experience led to the decision to develop a measure of patient experience. In accordance with the demands of developing a patient experience measure great attention was paid to identifying the issues important to patients.

The development of the questionnaire involved both primary and secondary research to ensure it was thorough and rigorous. A review of the literature was carried out to identify previous studies that reported on their experiences of care. Then, individuals typical of all those who would be involved in using the questionnaire were able to contribute to its development. Cancer Networks who were likely to be involved in the administration of the questionnaire were surveyed and a sample interviewed. Interviews of CSC Leads and voluntary sector workers were also undertaken to ensure a complete range of perspectives would inform the measure. Patients who will complete the questionnaire were interviewed initially to help determine the issues that the measure should address and again later to check the comprehensibility and layout of the questionnaire. The piloting and testing took place in 12 hospitals across the country with well over 1,000 patients to

ensure that feedback came from a wide range of patients with prostate cancer. Healthcare professionals who are likely to be involved in the administration of the questionnaire, as well as acting on the findings, were able to use it with their patients and were then interviewed to check its utility and help finalise the content. During this process the research team and Panel periodically reviewed the drafts of the questionnaire to comment, discuss and agree changes, before PCQ-P was finalised.

The strengths of the questionnaire development were the gathering of information from a variety of sources to gain a rounded view of the important issues in patient experience of prostate cancer care. Reviewing the literature and interviewing patients and healthcare professionals are common approaches in the development of patient questionnaires. This study went beyond this and incorporated the views of carers, Cancer Network staff and voluntary sector staff. While this was a time consuming process it helped to ensure engagement and contributions from people with relevant but different experiences and perspectives. Furthermore, people from these groups were part of the ongoing process of reviewing and developing the questionnaire. The willingness of patients to contribute significant amounts of their time to the development process should be noted and is very encouraging for future research. However, there were some problematic areas, particularly the difficulties faced by hospitals in administering the questionnaire. In spite of the willingness of healthcare professionals to participate in the study they often found it difficult to access the administrative support needed.

The questionnaire was subjected to three rounds of piloting in hospitals and a variety of testing for validity and reliability. This rigorous approach has ensured that the questionnaire is ready for use and can be used with confidence, producing data that can be interpreted to inform service delivery.

However, there are some aspects of the development of the questionnaires that could be improved upon. First, the involvement of BME (Black Minority and Ethnic) patients in the development and review process was disappointingly low at times. Successful efforts were made to recruit BME patients to interview to develop the questionnaire, but their involvement in completing and returning draft versions of the questionnaires sent out by hospitals was rather low. This may be particularly difficult to control if it is a non-NHS employee administering the questionnaire or if records do not record the ethnicity of the patients. However, with rates of prostate cancer particularly high amongst African-Caribbeans it is something that should be addressed to ensure a reasonable response rate from BME patients so that their experiences can be captured and any appropriate action taken. This may also involve the need to consider how to make the questionnaire easier to complete for those who have limited understanding of English, or problems with written or spoken English. However, the further development of the questionnaire to tailor it to the needs of these patients, for example by using symbols and touch screen technology, would require significant extra development work and so is beyond the scope of this thesis. Secondly, there were some difficulties with parts of the testing process. The lack of an existing measure of patients' experiences of prostate cancer care meant that

a generic cancer questionnaire (NCSR questionnaire) was used as the best available alternative to test the construct validity of the questionnaire. Furthermore, the questionnaire was not tested for sensitivity to change because of concerns about the value and practicality of such a test for this questionnaire measuring patients' experiences of care. While it may be possible to test for sensitivity to change in some phases of care such as the treatment and monitoring phases, in other phases such as initial consultation with the GP it would not. In any event this requires significant extra work on design and testing that would constitute a further study and so renders it beyond the scope of this thesis.

As regards the decision to develop a measure of patient experience as opposed to patient satisfaction, the overwhelming majority of questions in PCQ-P did ask patients to record their experiences of care. Sometimes this was in a yes/no format, but sometimes required the patient to make a judgement, for example on how clearly an explanation had been given. This response format was used so that patients could match their experiences more closely to the responses available and provide more accurate information to act on. However, this approach did call on patients to exercise an element of judgement, involving personal perception, as in patient satisfaction questions. Consequently, the distinctions made in Chapter 1 between patient satisfaction and patient experience were found to be less clear cut in practice.

During the development of the PCQ-P it also proved undesirable to exclude all patient satisfaction type questions as there were occasions were it proved necessary to include such questions to make sense of an answer given to a previous patient experience question. For example, a question that ascertained the time a patient waited for referral from primary care to secondary care was of limited value without knowing how satisfied the patient felt about the time they waited.

The final issue to be considered here is does a patient experience measure, such as the PCQ-P, still measure satisfaction? It is certainly possible to use PCQ-P as a tool for measuring satisfaction as the responses given by patients can be aggregated to produce scores for aspects of care and these may then be examined to determine how satisfactory they are. However, it was not intended that the scores be used in this way and no guidance was given to encourage this approach. The PCQ-P does provide data on specific aspects of care within the different phases of care and so provides the opportunity to identify what should be addressed to improve service delivery. Consequently, this approach can help to bring about improvements in the quality of care even in phases of care that may have been judged to have yielded satisfactory scores overall. It should also be noted that the data produced from the completion of the patient experience questions was found by hospitals to be easy to act upon, as it required little interpretation.

8.3 Issues for further research

The questionnaire that has been developed addresses experiences of care through a number of different phases, from initial consultation with the GP, through further tests at the hospital, diagnosis and treatment decision, treatment, and monitoring. This will cover the experiences of most men. It is intended that one or two sections of the questionnaire will be used at any one time to keep the number of questions to an acceptable level and to cover a phase, or phases of care, that have recently been experienced by the patients.

However, there is scope for further research to develop other related measures of prostate cancer care. First, there may be circumstances when those using the questionnaire (e.g. hospitals, Cancer Networks) would wish to review patients' experiences across all the phases of care to get an overview, or perhaps to identify if any phases of care require further investigation. In such circumstances a shortened version of the questionnaire covering all the phases of care would be useful. This was developed from the existing full-length questionnaire, but is out with this thesis. Secondly, a further phase of care could be addressed: palliative and end-of-life care. Some patients experience a recurrence of prostate cancer and may receive further treatment (e.g. chemotherapy). Their experiences can be captured with the treatment section of the questionnaire. However, the disease of some patients advances so that they need palliative and end-of-life care. This phase of care has not been covered by the questionnaire and would require further research

and development to determine both the format and content of such a measure.

The NHS Plan 2000 identified the importance of patient-centred care in the NHS and the NHS Cancer Plan 2002 addressed this in cancer care. Consequently, the development of other measures of patient experience for other cancers may be appropriate and the approach used here may be used as a guide for developing these measures.

A patient experience measure can be used in quality improvement initiatives, but its use alone does not guarantee that quality will be improved. Cancer Networks, hospitals, and other providers involved in caring for men with prostate cancer need guidance on how changes in services and performance can be brought about. Research into methods for implementing change, and translating research evidence into practice, such as that being undertaken in the new NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) may be able to throw some light on this issue.

Finally, the studies undertaken to develop PCQ-P have not explained the reasons why patients with prostate cancer report worse experience of care than patients of other common cancers. However, although the studies were not designed to address this question, they do highlight the significance of information, explanation and involvement. Further research into these issues would help to show whether these or other factors explain the poorer reported experience of prostate cancer patients.

8.4 Recommendations for use of the questionnaire

The PCQ-P has been designed primarily for use in hospitals in England. The questionnaire could be used to review some aspect of service provision, for example to identify areas where patient experiences were below acceptable levels and then, later on, to monitor the effect of changes undertaken to address these issues. It could also be used to identify aspects of care where patients report positive experiences, so that existing best practice can be identified. Furthermore, the scores produced by the completion of a section of the questionnaire can be used for judging the quality of the service overall and for comparison, either against national benchmarks or to make direct comparisons between individual hospitals. However, the use of summary scores for the sections of the questionnaire also has limitations as the experiences of specific aspects of care that indicate a need to review service delivery may be overlooked if only summary scores are considered.

Surveys, using the questionnaire, could be conducted in a variety of ways including: a urology department in a hospital handing it out to patients who visit the outpatients clinic over several weeks; a Cancer Network organising hospitals in their area to post it to all their patients; and a national survey similar to those carried out for all cancer patients in 1999/2000 and 2004. During the development of PCQ-P, it was found that hospitals often had difficulties in administering surveys because of the time and resources involved. Given these difficulties there are significant challenges to be overcome if the original aim for the measure to be used in routine practice is to be achieved. The support required to administer the questionnaire is likely

to be significant in the first instance but should tail off as staff become skilled at administering the questionnaire, entering and analysing the data, and acting on the findings. Audit departments may have an important role to play here, especially in the absence of new and dedicated resources. Finally, it should also be noted that not all staff are likely to welcome either the extra work that may be involved in the process of using the questionnaire or the findings it generates. During the piloting of the questionnaire in hospitals most of the clinical staff had volunteered or agreed to take part. As was noted in the survey of Cancer Networks some senior clinical staff remain suspicious of the use that patient experience questionnaires may be put to, and questioning of the resources they use and the usefulness of the results.

Careful thought will need to go into the planning and administration of the survey. It is important to be clear about the objectives of the survey and to introduce it in a sensitive way that encourages healthcare professionals either to take part and/or give appropriate consideration to the implementation of the findings. A system of support and incentives for hospitals to conduct surveys is one possible solution, as is withholding financial payments for not carrying them out. Another approach is to pay an organisation outside the NHS that specialises in administering patient surveys to conduct a national survey of prostate cancer patients to establish benchmarks.

Whichever method of administering PCQ-P is chosen a User Guide would help to ensure consistency in the administration of the questionnaire. One was developed and used successfully by the hospitals during the final piloting

of the questionnaire. In addition the development of a database to enter questionnaire responses was undertaken. Given the preponderance of closed questions which can be coded for data entry (e.g. yes=1, No=2) this was achievable and was coupled with providing cumulative results in both numbers and percentages. The database, hosted on a website on the internet, was accessible via desktop and laptop computers and helped facilitate the use of the questionnaire. Both of these developments are out with this thesis.

A large part of the rationale for the development of the questionnaire was the poorer experiences of care of patients with prostate cancer compared with other cancer patients (Department of Health, 2002; National Audit Office, 2004). Consequently, of crucial importance is the implementation of service changes identified from whatever type of survey is carried out. Change can be brought about in a number of ways. These include gaining the commitment of staff, providing resources to support changes, and the threat of penalties or public reporting for not implementing changes. Monitoring adherence to NICE guidelines for diagnosis and treatment of prostate cancer represents another lever for change. Finally, the role of the National Cancer Director is vitally important in both ensuring the use of the questionnaire and the implementation of findings as part of the overall strategy for bringing about significant and widespread improvements in the quality of prostate cancer care.

The PCQ-P may also be used in health research. For example, it could be used as an outcome measure to ascertain the effects of changes to service delivery on patients' experiences of care. This might be in the context of a randomised control trial testing a new intervention to improve patient care and PCQ-P was administered before and after the intervention to both groups of patients. This would also provide an opportunity to test the questionnaire for sensitivity to change.

It would be important to select only the appropriate sections of the questionnaire to ensure that only relevant data was collected and to minimise the administrative burden for researchers and respondents alike. Based on the experiences of hospitals that used PCQ-P the provision of a User Guide and an internet-hosted database for recording the responses of participants would prove invaluable to researchers and facilitate the use of PCQ-P