

# ResearchSummary

**NHS**  
National Institute for  
Health Research



## Improving patients' experience of prostate cancer care

In England, improvement of cancer services is a policy priority, and improving patients' experience of cancer care is an important element of this policy. National surveys of patient experience of cancer care have shown that patients with prostate cancer report less positive experiences of care than patients with other cancers. Strategies to improve patients' experience of prostate cancer care are being implemented at national and local levels. However, we still lack good quality information in this area about patients' as well as carers' experience of care.

This summary is based on research conducted by a team led by Richard Baker at the University of Leicester (Baker *et al.* 2007) and commissioned by the NIHR Service Delivery and Organisation Programme (SDO). It is for any health professionals interested in improving the quality of care for patients with prostate cancer and their carers, including clinicians, policy makers, health managers and those in the voluntary sector.

### Key findings

- Two national surveys have reported that patients' experience of care for prostate cancer is less positive than for other cancers in a number of areas, e.g. no discussion how treatment had gone or information provided about support or self-help groups.
  - Research suggests that patients and their carers lack knowledge about prostate cancer and may experience difficulties during decision-making on the treatment options.
  - The study found that patients with access to specialist nurses reported a better experience of care. Access to specialist nurses at all stages of treatment would improve services for men with prostate cancer.
  - At the same time, all staff need better information about the experience of this care group to help them improve the quality of care.
- Based on a survey of the literature, and in consultation with professionals and users, the researchers devised two Prostate Care Questionnaires (PCQ): one for patients with prostate cancer (PCQ-P); the other for carers (PCQ-C).
  - The researchers found the PCQ-P and PCQ-C to be valid and reliable measures of the experience of care. In particular, they can:
    - investigate all or separate stages of care depending on particular needs and interests
    - detect differences in patient and carer experience between hospitals.
  - Staff found the PCQ easy to use and it provided them with relevant information for planning care.
  - The PCQ, together with information on how to use it, can be accessed online (see page 4).

# Background

Prostate cancer is the most common cancer in men in England and accounts for about one quarter of male cancers. It is also more common with increasing age. Management options for early disease include observation, hormone therapy, surgery, and radiotherapy, including a type where small radioactive 'seeds' are implanted directly into the tumour. Each option has associated benefits and risks and decision making can be difficult for both patient and clinician.

A diagnosis of prostate cancer comes as a shock to many men and their partners; accordingly, health professionals have a duty to impart sensitively and effectively information to those affected – about the disease, the treatment options and possible side effects. Patients with prostate cancer and their carers have needs similar to those in other care groups: for adequate information, explanation and support, from initial presentation to follow-up after treatment. However, the level of information and support that patients with prostate cancer receive is not as good as it could be. For example, two national surveys in 2000 and 2004 (see Baker *et al.* 2007) reported that the experience of care of patients with prostate cancer is generally less positive compared with patients with other types of cancer.

The reasons for these shortcomings are not clear. It is known that men tend to be relatively uninformed about prostate cancer. Patients' pre-existing lack of knowledge and awareness can make it harder for them to make informed decisions about treatment; it can also act as a barrier to them feeling involved in the planning of their care. Providing information tailored to patients' individual needs is therefore an important part of improving their experience of care, not just at

diagnosis but at all stages. In designing services around the needs of men with prostate cancer, initiatives to improve the provision of such information should be a priority. Meeting this priority means starting by asking patients themselves to identify the kind of information they need and value most.

## **Patient experience, evaluation or satisfaction?**

Various types of measure are available for getting the views of patients on the health care they have received. These include:

1. *Satisfaction ratings*, e.g. 'How satisfied are you with information provided about treatment options?' – very satisfied, moderately satisfied, and so on.
2. *Evaluation ratings*, e.g. 'How would you rate the information provided?' – (a) too much (b) about right (c) too little.
3. *Experience ratings*, e.g. 'Were you provided with information about the treatment options?' – (a) yes, I had enough information (b) yes, but I would have liked more information (c) no, I was not provided with any information.

An important feature of the third type is that it takes into account the influence of patients' expectations of the care they receive. Provided that an experience rating is carefully designed, rigorously tested, and identifies the issues that patients consider important, it has the potential to produce findings that are more informative, easier to interpret and more reliable. Consequently, measures of patient experience are becoming more common and are increasingly preferred in monitoring health service improvements. It is this type of measure that the present study set out to investigate.



# Reviewing the evidence

A systematic review of published studies was undertaken by the researchers (see page 6). Key findings and implications included the following.

## Implications for clinical practice

- *Improving levels of knowledge and awareness.*  
Men's knowledge of prostate cancer is often poor. Interventions that made information more available to patients helped them to cope better, reduced their levels of anxiety and enabled them to make decisions. There thus needs to be better information given to patients before initial testing and diagnosis and sufficient time allowed for discussion at all stages of the care pathway.
- *Breaking bad news.* A diagnosis of prostate cancer is a shock for many patients and their partners. Offering them a break between diagnosis and discussing treatment options allows them time to regain composure so that they are better able to understand and discuss the options.
- *Ongoing support.* 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.

Respondents in reported studies were predominantly white and not socio-economically disadvantaged. So the above findings should be applied with caution to other ethnic or disadvantaged groups.

## Measuring patients' experience

No standard measure of patients' *experience* of prostate cancer care was identified in the review. A review of outcome measurement in prostate cancer published while the present study was underway also found no standard measures of patient satisfaction relating to prostate cancer screening and treatment (McNaughton *et al.* 2004). Therefore, the development by the present study of a measure of patient *experience* to inform service improvement was appropriate. Lessons learned from the review (see 'Implications' above) were that any such measure should meet certain criteria. It should:

- be usable throughout the care pathway
- seek patients' experiences of receiving information and taking part in decisions
- assess patients' experience of coping with anxiety and self-care, availability of support, management of treatment effects and continued monitoring of their condition.

## Prostate Care Questionnaires (PCQ)

A tool for measuring patient experience – the Prostate Care Questionnaires (PCQ) – was designed, developed and tested by the research team for use in routine practice. The PCQ consists of two measures:

- a self-completion questionnaire for patients with prostate cancer (PCQ-P)
- a self-completion questionnaire for carers (PCQ-C).

The PCQ was developed in three stages:

1. *Identifying the issues to be included in the PCQ*, and the preferred format, taking account of the ways in which it would be used by multi-disciplinary cancer teams locally and nationally
2. *Devising, reviewing and piloting two draft PCQs*, including via postal questionnaires and interviews with samples of patients attending three hospitals and carers. Piloting ensured that patients and carers with a range of characteristics from different parts of the country were able to use the questionnaires. In particular, piloting involved a number of patients who moved between different hospitals during their care.
3. *Administering a revised PCQ* to samples of patients attending five hospitals and carers. Then, in four different hospitals, the revised PCQ was used by hospital staff with the support of a user guide and web-based software for data entry and analysis. Staff using the PCQ in these hospitals were interviewed to investigate ease of use.

For further information on the methods used and results, see page 6.

Each of the two questionnaires can be used on its own or with the other and each is divided into sections. For example, the PCQ-P contains questions grouped around the following:

- A. The first time you saw the doctor or nurse about your possible prostate problem
- B. Having tests for possible prostate cancer at the hospital
- C. Getting the diagnosis
- D. Your treatment
- E. Monitoring (checking) you
- F. About you and your health.

The PCQ has been designed to investigate all or different stages of care depending on particular needs and interests, as well as detect differences in patient and carer experience between hospitals (see 'Using the PCQ').

# Recommendations

The review and development of the PCQ identified a number of implications for practice, policy and research, as summarised below.

## Practice

Health care organisations and teams that want to improve services for men with prostate cancer should focus on the following aspects of care:

- *Helping patients decide.* Since decisions on the investigation and treatment of prostate cancer can be difficult, information, explanation and involvement are especially important. Although decision aids may have a part to play (Wirrman and Askham, 2006), the communication and involvement skills of health professionals, and the time allowed for talking with patients, both need attention. Allowing patients time to think through their options, explore their preferred way of making decisions, and return to ask further questions, would also help. Patients need to be clear that they can change their treatment decision without the worry that they will be considered 'difficult'.
- *Information and specialist care.* Readily available written information and access to a specialist nurse throughout the care cycle for all patients would be a step forward. (See 'Role and value of the specialist nurse')
- *Carer involvement.* Involving carers, with the patient's approval, is another helpful approach.

## Using the PCQ

The PCQ can be administered on paper or via a computer (this latter method was not tested with patients during the study). Patients and, where appropriate, carers, can complete the paper-based versions at home or when attending appointments or as inpatients. Completion during a clinic attendance can give early warning of any problems in care and encourage hospitals to act quickly to implement improvements.

Results from the PCQ can be used in a variety of ways, for example, in:

- local quality improvement networks
- local service planning
- improving care across the primary-secondary care interface
- professional development activities
- regional or national surveys
- research studies.

Data from completed questionnaires may be entered into a database on the web and descriptive statistics obtained automatically.

To access the PCQ, visit

[http://wads.le.ac.uk/hs/sdo/home\\_page.html](http://wads.le.ac.uk/hs/sdo/home_page.html)



## Role and value of the specialist nurse

Prostate cancer patients have lower levels of access to specialist nurses than patients with other types of cancer (NAO, 2005). Individuals and organisations involved in prostate cancer care have pointed to the availability of specialist nurses as a key priority for government action (Prostate Cancer Charter for Action, 2007). The researchers conducted a questionnaire survey and face-to-face interviews with patients to explore whether those who saw a specialist nurse had different experiences of care to those who did not.

For example, findings from the questionnaires showed that patients who saw a specialist nurse were:

- significantly more likely to say they were given enough printed information about their test results and treatment options
- more likely to feel that their treatment options were clearly explained
- more likely to say that they made the treatment decision themselves, although there was no significant difference between the groups in the extent to which they felt involved in the treatment decision
- more likely to have been told that they could discuss the treatment decision again, and could change their mind about treatment.

Patients interviewed highlighted two key features of the specialist nurse role which distinguish it from the role of other health professionals involved in prostate cancer care:

- the availability of the specialist nurse to the patient
- the ability of the specialist nurse to liaise between the medical system and the patient.

Taken together, these findings suggest that specialist nurses make a unique and valuable contribution to patient experience of prostate cancer care. Patients who did not see a specialist nurse after getting their diagnosis highlighted the lack of unconstrained time to talk things over, which had a negative emotional impact on them.

***'I will go back and be checked from time to time and honestly, my nurse specialist is always there and I will require that service for some time to come.'***

**Patient with prostate cancer**

### **Policy**

A number of policy implications arise in relation to the PCQ, notably the following:

- *The Cancer Reform Strategy* (Department of Health, 2007). This recognises the need to improve patients' experience of cancer services, both during and after treatment. National tumour-specific pathways are to be launched in 2008. A guide for commissioners is being developed and commissioners have been instructed to pay particular attention to the provision of specialist nurse support, of which there is currently a shortage in the field of urological cancer. The Strategy also sets out plans for an NHS Cancer Patient Experience Survey Programme, with surveys to be undertaken on an annual basis.
- *Quality improvement*. Multidisciplinary cancer teams and Trusts should be encouraged to include assessment of patient and carer experience.
- *Increased role of commissioners*. The greater involvement of commissioners in the future will present an additional opportunity to monitor and improve patient experience. Commissioners should be encouraged to take account of the findings of patient surveys when planning care for men with prostate cancer and could use the measures described here to monitor performance in occasional surveys. They should also give attention to the needs of carers of men with prostate cancer.
- *Future national patient surveys*. The PCQ makes possible the provision of good quality information to guide policy and service development. If a survey specifically focused on prostate cancer is undertaken the PCQ should be used: development of another instrument is currently not justified. In such a survey, consideration should be given to the inclusion of carers.

### **Research**

The study highlighted gaps in our knowledge. There is relatively little evidence about patients' experience of the following stages of the care pathway:

- referral when the possibility of prostate cancer is first indicated
- diagnostic investigation
- long term monitoring after initial treatment
- management of relapse
- palliative and terminal care.

Further research into these stages of care is required, and the PCQ provides a tool for seeking to capture patients' experience of these.

### **Conclusions**

The PCQ has been systematically developed and is now available for use. The PCQ is now available for use in quality improvement initiatives at both the local and national level. Those involved in its development hope that quality leads and service commissioners will encourage its adoption as a standard instrument. The study did not set out to explain why patient experience of care for prostate cancer is less positive than for other cancers, but it points to ways in which experience could be improved and provides practical measures for use in guiding and monitoring improvements.

## About the study

The aim of the study was to develop valid, reliable and usable measures of patient experience of prostate cancer care suitable for use in routine practice. The study was in three stages.

**Stage 1.** The researchers sought to identify the issues to be included in the measures, and the preferred format, taking account of the ways in which it would be used by multi-disciplinary cancer teams locally and nationally. A questionnaire survey of Cancer Networks (n=26 out of 34) was conducted, supplemented by interviews (n=27) of Network staff. Relevant health professionals and voluntary sector staff (n=14) were also interviewed, as well as a sample of patients (n=35) and carers (n=10). A review of published research was also undertaken. From a total of 1263 articles identified 87 met the inclusion criteria and included 14 trials of interventions.

**Stage 2.** Two draft measures were devised and reviewed by a Delphi Panel (n=19) comprising patients, health professionals and voluntary sector staff. The draft questionnaires were then tested for content and comprehensibility with patients (n=18) and carers (n=6) through interviews at patients' homes. Testing of the first pilot measures through postal questionnaires was then conducted in two hospitals: 159 completed patient and 95 carer questionnaires were returned. A similar approach was used in a revised, second pilot, with 132 patient and 95 carer questionnaires being returned also from two hospitals.

**Stage 3.** Different versions of the revised third set of measures were administered to samples of patients of five hospitals and investigated for reliability, validity and, for the patient measure only, sensitivity to change. This testing phase was staged over 4 months. Then, in four different hospitals, the revised measures were used by hospital staff with the support of a user guide and web-based software for data entry and analysis. Staff using the measures in these hospitals were interviewed to investigate ease of use.

For further information on the methods and results, including numbers of samples and respondents in Stage 3, please consult the full report.

### Members of the research team

**University of Leicester,  
Department of Health Sciences**  
Richard Baker (principal researcher), Paul Sinfield, Shona Agarwal, Carolyn Tarrant

**University of Leicester,  
Department of Psychology**  
Andrew Colman

**University of Leicester,  
Department of Cancer Studies**  
William Steward

**University Hospitals of Leicester,  
Department of Urology**  
John K Mellon, Roger Kockelbergh

**National Centre for Social Research**  
Kerry Sproston

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## Further information

The full report, this research summary and details of current SDO research in the field can be downloaded at: [www.sdo.nihr.ac.uk](http://www.sdo.nihr.ac.uk)

For further information about anything included in the report, please contact Professor Richard Baker, Department of Health Sciences, University of Leicester, 22-28 Princess Road West, Leicester, LE1 6TP Email: [rb14@le.ac.uk](mailto:rb14@le.ac.uk)

### Feedback

The SDO Programme welcomes your feedback on this research summary. To tell us your views, please complete our online survey, available at: [www.sdo.nihr.ac.uk/researchsummaries.html](http://www.sdo.nihr.ac.uk/researchsummaries.html)

### About the SDO Programme

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The NIHR SDO Programme improves health outcomes for people by:

- commissioning research and producing research evidence that improves practice in relation to the organisation and delivery of health care; and
- building capacity to carry out research amongst those who manage, organise and deliver services and improve their understanding of research literature and how to use research evidence.

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**NCCSDO, London School of Hygiene  
& Tropical Medicine**  
99 Gower Street  
London WC1E 6AA

**Tel: +44 (0)20 7612 7980**  
**Fax: +44 (0)20 7612 7979**  
**Email: [sdo@lshtm.ac.uk](mailto:sdo@lshtm.ac.uk)**



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