

The Development of the Prostate Care Questionnaires for Patients (PCQ-P) and Carers (PCQ-C)

Prostate Cancer Care: Improving Measures of the Patient Experience

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO)

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Executive Summary

Background

This Summary briefly sets out the work undertaken to develop new measures of experience of prostate cancer care – the Prostate Care Questionnaire for Patients (PCQ-P) and the Prostate Care Questionnaire for Carers (PCQ-C). Both measures are now ready for use, and are supported by a User Guide and web-based software to facilitate data entry and analysis by NHS organisations.

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 of patient experience of cancer care undertaken in 2000 and 2004 have shown that patients with prostate cancer report less positive experiences of care than patients with other cancers.

Strategies to improve patient experience of prostate cancer care are being implemented at national and local levels, but the planning and monitoring of such improvements requires good quality information about patient experience of prostate cancer care.

Aim

To develop valid, reliable and usable measures of patient experience of prostate cancer care suitable for use in routine practice.

Specific objectives:

1. investigate through interviews and mailed survey the cancer teams needs for the measures
2. review relevant literature and interview patients, carers, voluntary sector staff, members of cancer networks and multidisciplinary cancer teams to ensure the measures cover all relevant aspects of patient experience and take the most appropriate formats
3. reduce the number of questions to a minimum through evaluation in pilot tests
4. administer the measures to a sample of patients and carers to test reliability, validity and sensitivity to change
5. compare the performance of the measures with other measures of patient experience

6. prepare a User Guide on the use of the measures, and then investigate utility and ease of use by cancer teams
7. develop and provide an analysis package for local use, and facilitate national aggregation

About this study

The objectives were addressed in three stages. In stage one, we 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 (Objectives 1 and 2 above). A questionnaire survey of Cancer Networks was conducted, supplemented by interviews of Network staff. We also interviewed relevant healthcare professionals and voluntary sector staff, and a sample of patients and carers. A review of published research was also undertaken.

In stage two, we undertook two pilot tests of the draft measures in three hospitals leading to removal of surplus questions, and improvements in wording and comprehensibility (Objective 3 above).

In stage three, the measures were administered to samples of patients in five hospitals. We investigated reliability (internal consistency and test-retest reliability), validity (face, content and criterion), and, for the patient measure only, sensitivity to change (Objectives 4 and 5). Then in four different hospitals, the revised measures were used by the hospital staff with the support of the User Guide and web-based software. We interviewed staff using the measures in these hospitals to investigate ease of use (Objective 6).

Key findings

PCQ-P and PCQ-C have been developed through a detailed, systematic process, and are now ready for use. They have the following characteristics:

- a) long and short versions offering detailed information or an overview of patient and carer experience
- b) long versions are divided into sections related to different stages of care. The sections can be used independently or together in a single questionnaire, and enable hospitals, commissioners and others to investigate stages of care depending on their particular needs and interests.
- c) findings can be presented by individual question and as scores for sections and components of sections.

The measures were shown to have acceptable reliability and validity. Tests of sensitivity to change were reassuring, although an ideal means of assessing change in experience was not available. PCQ-P and PCQ-C detect differences in patient and carer experience between hospitals,

can achieve satisfactory response rates, and hospitals reported that they were easy to use. Staff shortages and competing priorities can affect the resources hospitals set aside for conducting surveys.

Patients involved in the study reported varying needs for information, explanation and involvement at all stages of care. Carers also wanted information and support. Services for patients with prostate cancer should ensure that their differing needs are met, and the new measures are used as part of initiatives by providers and commissioners to improve patient and carer experience.

PCQ-P and PCQ-C may be administered at different stages of care, from initial presentation onwards. They can be administered when patients attend for care or can be mailed in local or national surveys. Local use of the measures involves four steps: (1) planning – a high priority should be placed on patient experience and a systematic plan put in place to ensure the survey is conducted efficiently; (2) administration of the measures – the methods and patient and carer samples should be chosen in accordance with the aims of the survey; (3) data entry and analysis – the web software can be used; (4) dissemination of the results and development of action plans – action should be taken to implement improvements if required, with the improvements being monitored in follow up surveys with the measures.

Conclusions

PCQ-P and PCQ-C have been systematically developed and are now available for use. Their use by providers and commissioners at local level in quality improvement initiatives is now required. They can also be used in national surveys to guide planning and policy. This study points to ways in which patient and carer experience of prostate cancer could be improved, and has provided measures that can be used in guiding and monitoring improvements.

Disclaimer

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health

Addendum

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