**PROGRAMME OF RESEARCH ON ORGANISATIONAL FORM AND FUNCTION**

**CANCER SERVICES QUALITY: CA2 – 'PROSTATE CANCER CARE: IMPROVING MEASURES OF THE PATIENT EXPERIENCE'**

## Introduction

The SDO Programme wishes to commission **two** interrelated research projects in this field: the projects combine both primary and secondary research.

> **CA1: 'Assessment of interrelationships between different measures of the quality of cancer services.'**
>
> **CA2 : 'Prostate cancer care: improving measures of the patient experience.'**

This brief describes **CA2**.
Project **CA2**: involves development of tools to measure patient experience in prostate cancer care.

The aim of the project is to derive robust and reliable measures of patient experience in prostate cancer care which can be used in routine practice to compare performance, to assess the impact of innovations and to direct resources more appropriately. Some 1500 cancer service teams are active in England, around 600 of which have quality improvement initiatives, linked to the Cancer Services Collaboratives (CSCs).

There have been a number of recent surveys and assessments of cancer care. From these surveys it is evident that the quality of cancer care varies considerably across England and Wales.
Some of the quality improvement initiatives, linked to the Cancer Services Collaboratives (CSCs) are directed at prostate cancer services, where there is a general perception that the scope for quality improvement is wide. Together with the Modernisation Agency and the National Cancer Director, we therefore wish to commission work on the patient experience in prostate cancer care.

## Background

A challenge that teams encounter when implementing service improvements through a CSC, is the lack of robust but easy to use tools to measure change in patient experience. The recent National Cancer Patient Survey (NCPS) included around 8000 patients with prostate cancer and has provided the benchmark against which quality improvement policy can be judged in the coming years at a national level. However, local services also need tools that can be used in local contexts to provide more immediate feedback about service improvement initiatives, and which can then be used to influence further change.

The NCPS questionnaire could provide the basis of a simple tool to measure patient experience, to undertake evaluation of a local change in service provision e.g. a before- and after- evaluation of a new service. However further work will be required first to:

1. establish contextual information from CSCs as to how such tools might be used and exactly why they are needed.
2. review the NCPS questionnaire content to ensure that it covers all relevant dimensions of patient experience, including for example, the hospital environment
3. reduce the number of questions to an irreducible 'core'
4. test the tool's reliability, validity and sensitivity to change
5. compare it to any existing quality measurement tools based on patient experience
6. implement, and then test its ease of use, in local service settings, based on the principle that the tool should be usable and produce meaningful findings without researcher support
7. develop an easy-to-use analysis package, based on readily available software, for use in local settings but with the potential for aggregation at national level.

Generalisability to other cancers or to areas other than cancer care should be considered as also should scope for developing more detailed modules to evaluate specific domains of care (for example, privacy, information giving).

The NCPS questionnaire was originally designed and implemented by the National Centre for Social Research. It is expected that the successful team would need to work closely with this centre in developing the quality improvement measurement tool.

**Content**

Outline proposals for research funding for project **CA2** should be submitted. A short review of current evidence should be included where applicable. Proposals should clearly demonstrate that the research will add to knowledge and that the proposed research has not already been or is not already being undertaken.

Applicants should demonstrate how they will undertake the proposed research. Methods, (including both qualitative and quantitative methods where appropriate) should be described. Proposed outputs should be listed.

Applicants will also be expected to demonstrate that they are able to draw on a broad range of both evidence and theory. Applicants should be able to demonstrate a broad awareness of international research as well as UK-based research in this field. Relevance to the NHS should be made explicit.

Applicants will also need to demonstrate clear conceptual frameworks to consider the issues relating to measurement of the patient experience in health care.

We anticipate that the work will be of a multidisciplinary nature and may incorporate both quantitative and qualitative research. Applicants should

demonstrate that their team covers the necessary skills and range of disciplines including psychometric skills, understanding of the patient experience and of quality of life issues in cancer care and of their measurement as well as experience of software development.

Applicants should familiarise themselves with relevant research already commissioned by SDO and by other NHS R&D programmes (such as the Policy Research Programme and the Health Technology Assessment Programme) and the relevant work of the Modernisation Agency to ensure that they can demonstrate that their proposals do not duplicate other research.

Applicants should refer to the general criteria for prioritising research topics, developed and agreed by the SDO programme board, available on the SDO website (www.sdo.lshtm.ac.uk).

**Outputs**

Proposals should demonstrate awareness that the *principal final product* of the research will be a detailed report that should:

- critically describe the background and available literature in relation to the topic and provide a rigorous and detailed analysis and conclusions of what is currently known about the topic area and of the strength of the evidence on which this is based
- critically describe the methods used in the research
- provide a rigorous analysis of the data gathered
- draw justifiable conclusions
- describe robust measures of the patient experience in prostate cancer services
- identify areas for further research and how they might be addressed. This could include reviews of the literature and/or primary research
- locate the findings in the current policy and practice context within the NHS.

Successful applicants will be asked to make a short oral presentation of their completed research to the SDO Programme Board. In addition, successful teams are expected to report on progress at annual intervals to the SDO programme and as required to the National Cancer Director and the Cancer Portfolio Director. We also anticipate that there might be informal discussions with NCCSDO during the research to clarify issues as they arise.

Research outputs will need to be presented both in an academic format and in a format that will be helpful to end-users, particularly those with responsibility for improving the patient experience in cancer care. One of the key audiences for the work will be those working in the NHS for example with direct clinical and clinical governance responsibilities.

**Guidance Notes for submitting an outline proposal**

Outline proposals should cover no more than **four pages**. They should identify the proposed research team and describe the location and context of the proposed study. They should include a description of the methods to be

used, and the intended outputs of the research. They should also include arrangements for project management, such as an advisory board and user input. Applicants should clearly outline their plans for the dissemination of their findings.

In addition, applicants should indicate how they will:

- ensure that their team includes researchers whose knowledge and skills are sufficiently broad to deal with the variety of topic areas and methodologies which will need to be considered.
- ensure the relevance of the research to bodies at national and local level which have an interest in the topic, both within and outside the health and social care sectors.
- demonstrate the involvement of users and other relevant stakeholders at each stage of the proposed research project;
- build in an active programme for disseminating the results, and discussing them with those who plan, manage and deliver services.

**Application process**

The process of commissioning the study will be in **two stages** and applicants should submit **outline proposals**. **One** proposal for project **CA2** will be selected. An organisation may submit proposals for both **CA1 and CA2** projects if they wish.

Applicants must submit proposals using the A4 Outline Proposal application form, which is available as a Word 97 file or Rich text format from:

- the SDO website: http://www.sdo.lshtm.ac.uk/cancerservicescall.htm, or
- by Email from: damian.o'boyle@lshtm.ac.uk

**Please do not use any previously obtained version of an SDO Programme application form.**

Applicants are asked to submit proposals by **Wednesday 25th June 2003 at 1pm to:**

Mr Damian O'Boyle
Commissioning Manager
NCCSDO
London School of Hygiene and Tropical Medicine
99 Gower Street
London
WC1E 6AZ

**TWENTY-FIVE HARD COPIES** of the completed A4 Outline Proposal application form should be submitted together with a copy on disk or CD. Please note we will not accept electronic submissions or hand written proposals. **No late applications will be considered.**

Guidance notes for the completion of the Outline Proposal application form can be found at the front of the application form.

Funding of up to **£350,000** is available for funding **one** project in this topic area. **Applicants should note that value for money is an important consideration in respect of this research.** Proposed costs of the project should not exceed the limits stated above.

Following submission of outline proposals successful applicants will be notified no later than the **end of July 2003.** They will then be invited to submit full proposal by **late September 2003.** The outcome of the review of full proposals will be notified by **late November 2003.** The project should take no longer than **three years** to complete and start no later than **December 2003.** Please note that these dates are approximate and may be subject to change.

In addition, applicants should indicate how they will work with the SDO Programme and relevant stakeholders to build in an active program for disseminating their research findings in policy, practice and research contexts.

Please clearly label the outside of the envelope in which you submit your proposal with the following: **'Tender Documents'**. This will enable us to identify proposals and keep them aside so that they may all be opened together after the closing date and time.

Teams should ensure that their proposal complies with the Research Governance Framework, which can be found on the Department of Health website, or via a link on the SDO website under the 'Call for Proposals' page.

**Before funding, successful teams will be required to provide proof of research ethics committee approval for their project, if this is required (information regarding this can be found on the SDO website under the 'Calls for Proposals' page).**

We anticipate that there will be informal discussions with NCCSDO throughout the duration of the project regarding the final report.

Applicants should visit the SDO website: http://www.sdo.lshtm.ac.uk to familiarise themselves with the work of the SDO Programme in general and with previous scoping exercises in other topic areas.

**Addendum**

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk.