



**Prostate  Cancer
Support Federation**

ProstateResearch
PROSTATE CANCER RESEARCH FOUNDATION

Prostate Cancer Priority Setting Partnership

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The Prostate Cancer Research Foundation (PCRF) and the Prostate Cancer Support Federation (PCSF), in partnership with the James Lind Alliance (JLA), have set up a Priority Setting Partnership (PSP) which aims to identify uncertainties about prostate cancer, in particular its treatment, but including diagnostic techniques and prevention measures, which are important to patients and clinicians, and then to work with patients and clinicians to prioritise them for research. Full details of the PSP are given in the Protocol, which may be viewed on-line at

http://www.lindalliance.org/pdfs/Prostate%20C/JLA%20PC%20PSP%20Protocol_FINAL.pdf.

Why is this programme important?

Prostate cancer is unique amongst the major cancers in a number of ways: it is often slow growing and effectively harmless, yet it kills a third of those diagnosed; there is no recognised test that simply establishes the prognosis for a man who may have the disease; treatment options vary considerably depending on the stage of the disease, but also according to the lifestyle preferences of both the man it affects, and his partner; dietary and environmental factors seem to have a profound effect on both the incidence of the disease and its progression. As a result there is considerable controversy amongst clinicians about optimum treatment, indeed whether to treat at all, and, in particular, the advantages or otherwise of testing to promote early detection. Directed research is needed that is aimed at clarifying these issues so that the unacceptable death rate can be reduced.

What are treatment uncertainties?

‘Treatment uncertainties’ occur when there are questions about treatment that cannot be answered by up to date information based on research evidence. For this exercise we interpret ‘treatment’ in its broadest sense, and we include dietary prevention and diagnostic testing. We want as wide a spectrum of patients and clinicians as possible to tell us what they believe are the uncertainties about prostate cancer. So if **you** believe that answering particular questions will improve the lot of men with prostate cancer, and you think these questions need to be answered by research, this is your chance to make your views known.

What will happen to the uncertainties?

The uncertainties which are submitted to the study will be checked to ensure they are true uncertainties, which have not been answered by existing research elsewhere. They will then be combined with uncertainties which have been identified through a review of existing research and literature. These will then be entered into the Database of Uncertainties of the Effects of Treatments (DUETs – www.library.nhs.uk/duets). They will then go through a process of prioritisation, in which you can also get involved, to identify ten priorities for research which are of the most importance to both patients and clinicians. This list will be published and provided to organisations that fund research.

Why patients and clinicians?

Research on the effects of treatments often overlooks the shared interests of patients and clinicians, and questions they both consider important are not addressed. The pharmaceutical and medical technology industries and academia play essential roles in developing new treatments, but their priorities are not necessarily the same as those of patients and clinicians. For this reason many areas of potentially valuable research are neglected.

How can I get involved?

If you would like to participate in the programme, you should complete the accompanying short survey (Part I) about you and your organisation (if you represent one, i.e. you are not participating as an individual). You should then use Part II to give details of all the uncertainties that you or your organisation wishes to be entered into the prioritisation process.

If you wish to complete the forms by hand, please print this document out using the “back to back” printing on your printer, and post it to Emma Halls, the Prostate Cancer Research Foundation, Rm 305, The Blackfriars Foundry, 156 Blackfriars Road, London SE1 8EN, Telephone: 020 7953 7192. You may complete the forms electronically, in which case please use the Word document provided. **Please do NOT change any styles or otherwise alter the formatting, or delete any of the preamble** (which might result in messing up the formatting.) When completed, please email the form to Emma Halls at the PCRF, ehalls@thepcrf.org.

The closing date for submission of uncertainties is 23rd October 2009.

Confidentiality and consent

Your contact details will be kept confidential and securely, in accordance with the Data Protection Act. As part of the process, your uncertainties may be published in DUETs, and we will need your permission for this to happen. Your name/organisation will NOT be published in association with the uncertainty.

Contacts

For further information, or if you have any concerns or complaints about this process, please contact Emma Halls at the PCRF, ehalls@thepcrf.org, Telephone: 020 7953 7192.

Useful websites

Prostate Cancer Research Foundation (PCRF): www.thepcrf.org.uk

The Prostate Cancer Support Federation (PCSF): www.prostatecancerfederation.org.uk

James Lind Alliance: www.lindalliance.org

Database of Uncertainties about the Effects of Treatments: www.library.nhs.uk/duets

Part I – About you and your organisation

Organisation Name:
(if you are participating as a representative of an organisation – individual submissions are also welcome)

Date submitted:

Contact Name:

Address

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Post Code

Phone:

Email:

Please tell us the role in which you are submitting uncertainties. If more than one of the roles below apply, please indicate only the primary one, but list the others against the ‘Other’ option.

- A health professional working in the field of prostate cancer
 - A patient with prostate cancer
 - A carer of someone with prostate cancer
 - Other – please describe
-

Please tell us what kind of organisation (if any) you represent. If more than one of the categories below apply, please indicate only the primary one, but list the others against the ‘Other’ option.

- A clinical organisation with strong research activities
 - A clinical organisation with little or no research activities
 - A patient support group
 - An organisation that funds research
 - An organisation that conducts research
 - A commercial organisation that sells goods or services associated with prostate cancer
 - Other – please describe
-

If your organisation specialises in any particular aspect of prostate cancer, please specify

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How you gathered your proposed uncertainties

Please describe below the process that you or your organisation has used to come up with the list of proposed uncertainties that you have supplied in the Part II Form. Please note that there will be no judgments made about the quality of input you are providing based on your answer to this question, but it will help the Steering Group to know to what extent your input is representative of the general views of organisations such as yours, or individuals such as yourself.

Ideally, the approach you use to ‘harvest’ uncertainties should be as transparent, inclusive and representative as practicable. Methods might include membership meetings, direct mail or email consultation, mail or web-based questionnaires, internet message boards and focus group work.

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Consent

As part of this research process, we may publish uncertainties you have identified in DUETS. Do we have your permission to do so? (Your name or the name of your organisation will **NOT** be published in association with the uncertainty.)

- Yes
- No

Signed **Date**

Part II - Uncertainties

Please use the form below to report what you or your organisation believe to be candidate uncertainties in prostate cancer treatments. These will then be assessed by the Prostate Cancer PSP Steering Group and assembled, categorised and refined into “collated indicative questions” which are clear, addressable by research and understandable to all. Similar or duplicate questions will be combined where appropriate.

If you wish to complete the forms by hand, please print this document out using the “back to back” printing on your printer, and post it to Emma Halls, the Prostate Cancer Research Foundation, Rm 305, The Blackfriars Foundry, 156 Blackfriars Road, London SE1 8EN, Telephone: 020 7953 7192. You may complete the forms electronically, in which case please use the Word document provided. **Please do NOT change any styles or otherwise alter the formatting, or delete any of the preamble** (which might result in destroying the formatting.) When completed, please email the form to Emma Halls at the PCRF, ehalls@thepcrf.org, by **23rd October 2009**.

Explanation of Headings

Please note that only those marked * are mandatory. However, it would help us understand the background to the proposed uncertainty, and why your organisation thinks it is important, if you added what detail you can in the other columns. To help you complete the form we have included an example, which is not necessarily true or important.

Uncertainty*: Please give the uncertainty a name in not more than 10 words that indicates the broad area where research is required. Examples might be: “Evaluation of Active Surveillance”, or “Is cancer spread caused by some biopsy procedures”, or “Does eating tomatoes prevent prostate cancer (N.B *uncertainties do not necessarily need to be true or important, simply, questions that you feel should be evaluated further by research*)

Details*: Please give a description, using as many words as you need, of what you or your organisation consider to be unknown about your suggested uncertainty.

Why it is important (optional): If you wish you can add a statement, backed by evidence if you are aware of any, explaining why you believe this uncertainty is important.

Answering the question (optional): If you wish, you may state here the broad nature of the research you think is needed to answer the question posed by your uncertainty.

Evidence (optional): If you can, give any evidence that you might be aware of supporting your belief that this is a genuine uncertainty. Please add many details as you can. Please note, this is not mandatory. Indeed, it may only be your own belief that this is a significant unknown – but be prepared to discover that someone knows the answer!

The closing date for submission of uncertainties is 23rd October 2009.

Uncertainty*

Quantification of Over-treatment

Details*

Frequent claims are made that as many as 50% of prostate cancers detected and treated in symptomless men through use of PSA Test alone are slow growing and require no treatment. These figures are all based on estimates from modelling e.g. autopsy results. There is a need to quantify them based on actual clinical outcome.

Why it is important (optional)

The estimated figures do not correlate well with the actual figures for reduction in mortality. One or other seems to be wrong, and this has important implications for the arguments for and against screening.

Answering the question (optional)

Study clinical outcomes to identify actual cases of over-treatment, and compare with resulting mortality or progression figures

Evidence (optional)

Draismmer et al, Lead Times and over-detection due to PSA screening; J Nat Cancer Inst 2003; 95:868-78

Uncertainty*

Details*

Why it is important (optional)

Answering the question (optional)

Evidence (optional)

Uncertainty*

Details*

Why it is important (optional)

Answering the question (optional)

Evidence (optional)

Uncertainty*

Details*

Why it is important (optional)

Answering the question (optional)

Evidence (optional)

Uncertainty*

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Evidence (optional)

Uncertainty*

Details*

Why it is important (optional)

Answering the question (optional)

Evidence (optional)

Uncertainty*

Details*

Why it is important (optional)

Answering the question (optional)

Evidence (optional)

**Thank you for your invaluable time completing this
survey.**

Prostate Cancer Priority Setting Partnership team