

# Setting priorities for prostate cancer research

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The Prostate Cancer Priority Setting Partnership has itemised the top priorities for prostate cancer research, taking into account the views of both patients and clinicians.

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How do we know whether a research charity's funding programme is making a real difference to the lives of men with prostate cancer? The answer is complex, as some research studies will take many years to bear fruit, while others seek to identify pieces of a puzzle rather than be an end in themselves.

In many cases, the relationship between a research study and eventual patient benefit can seem remote. This can be a source of frustration for patients, clinicians, fundraisers and cancer charities. Often stakeholders do not feel involved in the process of guiding the research agenda.

## THE PROSTATE CANCER PRIORITY SETTING PARTNERSHIP

Working with the James Lind Alliance (JLA; an organisation funded by the National Institute for Health Research and the Medical Research Council set up to bring patients, carers and clinicians together to prioritise unanswered questions in research), the Prostate Cancer Priority Setting Partnership (PSP) recently set about the process of finding out just what patients and clinicians think are the current priorities for prostate cancer research.

### The research challenge for clinicians and scientists

Most clinicians are not involved in the process of setting the research agenda in

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prostate cancer. Instead the vast majority work at the coalface, seeing and treating men according to nationally established guidelines. Those who do get involved in research can be broadly classified into those who undertake clinical research and those who do more laboratory research. The priorities for each group can be very different, although all share the guiding principle of improving care for patients. Traditionally, most clinical academics have been on either one or the other end of this spectrum, although there is now an increase in prominence of those who bridge both ends: the so-called translational scientists.

Currently, clinicians, academic clinicians and basic scientists all apply to the same sources for limited cancer research funding. Thus for academics and clinicians, defining research questions in prostate cancer can be framed by considerations of the funders and their priorities and a limited range of funding resources.

**Involving patients**

Patients and their families are increasingly knowledgeable about their disease through the internet and the media. This has resulted in an increasing interest in what research is being conducted and how it might change treatment and outcomes. Few research bodies have patient representatives on their grant panels. This is changing, however, as the lay community want to be involved in not just donating funds but being a part of the grant allocation process and setting the research agenda.

The aims of academics in clinical research are often similar to those of patients, but necessarily couched in different terminology. As an example, a very common research question from patients is 'How does prostate cancer start?' However, an academic may ask in a proposal 'What is the molecular basis for the transition of a benign prostate cell to a malignant phenotype?' It is the translation of one to

**BOX 1. The top 11 prostate cancer research priorities**

- 1 How can overtreatment for prostate cancer be prevented by identifying and excluding the treatment of harmless tumours?
- 2 Is there a genetic marker for prostate cancer that would be both more sensitive and more specific than prostate-specific antigen (PSA) serum level?
- 3 What can be done to delay or prevent the onset of hormone-independent prostate cancer?
- 4 Are there any dietary measures that can prevent prostate cancer or slow its progression?
- 5 Does serial PSA measurement in patients with prostate cancer accurately monitor disease progression?
- 6 Would prostate cancer screening targeted at high-risk groups, ie those with positive family history, and ethnic minorities with higher rates, improve the outcomes of treatment in these groups?
- 7 Does active surveillance work for management of prostate cancer?
- 8= Is there a vaccine that can prevent prostate cancer?
- 8= Do variations in GP awareness of prostate cancer affect outcomes?
- 8= Are there any non-intrusive diagnostic tests that will identify aggressive prostate cancers while not identifying harmless cancers?
- 8= What is the effectiveness of new treatments for prostate cancer such as high-intensity-focused ultrasound and cryotherapy?

the other that may not be recognised and can lead to the concept that clinicians and academics have different goals to patients.

The results of research are also often presented only at scientific and clinical meetings and rarely reach the lay community. There then seems to be very little tangible output that can benefit patients. In this context, the exercise of getting together patients, clinicians and funders becomes imperative. This collaboration can then set the research agenda in a language that all can subscribe to and feel ownership for. This is what the recent Prostate Cancer PSP co-ordinated by the JLA has achieved. It is indeed notable that many of the research questions were very similar at the end of this exercise, as exemplified by the high levels of agreement on the final top ten priorities.

**ESTABLISHING CLINICIANS' AND PATIENTS' PRIORITIES FOR RESEARCH**

The Prostate Cancer PSP project was a patient-inspired initiative from the start.

In 2009, the patients' representative on the Prostate Cancer Charter for Action proposed that, in updating its 'calls', the charter should suggest some priorities for research. The charter, however, felt that this would be beyond its own working remit. As an alternative, it was suggested that the JLA be invited to make a presentation to charter signatories about their PSP approach to establishing clinicians' and patients' priorities for research. As a result of this presentation, and to their eternal credit, the Prostate Cancer Research Foundation (now Prostate Action) agreed to fund a PSP for prostate cancer.

The process for determining patients' and clinicians' priorities is one that has been developed by the JLA over the past few years. Its primary output is a list of the top ten 'uncertainties', ie things that are not known about the field in question.

An initial call to patients and clinicians for suggestions resulted in more than 250 items, which, after removal of

duplications, was reduced to 134 uncertainties. Stakeholders were then invited to choose their ten most important items. Responses were received from over 40 organisations and individuals. The results of this initial vote were consolidated to reduce the list of uncertainties to one (the 'top 30') that would be manageable in a final stakeholder meeting. In this, approximately 30 individuals, representing clinicians and patients, sat down together to reach consensus on the ranking of the top 30, and agreed a list of the top ten items. Two separate teams (selected at random and reshuffled halfway through) achieved a remarkable consensus over the day, separately nominating exactly the same top seven items. In the subsequent discussions, a

very quick agreement was achieved on the ranking of all the top 30 items. The final 'top ten' (actually 11, as four items tied in eighth place) are shown in Box 1.

From a patient's perspective, it is interesting to note that a number of items address the issue of early detection, which reflects an almost universal common attitude of men who have had prostate cancer: either giving thanks that they were diagnosed early, or regret that they were not. After that, the next most important thing is to reduce the death rate by delaying, or making less lethal, the final stages of the disease.

The presence high on the list of an item about diet reflects the well-known

fact that this is a favourite area for patients. However, research in this area is notoriously difficult to get funded and even more difficult to do in a way that will satisfy the rules of scientific evidence.

The challenge now is to ensure that this list (agreed by patients and clinicians) will change the research agenda – no mean feat in austere financial times. We hope that through articles such as this, clinicians and researchers start to think more about what is not known so that in five years' time we have more answers than questions.

**Declaration of interests:** *none declared.*