Setting priorities for prostate cancer research

SANDY TYNDALE-BISCOE, EMMA MALCOLM AND VINCENT J. GNANAPRAGASAM

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

Sandy Tyndale-Biscoe, Chairman, The Prostate Cancer Support Federation, Stockport, Cheshire; Emma Malcolm, Chief Executive, Prostate Action, London; Vincent J. Gnanapragasam, MB BS, BMedSci, PhD, FRCS, FRCS(Ed)Urol, Lecturer in Uro-oncology, University of Cambridge; Consultant Urological Surgeon, Addenbrooke’s Hospital, Cambridge
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 top ten priorities.

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?
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 remarkably 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.