Dr Anne Mackie  
Director of Programmes  
UK National Screening Committee  
Imperial College Healthcare NHS Trust  
Mint Wing, Centre Block G  
South Wharf Road  
London W2 1NY  

21 September 2010  

Dear Dr Mackie,  

I am writing in response to the UK National Screening Committee’s (UK NSC) current consultation on prostate cancer screening.  

Executive summary  
The Prostate Cancer Charity welcomes the rapidity with which the UK NSC responded to the publication of findings from the European Study of Screening for Prostate Cancer (ERSPC) and the Prostate, Lung, Colorectal and Ovarian Cancer screening Trial (PLCO), to review its policy on prostate cancer screening.  

The Charity accepts the overall findings of this review - that the introduction of a national screening programme for prostate cancer is not currently appropriate given the available evidence about the benefits and harms of such a programme.  

However, the Charity believes it is no longer acceptable for the UK NSC to advocate an ‘informed choice’ approach to PSA testing by relying on the current Prostate Cancer Risk Management Programme (PCRMP) to deliver this opportunity in a way that is fair and accessible for all men.  

The Charity strongly recommends that the UK NSC supports the need for ‘universal informed choice’ - where every man in the UK is able to make an informed choice about the PSA test - and makes a formal commitment to this principle in its final policy statement on prostate cancer screening.  

It is imperative that we move immediately to a position of ‘universal informed choice’ as the ERSPC - the largest trial of prostate cancer screening to date - has demonstrated, for the first time, that screening is beneficial for some men and can reduce prostate cancer mortality. Whilst we await the development of a better screening test, men should not be denied the opportunity to consider the facts about prostate cancer and the PSA test and make an informed choice.
Unfortunately, we believe that many men are currently denied this opportunity because the PCRMP is not being delivered effectively or equitably. The Charity, recommends, therefore, that the UK NSC acknowledge the need for innovative approaches to delivering information to and counselling men about the PSA test, to ensure that every man has the opportunity to make an informed choice.

**The importance of informed choice**
Prostate cancer accounts for around 12% of male deaths from cancer in the UK and is the second most common cause of cancer death in men, after lung cancer. No significant improvement in prostate cancer mortality has been seen and mortality rates have remained fairly constant since the 1990s.

In the UK, national screening programmes have been introduced for other cancers – breast, cervical and colorectal – helping to reduce mortality from these diseases. However, there is currently no prostate cancer screening programme, despite it being the most common cancer affecting men in the UK. This leaves men at a significant disadvantage to women, who are able to access breast screening from the age of 47.

The Charity recognises that prostate cancer screening is not currently advisable because it would lead to a significant level of over-diagnosis and potential over-treatment of prostate cancer. However, for the first time, it has been demonstrated that screening can reduce mortality and the Charity believes it is now imperative that every man has access to balanced information about the pros and cons of the test so that they can make an informed and individual choice about whether to have it.

A consensus about the importance of informed choice has emerged since the publication of the ERSPC data, with the American Cancer Society (ACS) recommending that from the age of 50 men should begin conversations with their doctor about the pros and cons of the PSA test to enable them to make an informed choice. The ACS recommend that these conversations should begin at an earlier age for men at higher risk of the disease.

Men themselves also want access to information to help them make an informed choice about the test PSA test. In a recent survey of men aged 50 to 70 years conducted for The Prostate Cancer Charity, after reading information about the pros and cons of the PSA test, 95% of respondents agreed that all men should be given balanced information about the test to enable them to decide whether they should have it. 90% of respondents also agreed that it should be up to each individual man to decide whether he should have the test.

The Charity is calling, therefore, for 'universal informed choice' - where all men over 50 years and younger men at higher risk of the disease are able to make an informed decision about whether to have the PSA test. Unfortunately, the opportunity to make an informed choice about the PSA test
is not currently available to all men and an alternative approach is required to achieve universal informed choice.

**The need for an alternative approach to informed choice**

As you are already aware, the Prostate Cancer Risk Management Programme has been developed by the Department of Health to provide GPs with the necessary information to help asymptomatic men consider the issues around the PSA test.\(^{(5)}\) The PCRMP has also been adopted by the Health Departments in Scotland, Wales and Northern Ireland.

However, The Prostate Cancer Charity believes that the *opportunity* to make an informed choice is currently outside the reach of most men. This is due to the following factors:

**There is a significant lack of awareness of prostate cancer and the PSA test**

In 2008, a national survey using the Cancer Awareness Measure developed by Cancer Research UK, found that 57% of people do not know that prostate cancer is the most common male cancer and awareness is even lower amongst Black, Minority and Ethnic groups.\(^{(6)}\)

Similarly, a UK-wide survey of 50 to 70 year old men conducted for The Prostate Cancer Charity found that 46% of respondents were not aware that prostate cancer is the most common male cancer. Awareness was even lower amongst men from lower socio-economic groups. In addition, the same survey found that seven out of ten men aged 50-70 surveyed are not aware of the PSA test.\(^{(7)}\)

**The Prostate Cancer Risk Management Programme is not currently being delivered effectively or equitably**

The Charity believes all men should have the opportunity to make an informed choice about the PSA test. However, the PCRMP aims only to ensure that "men who are concerned about the risk of prostate cancer" receive clear and balanced information about the advantages and disadvantages of the PSA test and treatment for prostate cancer.\(^{(5)}\) It is therefore an entirely reactive programme.

**Accessing information about the PSA test**

The Charity believes that currently not all men are able to access information about the PSA test because:

- **A.** The PCRMP aims only to inform men who are concerned about prostate cancer; and
- **B.** The PCRMP is inaccessible to men who traditionally do not visit their GP

**A.** The PCRMP aims only to inform men who are already concerned about prostate cancer. However, the low levels of awareness of prostate
cancer and the PSA test highlighted above mean that many men will not be aware of the disease and/or the test and are unlikely to request an appointment with their GP to discuss their concerns about the disease. Low levels of awareness of the prostate cancer and the PSA test also make it unlikely that men will search online for information and access the PCRMP patient information that way.

Alternative approaches to delivering the PCRMP- that are not dependent on a man's pre-existing knowledge of prostate cancer - are needed if information about the pros and cons of the PSA test is to be fairly available to all men.

B. The PCRMP is also inaccessible to men who traditionally do not visit their GP. It has been hypothesised by organisations, such as the Men's Health Forum, that health services have traditionally been constructed to meet the needs of women more than the needs of men. For example, clinic and surgery opening times often fall within working hours and twice as many men are in work than women in the UK. (8)

A joint report by the Department of Health, the Men’s Health Forum and the University of Bristol, recognised the need to make primary care services more accessible to men by providing:

- a wider range of opening hours
- the delivery of some primary care services in non-surgery settings (e.g. workplaces or community settings); and
- invitations to attend surgery (or other healthcare settings) for a check-up. (8)

The report highlights a need for alternative approaches to delivering primary care services that need to be applied to the delivery of the PCRMP if this information is to be equitably accessible to all men.

GP awareness and use of the PCRMP
Low levels of awareness of the PCRMP amongst GPs also inhibits the effective and consistent provision of this information to men. Three out of four GPs surveyed on behalf of the Charity in March 2010 were unaware of the PCRMP, despite efforts by the NHS to promote the programme and disseminate the revised GP resource pack between July 2009 and March 2010. (9)

In addition, inconsistent practice amongst GPs prevents many of the men who are not aware of prostate cancer from receiving information about the test. Almost a quarter of GPs surveyed reported that they never discuss the PSA test unprompted with asymptomatic men aged 50 to 70 years and half of GPs discuss the test unprompted only 'occasionally'. (9) More worryingly, 1 in 5 of the GPs surveyed reported that they do not raise the issue of the PSA test with men at higher risk of prostate cancer, for
example, men with a family history of the disease and African Caribbean men.\(^{(9)}\)

**GP opposition to the PSA test**
Finally, the Charity is aware that some GPs are not willing to provide balanced information about the pros and cons of the test. Although only anecdotal evidence, we do regularly receive complaints to our Helpline from men who feel they were denied the test by their GP. Furthermore, 15% of the GPs we surveyed stated that they do not support the right of asymptomatic men to have access to the PSA test even after they have considered its pros and cons.\(^{(9)}\)

We need to urgently address these inequalities to ensure that all men have the opportunity to make an informed choice about the PSA test and are not denied the test by their GP.

**New approaches to delivering information to men are needed to enable universal informed choice**
The Charity wants all men to have access to balanced information about the PSA test so that they can make an informed choice. This requires innovative approaches to delivering information to overcome some of the problems outlined above.

In 2007, the Cancer Reform Strategy acknowledged the need to explore alternative approaches to improving the information and support provided to men about prostate cancer and the PSA test because of the complexities around prostate cancer diagnosis.\(^{(10)}\) As yet, no alternatives have been piloted.

Over the past year, the Charity has been working in consultation with health professionals, men aged 50-70 who have not been diagnosed with prostate cancer and other stakeholders to develop three possible new approaches, which seek to provide every man with the opportunity to make an informed choice about the PSA test. An outline of these models and the rationale behind each approach is attached with this letter (Appendix 1).

Over the coming months, the Charity will be seeking to work with the health departments across the UK and other stakeholders to pilot and evaluate these models to better understand the impact they will have on informed choice, prostate cancer diagnosis and the NHS more widely. The Charity would welcome the opportunity to present these models to the UK NSC at your meeting on 10\(^{th}\) November 2010.

The Charity also asks that the UK NSC agree to review the findings from these pilots once evaluated as part of its ongoing review of the evidence into prostate cancer screening.
Responding to new evidence on prostate cancer screening
Due to the increasing media and public interest in prostate cancer screening, it is important that the UK NSC clearly states that it will continue to review new evidence on prostate cancer screening as and when it emerges.

Increasingly, new research data on population-based and targeted screening approaches are being published and it is anticipated that further data from the ERSPC study will be published later in 2010.\(^{(1)}\)

The UK NSC should state clearly when and how it will review new evidence as it emerges to reassure the public that it will be responding promptly to this data.

Thank you for taking the time to read through our response. The Charity is happy for its consultation submission to be used publicly by the UK NSC.

Yours sincerely,

John Neate
Chief Executive

CC. Tim Elliot (Cancer Policy Team, Department of Health); Professor David Neal (Co-Chair, Prostate Cancer Advisory Group), Professor Mike Richards (National Clinical Director for Cancer, Department of Health)

References


(7) ICM Research interviewed a random sample of 1000 men aged 50+ by telephone between 16 and 21 February 2010 on behalf of The Prostate Cancer Charity. Interviews were conducted across the country and the results have been set to reflect the age split and regional split of the over 50’s male population.


(9) Kantar Health interviewed conducted web based interviews with 250 GPs from across the UK drawn from TNS healthcare professional panels. Interviews took place between 5th and 15th March 2010. A quota was set to achieve a sample of 60 GPs based in Scotland.


Appendix 1: Innovative approaches to enable equitable access to information about the PSA test

Traditional approaches to early detection of cancer - through screening or raised awareness of symptoms - are not suitable for prostate cancer. Early stage prostate cancer is often symptomless\(^\text{(1)}\) and screening for the disease using the PSA test carries a significant risk of over-diagnosis, so a national screening programme is not recommended. These complexities require innovative approaches to prostate cancer diagnosis.

In 2007, the Cancer Reform Strategy acknowledged the need to explore alternative approaches to improving the information and support provided to men about prostate cancer and the PSA test because of the complexities around prostate cancer diagnosis.\(^\text{(2)}\) It recommended community-based prostate health clinics as a potential model.

In 2010, no model has been tested despite the publication of research from the European Randomised Study of Screening for Prostate Cancer (March 2009) demonstrating, for the first time, the benefits of early diagnosis of prostate cancer for some men.\(^\text{(3)}\)

The Charity recognises that a national screening programme for prostate cancer is not yet advisable, because it would lead to significant levels of over-diagnosis and over-treatment of the disease.\(^\text{(3)}\) However, the Charity believes that the ERSPC data emphasises the need for all men to have the opportunity to consider the complex issues that surround prostate cancer diagnosis and make an informed choice about whether the PSA test is right for them.

The Prostate Cancer Charity has identified three models through which informed choice could be accessible to all men. Due to the incidence of prostate cancer in older men, the models are targeted at men from the age of 50 years and younger men at higher risk of prostate cancer, such as African Caribbean men and men with a family history of the disease.\(^\text{(4)}\)

The Charity is currently consulting with health professionals, men aged 50 to 70 who have not been diagnosed with prostate cancer and other stakeholders to further develop and refine these models.

**Information and decision-counselling to deliver informed choice**

Men should have the opportunity to consider balanced informed about the PSA test and have the opportunity to be counselled through the decision-making process by a health professional or health adviser.

The following three principles underpin each of the models advocated within this paper:
1. Informed choice
There is currently no screening programme for prostate cancer, but an informed choice approach is advised by the NHS Cancer Screening Programme.\(^{(5)}\)

An ‘informed choice’ is one where a reasoned choice is made by an individual using relevant information about the advantages and disadvantages of all the possible courses of action, in accordance with the individual’s own beliefs.\(^{(6)}\)

To make an informed choice about the PSA test, men need to be able to access balanced information about the pros and cons of the test.

2. Shared decision-making
In addition, men also need to share the decision-making process with a health professional or health adviser.

‘Shared decision-making’ is an essential component of informed choice: it involves a shared responsibility between a patient and a health professional in securing the most appropriate course of action by involving the patient – as much as they wish to be involved – in decisions about their care and treatment.\(^{(7)}\) It is appropriate in all those situations when:

- there is more than one reasonable course of action
- no single option is self-evidently the best one to choose
- different options have different benefit:risk profiles
- patients values, preferences and attitudes to risk are relevant to the decisions about whether and how to treat.\(^{(7)}\)

Therefore, to make an informed choice, men should also have access to a decision-counselling service.

3. The use of decision aids
Prostate cancer decision aids should be used to help men make an informed choice about the PSA test.

Decision aids are “evidence-based tools designed to prepare clients to participate in making specific and deliberated choices among healthcare options in ways they prefer.”\(^{(8)}\) A 2009 Cochrane review of decision aids for people facing health treatment or screening decisions confirmed findings from previous reviews that decision aids performed better than usual care interventions in terms of: greater knowledge; lower decisional conflict related to feeling uninformed; lower decisional conflict related to feeling unclear about personal values; reduced proportion of people who were passive in decision making; and reduced proportion of people who remained undecided post-intervention. Similarly, decision aids resulted in a high proportion of people with accurate risk perception.\(^{(9)}\)

There are already a number of decision aids available in the UK that aim to support men in making the choice about whether or not to have a PSA test, including the
Prostate Cancer Risk Management Programme patient information leaflet and web based resources such as Prosdex.\(^{(5)}\)\(^{(10)}\)

Prostate cancer decision aids improve knowledge of PSA testing, at least in the short term, and make patients more confident about decisions.\(^{(11)}\) For example, the PCRMP has been found to lead to a significant increase in knowledge of prostate cancer and the PSA test.\(^{(12)}\)

**Ensuring equitable access to a PSA information and decision-counselling service**

Currently, not all men are able to make an informed choice about the PSA test, because:

- Men have to visit their GP to receive balanced information about the PSA test
- Not all men are aware of the PSA test and men from less affluent socio-economic groups are less likely to be aware of the test\(^{(13)}\)
- Many GPs are unaware of the Government’s programme for delivering balanced information to men – the Prostate Cancer Risk Management Programme\(^{(14)}\)
- A significant minority of GPs think that men with no symptoms of the disease should not have access to the test\(^{(14)}\)

The Charity wants all men to have access to balanced information about the PSA test so that they can make an informed choice. This requires new approaches to delivering information to overcome some of the problems outlined above.

The following suggested/potential models seek to provide innovative ways to ensure that all men have access to a PSA information and decision-counselling service and are based on recommendations made by a joint study between the Department of Health, the Men’s Health Forum and the University of Bristol, which recommended that primary care services could be more accessible to men if they provided:

- a wider range of opening hours
- the delivery of some primary care services in non-surgery settings (e.g. workplaces or community settings); and
- invitations to attend surgery (or other healthcare settings) for a check-up.\(^{(15)}\)

**Model 1: A GP-led service**

**Rationale**

Traditionally, GPs have played a fundamental role in the provision of information to men about the PSA test. As the first point of health advice for most people, the GP is responsible for responding to patients’ concerns about prostate cancer and guiding them through the decision-counselling process when appropriate.

The Prostate Cancer Risk Management Programme has developed a GP resource pack to enable GPs to deliver balanced information about the test to
men concerned about prostate cancer. A patient information leaflet was provided as part of this pack for GPs to pass on to patients.\(^5\)

However, GPs have only been expected to provide patients with information about the PSA test if and when a patient presents with concerns about the disease. With seven out of ten men aged 50 to 70 not aware of the PSA test, a large number of men do not know that they can visit their GP for this information.\(^{13}\) In addition, three out of four GPs are unaware of the Prostate Cancer Risk Management Programme.\(^{14}\)

It can be argued that the GP is currently best placed to deliver health information to men, offering patients the first point of advice for health information. GPs also see themselves as the gatekeepers to cancer care. A report by the Department of Health and Cancer Research UK found that GPs see themselves as gatekeepers to diagnostic services, vigilantly identifying potential symptoms of cancer and referring to secondary care as quickly as possible.\(^{16}\) A study by The Prostate Cancer Charity also found that eight out of ten GPs felt it should be the GP who delivers information to men about the PSA test.\(^{14}\)

For GPs to effectively deliver information to men about the PSA test a new approach – outlined below - should be pursued to engage all men about prostate cancer and the PSA test to ensure that they all have the opportunity to make an informed choice about the PSA test.

**Key features**

- Men are contacted by their GP surgery from the age of 50 with information about the PSA test and an invitation to attend an appointment to be counselled about the test and a patient information sheet / booklet on the test\(^*\)
- Men are then counselled about the test by either the GP or Practice Nurse
- This discussion could take place as part of a wider mid-life health check and may be preferable in terms of maximising the value of the visit to the GP.

**Alternative models**

Alternative models for engaging men with information about the PSA test may also be required if access to this information is to be equitable. Traditionally, men have experienced worse health outcomes than women. One suggested reason for this is that men are less engaged than women in their health.\(^{15}\)

There is some concern that men experience poorer health outcomes because they do not use traditional primary care services as frequently as women.\(^{15}\) It has been hypothesised by organisations, such as the Men's Health Forum, that health services have traditionally been constructed to meet the needs of women more than the needs of men. For example, clinic and surgery opening times often fall within working hours and twice as many men are in work than women in the UK.\(^{15}\) It is

\(^*\) This patient information booklet could be the PCRMP patient information leaflet or The Prostate Cancer Charity's *Understanding the PSA test* booklet.
thought that by making health services more appropriate and available to men, they will be more likely to make use of them and engage with health information.

Whilst there is little published evidence on how to improve men’s uptake of services, the *Gender and Access to Health Services Study* \(^{(15)}\) argues that community-based outreach services and walk-in clinics may be more successful at reaching men who would not normally visit their GP.

Services delivered in community settings may help overcome some of men’s other reservations, such as only going to see the GP only when they are ‘ill’. Community settings are also well suited to focusing on particular groups of men (e.g. those with lower incomes or from black and minority ethnic communities) rather than all men.

Delivering information and decision-counselling in a community setting may, therefore, be a better way of engaging African Caribbean men with prostate health issues.

Nurse-led NHS walk-in centres also offer an alternative for men to access health advice, providing an efficient and modern alternative to improving access to high quality health care.

**Key features of NHS walk-in centres** \(^{(17)}\)

- Wide opening hours
- Walk-in access
- Convenient location
- Provision of information and treatment for minor conditions
- Offer health promotion
- Build on, not compete with, existing services
- Maximise the role of nurses
- Good links with general practice
- Services that meet the needs of an identified population

The primary aim of NHS walk-in centres is to improve access to health care and a 2002 study found that men aged 50 to 70 years use NHS walk-in centres almost as much as GP consultations. \(^{(17)}\)

**Model 2: A community walk-in clinic**

**Rationale**

The Cancer Reform Strategy (2007) outlined the role that community-based prostate health clinics could play, providing men with improved support when making decisions about further investigation or treatment and ensuring that men have the best possible information and support when making difficult decisions. \(^{(2)}\)
A community-based prostate health service would be there for:

- Men without symptoms considering having a PSA test or equivalent;
- Men with lower urinary tract or other potential symptoms of prostate cancer;
- Discussing with men considering a PSA test the implications of referral and possible prostate biopsy;
- Men diagnosed with benign prostate disease.\(^2\)

The Cancer Reform Strategy also stated that improving the support that men receive will ensure that more appropriate referrals for biopsy or further care will be made, reducing unnecessary interventions and complications, saving significant levels of NHS resources.

**Key features**

- A local walk-in clinic is established where men can come to talk through their concerns about their prostate health and receive information about the PSA test.
- Men are made aware of the service through a local public awareness campaign or receive an invitation to attend the clinic.
- Clinic opening hours are accessible for all men.
- Men can be counselled through the decision-making process by a GP, Clinical Nurse Specialist or other ‘health adviser’ trained in PSA decision-counselling.

**Model 3: A 'roadshow’ clinic**

**Rationale**

Research into interventions to raise awareness of cancer is limited. However, pilots to raise awareness of prostate cancer have recently taken place and focussed on community health promotion techniques in pubs, clubs and workplaces. For example, the Football Foundation's *Ahead of the Game* initiative has sought to raise awareness through the power of football to increase the knowledge of the signs, symptoms and risk factors of bowel, lung and prostate cancer amongst older men (55 years and above).\(^18\)

The use of community health promotion techniques to improve access to information about the PSA test should be explored, ensuring that the opportunity for men to be counselled about the test is an integral part of this service.

**Key features**

- This is a roaming service that takes information out to men, for example, at football matches, in the workplace, to community centres etc.
- Information about the PSA test and the opportunity to speak with a health professional or health adviser trained in PSA decision-counselling would be provided as part of a touring service. For example:
- a ‘roadshow’ could be taken to football matches where information about the PSA test is made freely available and a space is set aside for men to receive ‘on the spot’ decision-counselling
- an occupational health nurse could take the information to men in the workplace and provide them with an opportunity to sit down and talk through the pros and cons of the test

- Methods for raising awareness of the service would vary depending on where the service was taking place on any one occasion.
- Men who wanted further information about prostate cancer and the test or to have a test would be encouraged to visit their GP

**Further considerations**
These models should be considered alongside the following considerations:

**The role of public awareness campaigns**
When raising awareness of prostate cancer and the PSA test, care is needed to avoid misleading people by presenting only the positive side of screening. Campaigns solely focused on raising awareness of the PSA test and its availability through the NHS are not advised. Any public awareness campaign should be focused on raising awareness of the service to ensure that men are directed to balanced information about the test and are counselled through the decision-making process.

**The role of health professionals and advisers**
Traditionally health professionals, particularly GPs, have delivered information about the pros and cons of the PSA test to men, but there is scope to explore the role that other trained health advisers can play.

Research carried out by The Prostate Cancer Charity has found that GPs do not always discuss the pros and cons of the PSA test with men and some GPs do not agree that asymptomatic men should have access to the test.14 GPs are also concerned that taking a more proactive role in delivering information to men about the test they will lead to an increase in demand on their time.14

The role that other health professionals or advisers can play in the delivery of PSA information and decision-counselling services should be considered. For example, genetic counselling may provide an alternative model for training 'health advisers' to deliver information about the PSA test and counsel men through the decision-making process as genetic counsellors enter the field from a variety of disciplines, including biology, genetics, nursing, psychology, public health and social work.

Practice nurses, cancer nurse specialists and community health trainers could also be trained to deliver PSA information and decision-counselling services.

**Next steps**
The Charity is currently consulting with stakeholders, including health professionals and men aged 50 to 70 not diagnosed with prostate cancer, to further develop and
refine these models. The final models should then be rapidly piloted and evaluated to understand the impact that they will have on informed choice, prostate cancer diagnosis and on the NHS.

For further information please contact Katie Scott (Policy and Campaigns Manager, The Prostate Cancer Charity) via katie.scott@prostate-cancer.org.uk or by calling 020 8222 7637.

References
(13) ICM Research interviewed a random sample of 1000 men aged 50+ by telephone between 16 and 21 February 2010 on behalf of The Prostate Cancer Charity. Interviews were conducted across the country and the results have been set to reflect the age split and regional split of the over 50’s male population.
(14) Kantar Health interviewed conducted web based interviews with 250 GPs from across the UK drawn from TNS healthcare professional panels. Interviews took place between 5th and 15th March 2010. A quota was set to achieve a sample of 60 GPs based in Scotland.