

East Lancashire Prostate Cancer Support Group Newsletter



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Staff at Tackle

Burnley prostate cancer charity 'back in the game' with testing day return

Barry Kilby Prostate Cancer Appeal has announced it is 'back in the game' with their first PSA testing day since the start of the pandemic.



The October test day will be held at Burnley Golf Club, Glen View, and will be for members only.

Mr Barry Kilby said: "We have chosen to make the test day a members only and not a public event as this will help us to be able to control the event more effectively with the many government stipulations we will have to put in place.

"This will allow us to plan for more public events to hopefully be held this year. We are really pleased that we will be able to continue to raise awareness of the disease and save lives in the not too distant future".

Alan Green, Burnley Golf Club secretary, said "We are really pleased to be hosting the BKPCA testing at Burnley Golf Club. This life saving opportunity for

our members is not to be missed and we are very grateful to Barry Kilby and his team for choosing us.

"Several members' lives have already been affected by prostate cancer and this is a great chance to detect early and save lives."

The Covid-19 crisis has hit the charity hard with the ever popular annual bike ride postponed until next year, and vari-



ous other events having to be cancelled.

A BKPCA spokesman said: "Our lottery is a great way to support us! For just £10 a month, you could be in with a chance of winning up to £5,000!! Plus there are many other cash prizes to be won.

"The money raised through the lottery goes back into testing men for prostate cancer. Not only could you win, you may just save a life while you are at it."

Prostate Exam

"Ouch"

When I was getting my prostate exam, I asked the Doctor where I should put my pants..



"Over there, beside mine" wasn't the answer I was expecting.



SCREENING FOR PROSTATE CANCER

A risk-based, case-finding approach

A Joint Response to the UK National Screening Committee's Draft 5

SEPTEMBER 2020

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Organisations Supporting This Joint Response



Aylesbury Vale Prostate Cancer Support Group



Barry Kilby Prostate Cancer Appeal



British Uro-oncology Group



Coventry & North Warwickshire Prostate Cancer Support Group



East Suffolk Prostate Cancer Support Group



Friends of Prostate Sufferers



Graham Fulford Charitable Trust



Men's Health Forum



North Hampshire Prostate Cancer Support Group



North Tyneside Prostate Cancer Support Group



Prostate Cancer South



Prostate Matters



South Warwickshire Prostate Cancer Support Group

SCREENING FOR PROSTATE CANCER

A Joint Response to the UK National Screening Committee's (NSC) Draft 5

SEPTEMBER 2020

Executive Summary

Prostate Cancer (PCa) screening with the simple Prostate Specific Antigen (PSA) blood test aims to detect PCa at an early, curable stage. Although fully entitled, most UK men do not avail themselves of the test and GPs are not encouraged to provide the test on the grounds that the "harms" of screening outweigh the benefits of cure for a small number of men with aggressive PCa. However, over 12,000 UK men die from PCa every year, our mortality rate languishes below most of our western neighbours and the UK has not experienced the fall in PCa mortality seen in countries extensively using PSA. Indeed our death rate is rising.

That the "harms" of screening outweighed the benefits was arguably true during the first 20 years of PSA use due to PSA not being a specific marker for PCa and unable to differentiate between aggressive, lethal PCa and non-aggressive, insignificant PCa. Neither was there an accurate, non-invasive second line test to provide the answers. As a result, thousands of men diagnosed with cancers we would now consider harmless, underwent radical "overtreatment" with its significant risk of serious complications – impotence, incontinence and bowel damage. Consequently, in 2015 the NSC recommended against a national PCa screening policy and this has been endorsed by the latest NSC report.

A detailed appraisal of the 2020 NSC draft is attached in the Appendix, but in summary this latest NSC report draws principally on 3 randomised, controlled trials (RCTs) of PSA-based screening to draw its conclusion. Unfortunately 2 of these trials – "PLCO" and "CAP" – are entirely inadequate to draw this conclusion. Regarding the third trial – "ERSPC" – the report has emphasized its flaws but failed to acknowledge an overall reduction of PCa mortality of 30% or highlight individual trial centres within ERSPC reporting 50% reductions in PCa mortality.

Medicine does not advance on the basis of RCTs alone and the report's biggest omission is its failure to connect with actual clinical practice in western Europe and specifically the UK.

During the last 10 years good research evidence and clinical practice in the UK have entirely changed the diagnosis and management of early PCa. The key advances have been:

- The risk factors for PCa have been clearly identified.
- International screening guidelines have achieved a high degree of consensus, and there is comprehensive UK guidance available for the optimum use of PSA.
- mp-MRI has been confirmed as an accurate, non-invasive second line test capable of differentiating between aggressive and non-aggressive PCa.
- Over-treatment of non-aggressive PCa in the UK has been virtually eliminated with active surveillance proven as a safe "treatment" option.
- Screening studies running up to 20 years are demonstrating up to 50% falls in PCa mortality.
- Screening and early intervention is a superior clinical option providing better quality of life and at less cost than lengthy treatment and eventual death from advanced PCa.

In summary, this clinical evidence supports an urgent, clinically driven, re-appraisal of the options now open for PSA-based screening in the UK and a fundamental change in delivery. Anything less would be highly discriminatory.

Introduction

The objective of screening is to identify cancer at an early, curable stage to prevent death from late stage cancer. Prostate Cancer (PCa) is the UK's commonest male cancer and second commonest male cancer killer causing over 48,000 new cases and over 12,000 deaths every year, figures that continue to rise, with deaths now exceeding deaths from breast cancer¹. Half of UK men still present with late stage PCa with no sign that this ratio is decreasing².

However, statistics for England alone in 2018 show a remarkable rise to 49,029 new cases, an increase of 7,828 on 2017 attributed to the "Turnbull/Fry effect"³.

UK Background

In 2015 the UK NSC recommended against the introduction of a PSA-based national screening programme because PSA was not specific for PCa and could not discriminate between aggressive and non-aggressive PCa⁴. The former results in "false positives" leading to unnecessary invasive prostate biopsies whilst the latter leads to detection of non-aggressive PCa for which many men received unnecessary radical "over-treatment". The resultant harms of "over-diagnosis" and "over-treatment" thus outweighed the benefit of cure for a minority of men detected with early, aggressive PCa.

Although the UK has no national screening programme, the Prostate Cancer Risk Management Programme (PCoMPP)⁵ permits men over age 50 to have a PSA test, once counselled by a professional.

Alongside this somewhat paradoxical position, UK clinical practice has made substantial advances. The 6th National Prostate Cancer Audit (NPCA) for the latest clinical year, 2017/2018, shows that mp-MRI scanning is replacing prostatic biopsy as the optimum second line test for men with a persistently raised PSA⁶ and NICE guidance now recommends mp-MRI before biopsy⁷. The likelihood of an underlying aggressive PCa existing when an MRI is normal is extremely low⁸ leading to biopsy rates falling by 30%⁹. If an MRI is abnormal, more accurate, targeted biopsies can take place with the trans-perineal route being increasingly used to lessen the infection rate associated with the trans-rectal route¹⁰.

The 6th NPCA shows that the UK over-treatment rate has now dropped to only 4%¹¹ with Active Surveillance proven as a safe treatment option for men diagnosed with non-aggressive PCa¹².

Unfortunately, UK men still remain largely unaware of the potential risk of PCa and UK PSA test rates have still now remained low¹³. GPs are advised not to "pro-actively raise the question of PSA testing"¹⁴. Two surveys have shown that insufficient GPs are familiar with PCoMPP or have sufficient knowledge to offer balanced counselling^{15,16}. Substantial anecdotal evidence confirms that numerous men, even men at high risk, are refused a PSA test or told to report back only "when symptoms arise"¹⁷; PCa that has grown sufficient to cause symptoms is usually advanced and incurable.

The overall consequence is that the UK death rate from PCa continues to rise and our mortality rate continues to languish below most of our western neighbours.

International Background

In all countries extensively using PSA for screening after its introduction in the 1990s, the PCa mortality rate fell, but at the cost of substantial over-treatment. Whilst urologists then sought to bring order and consensus into PCa screening¹⁸, some early screening trials failed to show that screening reduced PCa mortality¹⁹. Thus in 2012 the influential United States Preventive Services Task Force (USPSTF) counselled unequivocally against screening²⁰. Since then the percentage of US men presenting with metastatic disease has risen²¹ and the death rate has started to rise for the first time²² forcing a change in the USPSTF's recommendation to one of individual, informed decision making for PSA tests²³.

During the last decade well conducted screening studies running up to 20 years are reporting reductions in mortality reaching 50%²⁴ or more²⁵.

Consequently, nearly all current major national and international urological guidelines recommend PSA-based screening for appropriately selected, counselled men who can then make an informed decision^{44,28}. In summary, the majority of international, expert panels recommend men should:

- Screen from age 45 for men with a family history of an immediate male relative with PCa and for black or mixed race men of African or African Caribbean descent (risk 1 in 4).
- Screening from age 45 with a family history of breast or ovarian cancer on the maternal side²⁴.
- Obtain a baseline PSA in a man's 40s to predict future risk:
 - For men aged 40-60 a "normal" initial PSA of 1-2ng/ml carries a 26% risk of later PCa; an initial PSA of 2-3ng/ml carries a 40% risk of later PCa²⁵.
- Do not screen men below 40 or with less than 10 years' life expectancy.
- Link PSA to a "risk calculator" to assess need and frequency of future PSA testing.

Summary of Research, Trial & Practice-based Evidence

- There are no new markers available to replace PSA as the initial screening test for PCa.
- There are comprehensive UK consensus guidelines available on the optimum use of PSA²⁴.
- Men confirm PSA is an acceptable test²⁶.
- PSA is a useful marker for identifying BPH²⁶.
- Risk prediction models can double the sensitivity of PSA for PCa detection.
- Men in PSA screening programmes running for up to 20 years are benefiting from c.50% reductions in PCa mortality with numbers needed to screen and to diagnose falling to 139 and 13 respectively to prevent 1 PCa death - numbers lower than current colon and breast cancer screening²⁶.
- A persistently raised PSA must be followed by second line tests before a prostate biopsy. In the UK mp-MRI is the NICE recommended test²⁶, but numerous blood and urine tests are competing for recognition.
- A normal mp-MRI indicates that a significant, aggressive PCa is unlikely to be present.
- mp-MRI has reduced the number of biopsies by approximately one-third and greatly reduced over-diagnosis.
- The UK treatment options are determined by multidisciplinary teams and together with informed choice have reduced the over-treatment rate over the last 4 years from 12% to 4%².
- NICE approved, individual prognostic models are available to assist men make appropriate choices in the treatment of non-metastatic PCa²⁶.
- Active surveillance is a safe treatment option for non-aggressive PCa²⁶.
- Minimally invasive treatments for localised PCa report reduced side effects and good cancer control.
- There is an economic case for increased PSA screening. PCa develops slowly in its early stages when detectable and curable but when diagnosed at a late stage, treatment is rarely successful and very costly. A robotic radical prostatectomy costs £15,000 compared with a typical cost of £300,000 for late stage palliation²⁷.

A risk-based screening model based on age, race and polygenic risk assessment can reduce over-diagnosis and provide a cost-effective screening programme for large populations²⁸.

Conclusion

The UK's current annual death rate of over 12,000 men – that's one death every 45 minutes – is unacceptable and the NSC report's claim that the harms of screening still outweigh the benefits is no longer valid.

The low rate of PSA testing in the UK has resulted in little opportunity to use the tools we already have for early detection, discrimination between aggressive and non-aggressive cancer and the cheaper option of early curative treatment compared with late, expensive, palliation of advanced PCa. Adoption of proven, best practice use of PSA on a national scale could halve the UK death rate.

The NSC report lacks clinical insight, is retrospective, based on flawed data and totally divorced from current clinical practice. Its adoption will continue to discourage and delay the early diagnosis and cure of men with aggressive PCa and cannot be accepted.

The status quo discriminates against men, especially those known to be at high risk. It is financially unsound and medically unsustainable. We therefore recommend a fundamental change in the delivery of PSA screening commencing with men at high risk as the first steps in establishing a systematic, case-finding approach to reducing the UK's unacceptable death rate from this most pernicious cancer.



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Consultant Urologist (Retired)

Clinical Director, CHAPS Charity

Clinical Advisory Board, National Federation of Prostate Cancer Support Groups

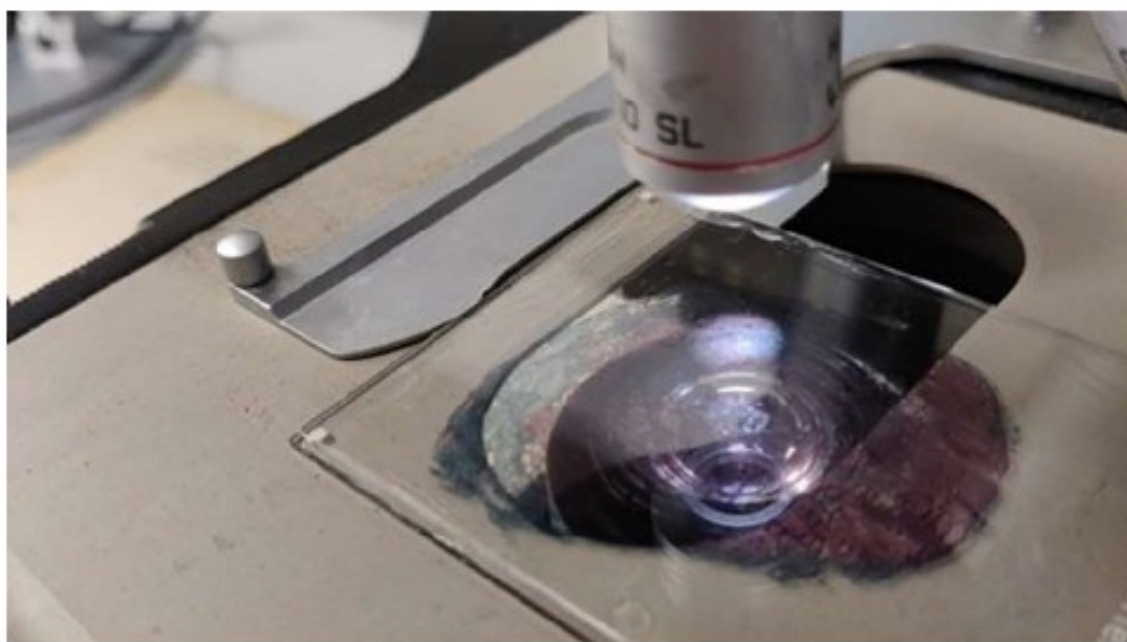
This submission is dedicated to Roger Weir (1949-2019), Chairman, National Federation of Prostate Cancer Support Groups.

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Dr Matthew Hobbs is “doubly excited” by new precision medicines for advanced prostate cancer.

Our Director of Research says thank you to those who've funded 25 years of research that make this progress possible.



22 Sep 2020

In - Research
Precision medicine
Clinical trials
Treating advanced cancer

Comments (1)

We've just seen very exciting results from research into two new precision treatments for advanced prostate cancer.

Our Director of Research, Dr Matthew Hobbs, joined scientists around the world at The European Society for Medical Oncology (ESMO) virtual conference on Sunday. Here Matthew explains the history of precision medicine for prostate cancer, what these results mean for men, and how people like you make this progress happen.

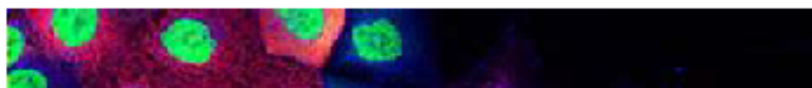


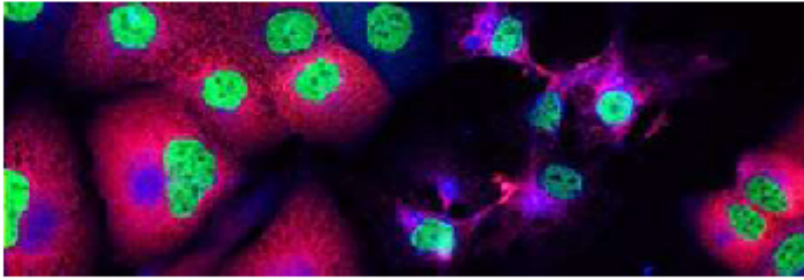
What is precision medicine?

Precision medicine can treat men based on the specific genetic characteristics of their prostate cancer. It means moving away from the one-size-fits all treatment approach that leaves some men responding well for many years, while others see little to no benefit. Ultimately, it will help men live longer and better with prostate cancer.

Precision medicine is already common practice in many diseases, like breast cancer and lung cancer, but has lagged behind in prostate cancer.

That's something we've been working to change for a long time. Especially since 2017, when we funded our two major [precision medicine programmes with help from Movember](#). We aimed to give men access to the new, targeted treatments they desperately need within the next decade. Our goal was to see the first precision medicine available by the end of 2020 with further precision medicines in phase III trials.





Our first success: Olaparib

Thanks to research supported by you, we're now tantalisingly close to making the first precision medicine, olaparib, available for men. Last year, olaparib was proven to slow the growth and spread of prostate cancer in men **with certain genetic mutations in their cancer.**

Back in 2014, Prostate Cancer UK and **Movember** funded research that showed which prostate cancers might respond to olaparib, paving the way for the large clinical trial that has now proven that this drug can extend the lives of men who have faulty DNA repair genes.

New results released this weekend have confirmed it could help those men with advanced prostate cancer to live a further 4.4 months. I'm hopeful we'll see olaparib move through the drug approval process to become available to the men who need it by early next year.

Ipatasertib: 25 years in the making

Now there's a second precision medicine hot on olaparib's heels, and we're not just in Phase III trials, we're seeing the first results from that trial. Ipatasertib works in a completely different group of men to olaparib, in those missing a specific gene called PTEN. Results from the trial show it does this effectively – enough to stop men's prostate cancer progressing for 2 months compared to current treatments. This means it's likely that if we can use more accurate ways to find the men with cancers that are likely to respond, we should be able to get even better results from this drug.

It's incredibly exciting to think after so many years of trying to get to this point, we may see two drugs bring precision medicine to prostate cancer within a few years of each other.

- Dr Matthew Hobbs, Director of Research

Over our 25 years as a charity, we've funded dozens of research projects studying PTEN. Between 40-50 per cent of men with prostate cancer potentially have cancer that is missing the PTEN gene, so we knew it had big potential to impact men's lives. In 2008, ground-breaking results proved us right. Our researchers showed that men with prostate cancer missing the PTEN gene had significantly worse outcomes from their prostate cancer than other men.

This insight ignited a new wave of research into the PTEN gene, to find out how we can treat these men with some of the most aggressive forms of the disease. The results are now credited as some of the most significant in this area by one of the scientists who worked on that research, and the leader of the phase III ipatasertib trial, Professor Johann de Bono. He told us, "The results published in 2010 were the first time anyone had proven how much this common genetic change could influence men's prostate cancer, and showed how important it would be to pursue new understanding and treatments in this area."



Your supporters have been crucial in laying the ground-work for the exciting results on ipatasertib that I presented over the weekend.

- Professor Johann de Bono, Institute of Cancer Research

Your funding has allowed Professor de Bono, along with many others, to investigate treatments for PTEN-deficient men. We've funded a further four research projects worth over £2 million with Professor de Bono to continue his study of PTEN.

He said, "Prostate Cancer UK's support has been tremendously important in uncovering the complex role of PTEN and the impact it could have on treating men with the most aggressive prostate cancers."

Our first successes in a precision treatment revolution

Olaparib and ipatasertib signal the beginning of a revolution in prostate cancer treatment – one that finally works in a targeted, specified way to give men the most benefit possible.

We're funding another four research projects looking at treatments for men missing the PTEN gene. One led by Dr Chris Armstrong at the University of Belfast, has already shown the importance of PTEN loss on treating men with localised prostate cancer. He's shown they're more likely to become resistant to radiotherapy. Understanding the impact of PTEN loss could help us give these men a different treatment, or even better, give them drugs that specifically target the PTEN pathway and make **radiotherapy** more likely to cure them first time round.

I can't wait to see results from projects like these. Our precision medicine programmes continue to deliver results for men with prostate cancer, and I'm confident this is just the beginning of a revolution in treatment that will transform the lives of thousands of dads, brothers, sons and friends affected by prostate cancer. Thank you so much.

Thank you for making this progress in precision medicine possible. **Donate now to keep up momentum**, and help men live longer and better with prostate cancer.



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From Left to Right Hazel Goulding (Treasurer) Leon D Wright (IT Admin) Stuart Marshall (Secretary) Steve Laird (Vice Chairman) Dave Riley (Chairman)

We are a group of local people who know about prostate cancer. We are a friendly organisation dedicated to offering support to men who have had or who are experiencing the effects of this potentially life threatening disease.

The East Lanc's Prostate Cancer Support Group offers a place for free exchange of information and help for local men and their supporters (family and friends) who may be affected by this increasingly common form of male cancer.

At each meeting we strive to be a happy, supportive and upbeat group of people; encouraging open discussion on what can be a very difficult and perhaps for some an embarrassing subject. We have lively, informative, interactive, sharing and above all supportive meetings.



24 Sep 2020

Dear Stuart

It is with great pleasure that I introduce you to Sarah Gray who started working with us last week as our new National Support and Development Manager for the 3-year project funded by the National Lottery.

As you will be aware, the project is to develop and support groups across England and assist them to support their members and encourage new membership, alongside growing our network of patient-led Prostate Cancer Support Groups by working with healthcare professionals to set up new support groups in identified areas and encourage referral for peer-to-peer support.

Sarah comes to us with a wealth of knowledge and experience gained from working in health and social care throughout most of her career. For the last 17 years, she has worked in national and regional roles at Macmillan Cancer Support, Parkinson's UK, the British Lung Foundation and, most recently, at Prostate Cancer UK.

Sarah is currently reading all the documentation and arranging meetings with trustees to gain an understanding of both our organisation and the objectives for the lottery project.

She hopes to meet, albeit in a virtual capacity, with many of you over the next couple of months to learn about your group, and how you can work with her on the objectives of the project.

Her email address is sarah.gray@tackleprostate.org and her phone number is 07725 083533. Sarah works Monday to Thursday.

Best regards
Ken Mastris
Chairman
