

East Lancashire Prostate Cancer Support Group Newsletter



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Are you a man living with cancer or do you know a man living with cancer?

If so, we hope the Look Good Feel Better Workshops for men will be of Interest!



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According to Macmillan, men represent **51%** of people diagnosed with cancer, but only **37%** of the calls to their helpline are from men. Macmillan recognise that men may find it harder to talk about cancer and this is one of the reasons why Look Good Feel Better has developed its services for men.

Our Skincare and Grooming Workshops not only offer some great practical advice from experts in their field, but also provides a safe place for men to connect with others on a similar journey, talk about what's going on and share experiences.

We are pleased to confirm we are running a Workshop on **Friday, 26th February 1 pm to 3 pm** which will be hosted by men's grooming expert, Mark Sproston, aka the Shave Doctor <https://www.shavedoctor.co.uk/> **Why not join us with a cuppa for a couple of hours and let us know what you think?**

The sessions take place on Zoom so the following is needed:

- Internet connection
- Computer, laptop, tablet or smart phone
- Speakers and a microphone **only needed if you are using a computer or laptop without these built in*
- Webcam **only needed if you are using a computer or laptop without a built in camera*



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To make a booking or for more information, please email info@lgfb.co.uk or call us at 07545 551531.

Once a booking has been made, Look Good Feel Better will send out an email confirming the details for Zoom, listing a number of products for attendees to try and bring with them if they want to take part in the demonstrations. This is by no means obligatory as guys are welcome to join us to listen, learn and ask any questions they may have.



Sarah Emerson | Regional Manager North

Prostate Cancer Research Patient Involvement Manager David James Talks on the work of Prostate Cancer Research & Talked on a couple of Specific Projects Which Members can Become Involved in.

In reference to the Plymouth Prostate Cancer Support Group Zoom Meeting
Thursday 18th February at 14.00

I hope this email finds you well.

My name is David, I'm the new Patient Involvement Project Manager at Prostate Cancer Research (PCR). I recently joined PCR to lead on two new patient-centred projects which I hope will be of interest to you and the members of the East Lancashire Prostate Cancer Support Group.

I know it is a challenging time right now, especially not being able to meet in person but I am impressed and amazed by the resilience of the patient community whenever I talk with patients and hear how well they are helping support one another. For everything that you do I thank you.

I was wondering if you would be willing to share some information with your members about our two patient projects which are coming up this month and next. Could you circulate the information below to your members by email and encourage any who might be interested to get involved? Additionally, I don't know if your group is meeting over Zoom at the moment but if you would be interested I would be more than happy to join your next meeting and talk a little bit about our organisation, some of the new research projects we are funding and tell your members some more about these initiatives.

Many thanks for everything that you do.

People who have been affected by prostate cancer are instrumental in shaping what we do at Prostate Cancer Research, so we're launching two new patient-centred projects starting this month. You don't need any medical knowledge to take part and would love for you to get involved if you can!

1. The Infopool

We'd like to invite you to help us develop our upcoming information and education website, called The Infopool. On The Infopool you'll have the chance to find out about – and share your views on – developments in prostate cancer diagnosis and treatment, including participating in a short survey. The aim of this survey is to ensure new treatments and clinical trials are designed with patients in mind and prioritised at the start. It is open to all patients. To find out more and get involved please click [here](#).

2. Talking Taboos

We're also running a special patient survey with Ipsen UK&I to understand topics that patients find most tricky to talk about. The hard things that come with prostate cancer may include the loss of sexual function, incontinence, fatigue, body issues and mental health challenges – and we'll use information drawn from the survey to launch a national campaign to raise awareness around these “taboos”. Patient involvement is key to showing others it's okay to discuss the issues that are hardest to face. More information will be available on our website later in the month: <https://www.prostate-cancer-research.org.uk>

By sharing your views on these you are helping us help other patients with prostate cancer in one of the most effective ways we can. Thank you!

Many thanks,

David James

Patient Involvement Project Manager

Prostate Cancer Research

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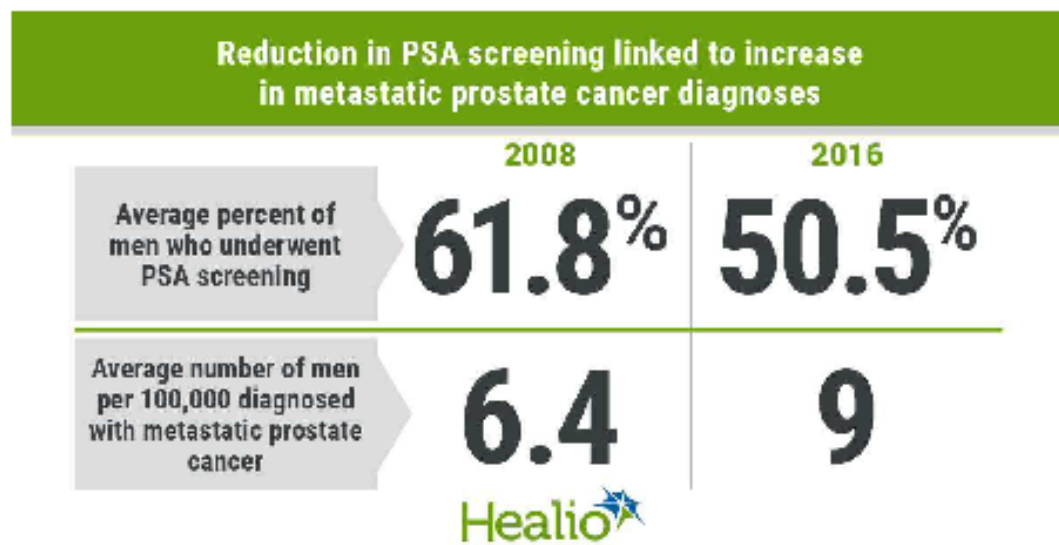
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Fewer PSA screenings linked to increases in advanced prostate cancer diagnoses

U.S. states with larger declines in PSA screening from 2002 to 2016 also had larger increases in incidence of metastatic prostate cancer at diagnosis, according to a presentation at Genitourinary Cancers Symposium.

"Our data strengthen the epidemiologic evidence supporting that the rise in metastatic prostate cancer at diagnosis may at least in part be explained by the decline in PSA screening, since states with larger declines in PSA screening tended to have larger increases in metastatic disease at diagnosis," Vinit Sharma, MD, health services fellow in urologic oncology at University of California, Los Angeles, told Healtio.



Sharma and colleagues had noticed an increase in metastatic prostate cancer at diagnosis in recent years and that the timing coincided with [U.S. Preventive Services Task Force recommendations against PSA screening](#) in 2008 and 2012. But the association of these factors had never been tested.

Researchers used 2002 to 2016 data from the North American Association of Central Cancer Registries to obtain age-adjusted incidences of metastatic prostate cancer at diagnosis, and they used the Behavioral Risk Factor Surveillance System to obtain data on PSA screening estimates for each state. They then combined these screening and metastasis data as a multipanel time series, which they analyzed using a random-effects linear regression model with random effects at the state level.



Vinit Sharma

"We had to break down data by looking at the individual states because if we looked at national data, there simply weren't enough years since the USPSTF recommendations to adequately associate changes in PSA screening with metastatic disease," Sharma said. "For instance, we considered using an interrupted time series approach with national data, but there were just too few data points (one per year available) since the new recommendations. Thus, we had the

idea to examine each individual state's PSA screening and metastatic prostate cancer at diagnosis data

points over time. We reasoned that there would be variation in changes in PSA screening over time between states, and thus we could test if this variation in PSA screening was associated with variation in metastatic disease at diagnosis between states and over time.”

In his presentation, Sharma showed those variations and the correlation between reductions PSA testing and increased prostate cancer diagnoses.

“[Prior to 2010], there was significant variation between states in PSA screening,” Sharma said.

“However, after 2010, there was a significant decrease in PSA screening across states. Similarly, [when looking at] incidence of age-adjusted metastatic prostate cancer at diagnosis per 100,000 men by state, once again, there is a significant variation between states but after 2010, the incidents rise across states.”

The percentage of men who reported ever receiving PSA screening ranged from 40.1% to 70.3%, and the age-adjusted incidence of metastatic prostate cancer at diagnosis ranged from 3.3 to 14.3 per 100,000, according to Sharma and colleagues.

Results showed the average percentage of men aged 40 years or older who underwent PSA [screening for prostate cancer](#) decreased from 61.8% in 2008 to 50.5% in 2016 and, at the same time, the average number of men diagnosed with metastatic prostate cancer (after adjusting for age) increased from 6.4 to 9 per 100,000 men ($P < .001$ for both).

The random-effects linear regression model showed the longitudinal reductions in PSA screening among states correlated with increased metastatic prostate cancer diagnoses (regression coefficient per 100,000 men, 14.9, 95% CI, 12.3–17.5). The variations in PSA screening explained 27% of the longitudinal variation in metastatic prostate cancer within states, Sharma and colleagues wrote.

“Broadly speaking, our study argues against a unilateral ‘never PSA screen’ approach, given the association with the decline in PSA screening and the rise in metastatic prostate cancer at diagnosis at the state level,” Sharma told Health. “Instead, we would recommend a shared decision-making approach with men who are candidates for PSA screening to help them make an informed decision.”

That includes the approach outlined in the updated USPSTF guideline, issued in 2018, which recommended screening as an option for men aged 55 to 69 years after a discussion with their clinician about the possible harms and benefits.

“Our study highlights that methods are also needed to optimize PSA screening practices, such that the harms of overdiagnosis and overtreatment of low-risk prostate cancer are balanced with the harms of missing more aggressive disease that can metastasize,” Sharma added.

Read more about:

[prostate cancer](#)

[metastatic prostate cancer](#)

[university of california los angeles](#)

[prostate-specific antigen](#)

[cancer screening](#)



**PROSTATE
CANCER UK**

Have you had a remote consultation for prostate cancer?

[View this email online](#)



Hi David,

Have you had a phone or video appointment with your hospital doctor or nurse during the pandemic?

If the answer is yes, we want to hear your views on them.

Please take our 10-minute survey so that **YOUR** views can help men with prostate cancer have the best experience of appointments in the future.

[TAKE THE SURVEY](#)

Your answers will help us understand:

- What men do and don't like about phone and video appointments
- Whether certain types of appointments work better over phone, video or in person
- Whether men want to keep having remote consultations once the covid-19 pandemic has ended.

Thank you for helping men to have the best possible experience of prostate cancer appointments in the future.

Kind Regards,

Rebecca Leszczynski
Senior Knowledge Officer
Prostate Cancer UK



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Unsubscribe:

[Unsubscribe from emails about our surveys](#)

[Unsubscribe from all Prostate Cancer UK emails](#)

Follow this link for the survey: [Experience of Remote Communications for Prostate Cancer Survey \(tolunastart.com\)](https://tolunastart.com)

**HAVE YOU HAD A REMOTE CONSULTATION FOR
PROSTATE CANCER?**

Sign our letters: Stand up for men caught in tug-of-war between NICE and Janssen

Search this on PCUK Website [Men set to lose out in abiraterone tug of war \(prostatecanceruk.org\)](http://prostatecanceruk.org)



[View this email online](#)



[Sign our letters: Stand up for men caught in tug-of-war between NICE and Janssen.](#)

David, do you believe men should have access to cost-effective treatments that can give them more time with their loved ones, regardless of where they live, their age or other conditions they have?

Abiraterone is a hormone therapy that's currently extending the lives of men with late stage advanced prostate cancer. Anyone currently having abiraterone treatment will continue to receive it, but unless we change the course of an ongoing approval process, men with earlier stage disease may miss out on this life-extending treatment in future.

What happens if we do nothing?

Men in England, Wales and Northern Ireland who can't tolerate chemotherapy, because of their age or other conditions, may lose out on additional months of life. Worse still, this decision could set the tone for other similar treatments down the line, with many more men missing out on time with their loved ones. This is our last opportunity to influence this decision and we need you to [send a message to NICE and Janssen](#).

Tony Collier (pictured above), has benefited from abiraterone for 4 years to manage his advanced prostate cancer. He says:



I know the difference abiraterone can make. I think this rejection is absolutely shameful. I want as many people as possible to sign up to **Prostate Cancer UK's campaign asking them to reach an agreement that puts men first.**

Tony Collier

Who can change this decision?

The National Institute for Health and Care Excellence (NICE) determines whether new and existing treatments and technologies provide cost-effective benefit for use on the NHS. Janssen make the hormone therapy, abiraterone. They cannot put their differences aside on the evidence required, and an affordable price. Men are caught in the middle of this tug-of-war. **We're extremely concerned that NICE is once again**

near to rejecting abiraterone as a first-line treatment that can give these men additional months of life. We urgently need both parties to put their differences aside and work together on the solutions that will give these men access to abiraterone.

What can I do?

Join us to urge key decision makers in both parties to work together for men across the UK, now and in future. [Please sign our letters to NICE and Janssen to show you stand with men and their families.](#)

SIGN THE LETTERS NOW

Men, we are with you.



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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.