

prostate matters

The Newsletter of The National Federation of Prostate Cancer Support Groups

Free Help Line - 0800 035 5302

prostate cancer

Action for patients

Registered Charity No. 1163152

May 2019 issue 44



Cycle to the Moon #Save a dad

Get on your bike...

I make no apologies for taking space in Prostate Matters again to publicise our continuing campaign to raise £250,000 (one pound for every mile from here to the moon).

Our relaunch for 2019 still has **Cycle to the Moon** as the theme, and we are contacting cycling clubs across the country to encourage them to support the campaign, which runs from March to September this year. Recognising the value of organised charity bike rides, we have secured a number of places at key cycling events this year, as a way of encouraging cyclists to raise as much money as possible towards our target. We already have three Tackle riders lined up for the 'Prudential 100' ride, which follows the 100-mile London Olympic route through Surrey and Kent this summer. We have five places on offer for the Liverpool Midnight ride in June and five more for the London to Brighton bike ride in September. These places are on a first come, first served basis. Please see our website for more details and some examples of the publicity we are receiving.

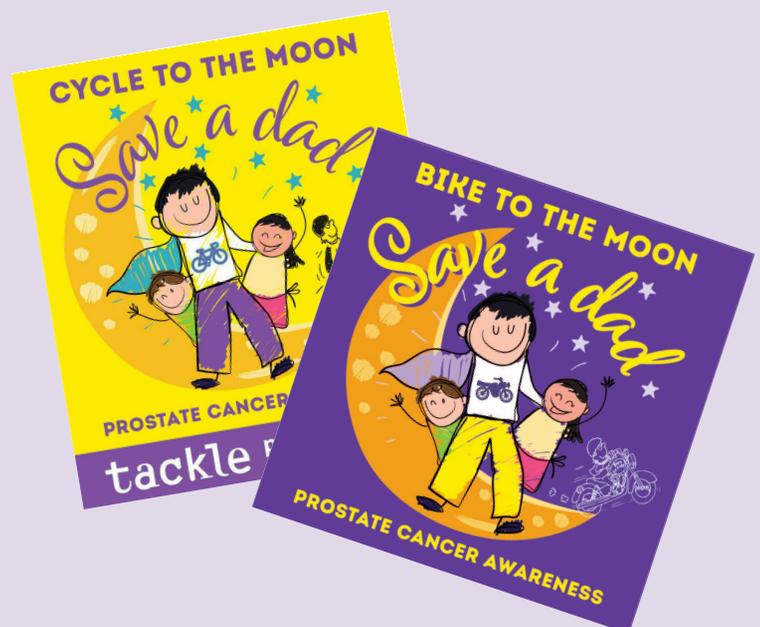
... or your motorbike

This year sees an added dimension to the campaign, namely **Bike to the Moon**. Many motorcycle clubs are generous donors to charitable causes and the age profile of many of their members is probably when men should be getting tested for prostate cancer. We're targeting events and rallies where you see lots of motorbike enthusiasts and have been

lucky enough to secure a stand at several Classic Racing Motor Cycle Club events around the country. It's possible we may get a stand at this year's Isle of Man TT race, too. The British Motorcycle Federation is also supporting the campaign.

Whether it is cycling or motorbiking, I would like to encourage all our support groups to think about organising an event, or individual sponsorship, so that we can work towards our overall target. Just visit us at www.cycletothemoon.tackleprostate.org.

Roger Wotton, Chairman of Trustees



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Mental health and prostate cancer: the elephant in the room?

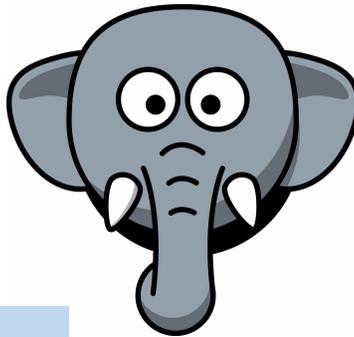
For a considerable time now, I've been very concerned that little has been done to look into the mental health aspects of living with prostate cancer. This is not just about us men suffering from the disease, but also about the effect on our loved ones.

Lockdown

How many of us at diagnosis go into some sort of lockdown? Finding that we didn't want to, or couldn't, talk to our loved ones about it, let alone anyone else? Perhaps we took the view that we can just thrash about in our bubble, not knowing where we want to go, living in a sort of mist, finding our energy levels are being slowly sucked out of us.

As time goes by, dealing with treatment options, we start on the pathway of change with feelings of denial, depression, anger, emotional outpourings, deep hurt, and other symptoms such as:

- Uncertainty about the future
- A feeling of loss
- Unable to understand feeling down about things
- Post-traumatic stress
- Anxiety and panic attacks (with or without continence issues)
- Irritability due to lack of sleep



What to do about it?

I don't have any easy answers but I do know we need to talk about this more; to understand how widespread the problem really is and see if Tackle, as a patient-led organisation, can help those affected. I know from Roger, our Chairman, we've embarked on a Freedom of Information request from NHS trusts across the country to try and establish what is being done. I look forward to what this will tell us, but I feel we might be disappointed with the results.

Perhaps we can do something through our support group network? As many of us meet others at meetings and events such as our annual conference, perhaps we should talk openly about the scale of the problem, to discover and understand what groups are doing already to help address the issues, and see if, together, we can develop an action plan.

Maybe we could involve some of the professionals to help us understand the problem and issues more?

Post-treatment sessions?

Finally, should we not be pushing for everyone to have a psychological session with an expert post-treatment? That would be a start. I shall be at our annual conference in June (see page 3) and would be happy to have a discussion on this topic with any colleagues also attending.

It seems to me there is an elephant in the room when it comes to talking about mental health and prostate cancer.

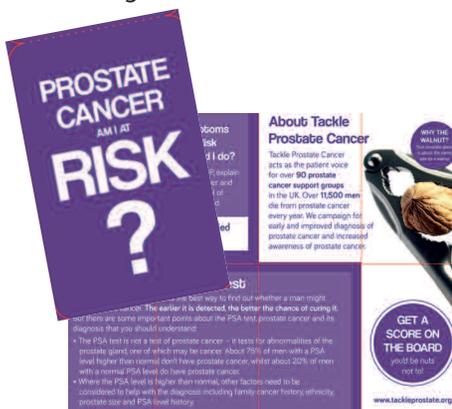
Article: Andrew Spencer, Derby Prostate Cancer Support Group

NEW! Z-fold leaflet

This smart, z-fold leaflet, which folds to a neat credit-card size, is perfect for handing out at awareness events. As the cover suggests, the main aim of the leaflet is to alert men to the risks of prostate cancer and urge those particularly at risk to 'get a score on the board' – in other words have a PSA test.

You can see the full text on [Tackle's website](#), which also gives details of how to order them.

All leaflets are free to members but we do charge P&P.



Shepway Veterans take on 3 Peaks Challenge for Tackle

Seven hardy (or foolhardy?) chaps in the Shepway area, Kent, decided to form a group to attempt challenges in aid of men's cancer charities. All of the men are over 45 and have loved ones lost to cancer, or still battling the disease (one group member is a survivor himself).

They hit upon the National 3 Peaks Challenge (to climb the highest peaks in Scotland, England and Wales in 24 hours) as a suitably crazy and attention-grabbing start.

They've already managed to get some great financial support out of a local company and have set up a donations page for anyone who would like to contribute at:

www.uk.virginmoneygiving.com/shepwayveterans

The brave Vets set off on 10 September 2019. Follow their story in forthcoming issues of Prostate Matters.

New state-of-the-art Urology Centre



On Tuesday 5 March 2019, Professor Stephen Langley, a member of the Tackle Medical Advisory Board (left), welcomed HRH the Duke of Kent to open the new £6m Urology Centre at the Royal Surrey County Hospital. Some £3 million was donated through the Prostate Project, spearheaded by chairman Colin Stokes MBE, who was treated for prostate cancer at the Royal Surrey 23 years ago. The rest of the £6 million cost has come from the NHS.

The new building, named the Stokes Centre of Urology in honour of Colin Stokes, features a cutting-edge theatre for brachytherapy. It also includes ultramodern consulting and treatment rooms, and a research laboratory.

Professor Langley told the audience that the opening of the centre was a 'dream come true'.

tackle AGM and Conference 2019

Theme: Prostate cancer – to screen or not to screen?

- Date:** Thursday 13 June 2019
- Venue:** Hornton Grange, 53 Edgbaston Road, Edgbaston, Birmingham B15 2RS
- Time:** The event starts at 10.30am and finishes at 4.30pm.
- Join us:** To reserve places, please register online here:
www.tackleprostate.org/agm-registration.php

We hope to see you there!

PSA testing success

Bedfordshire Prostate Cancer Support Group

The Bedfordshire PCSG held two free PSA testing days in Bedford during autumn 2018.



Signing in the mayor of Bedford

In September, we planned for 150 to 200 men but over 500 turned up, many with wives/partners making sure 'their man' didn't duck out at the last minute.

The phlebotomists from the Graham Fulford Trust were fantastic and didn't stop bloodletting for four hours. They'd brought 300 testing kits, but still 200 men had to be disappointed. We took their details and promised another testing day which we held on 10 November.

We were very surprised by the response at the first test day, but

recognise the efforts of all on the committee in publicising the event with flyers posted in many different places, a promotion slot on BBC Three Counties radio, advertising in local papers and on our Facebook page.

Altogether, we tested 436 men: 96 at 40 years; 135 at 50; 122 at 60; 65 at 70; 17 at 80 and 1 at 91. Twenty-three men tested at significantly over the PSA level for their age and 27 had raised levels – showing the message about the importance of the PSA test is spreading.

We hope we've helped some men by early detection of prostate cancer and alerted others to the risk, even if they weren't tested at our events.



Attendees queuing/filling in forms

Article: Steve Pearce

PSA testing events

If your group is holding a PSA testing event, we'll add it to the list on the Tackle website. Email info@tackleprostate.org with the date, time, town, postcode, contact name and phone number.

NEW!

Fundraising tips

Waitrose: Community Matters

Each month, every Waitrose branch donates £1000 to local good causes nominated by customers.

At the checkout, shoppers are given a green token which they can pop into one of the three Community Matters boxes they'll find on the way out. The money pot is divided according to the number of tokens each cause receives.

Your Prostate Cancer Support Group is eligible for this in-store initiative. All you need to do is go to your local Waitrose branch and ask for a nomination form, then fill in a few details about the support group and what it does.

Spread the word, and any time anyone shops in Waitrose they can collect a token and donate.

It's as easy as that!

If you have any quick and easy fundraising tips, please let us know and we'll publicise them in future issues.



Thank you to David Marsh

David Marsh, one of our long-term supporters, has held the fort on Prostate Matters since we lost Hugh, and has done a splendid job as interim editor. I would like to express my personal thanks for his commitment and professionalism. Taking over is Cheryl Lanyon, a professional editor helping us on a pro-bono basis, for which we are grateful.

Soon, we plan to survey our members about what they would like to see in Prostate Matters. If you have any views or comments, please email: editor@tackleprostate.org.

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European Association of Urology issue new policy paper on PSA testing

At the 34th annual EAU Conference in Barcelona, Professor Van Poppel of Belgium said that new evidence had emerged to demonstrate that a lack of PSA screening is reversing the trend of declining death rates for prostate cancer.

He said that because PSA testing has been discouraged, there is now an increasing mortality rate for prostate cancer in the USA; and more men are diagnosed late with advanced or metastatic disease in the UK.

The Professor admitted that the PSA test had been misused in the past but that doctors now have the tools they need to use PSA in a really smart way. They no longer 'over-detect' or 'over-treat' cancers.

The EAU has issued a second policy paper to address the need to reconsider structured, population-based screening for prostate cancer.

Studies in the UK and Holland, for example, some with as much as a 19-year follow-up, show more than 50% reduction in prostate cancer mortality with the use of PSA testing.

The EAU wants to bring these results to the attention of the EU parliament and have talked to MEPs and MACs (MEPs Against Cancer) about advocating the use of the PSA test in their countries.

Source: EAU video, 16 March 2019

Free website available from Tackle

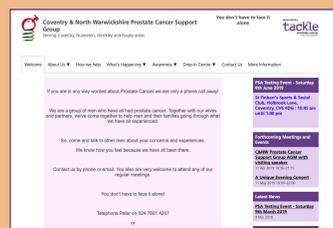
Would your group like a website? Are you looking to upgrade your website? Is your website costing you a lot? If you answered yes to any of these questions, why not consider Tackle's Group Template website.

Peter Smith from Coventry & North Warwickshire PCSG www.cnwpcsg.org.uk recounts his experience below.

If, like our group, you want to have a modern-looking website that's straightforward to maintain, try using the Tackle template to easily create your own site. Our group has been using it successfully for over two years and it serves us well.

Our key requirements were to:

- have a website which had a good feel about it – not amateurish (like our previous one)
- have a website which displayed well on a variety of browsers and smaller screens, especially mobile phones
- maintain the site ourselves. Therefore, it needed to be quick and easy to maintain so that any computer-savvy person could update it
- Contain costs – in fact, courtesy of Tackle, it costs us nothing because they pay for the hosting.



Welcome page of the North Warwickshire PCSG website, made using the Tackle Group Template website.

The Tackle template meets all our basic requirements.

Some particularly nice features are:

- You just enter a list of forthcoming events. They will be displayed in date order and when the date has passed that event is no longer available to view. This means the next event is always top of the list. Likewise, recent events are listed with the most recent at the head of the list.
- We list all our meetings and PSA testing sessions, and because it's so easy to maintain we include other relevant events such as neighbouring support group meetings and the Tackle AGM. It also encourages us to report on recent events, with photos wherever possible.
- The ability to draw particular attention to certain events and features, such as our next PSA testing session and the next couple of forthcoming meetings. This is done via 'adverts' in a side panel which is displayed alongside every standard page.

Finally, as well as the readily available support and advice provided by Tackle, several support groups are using this free template so there's advice and experience available should you need it.

To find out more, go to: www.tacklegroups.org.uk.

Tackle goes to the House of Commons

On 27 February 2019, Tackle co-hosted a discussion on screening for prostate cancer in the Churchill Room at the House of Commons. CHAPS and Orchid co-hosted. The evening was organised by Chris Booth, a member of Tackle's Clinical Advisory Board, and sponsored by Lord Bernie Ribeiro, Sir Bernard Jenkin MP and Mrs Ian Hunter.

Monique Roobol-Boots, a Dutch researcher in the Urology Department at Erasmus University in Rotterdam, gave an excellent presentation, clearly concluding that targeted screening for prostate cancer was beneficial.



Sir Mike Richards, an oncologist who was National Cancer Director in the UK from 1999 to 2013, gave an overview of the development of prostate cancer research over the years, recognising the advances made, but he stopped short of recommending screening.

Lord Ribeiro commented:

"The keynote speech struck just the right chord and will send many home appreciating the need for targeted screening, a powerful message."

Death – we need to talk about it

From an article by Keith Cass MBE, founder of the Red Sock Campaign, in the BMJ 5 September 2018

When I first saw Mark – my palliative care consultant – we talked mainly about my pain, which was poorly controlled at that point. I have advanced prostate cancer, and it has spread to nearly every bone in my body.

At my next visit the pain had improved substantially, and we talked about my wishes should I become more unwell. When Mark first mentioned 'Do not attempt cardiopulmonary resuscitation' (DNACPR), and what my views on it might be, I was taken aback. Of course I want everything done. I don't feel so bad — sign me up for full resuscitation please!

Using social media

Mark accepted my reaction, but it became clear that he thought that many people have a rose-tinted view of how successful cardiopulmonary resuscitation (CPR) is, perhaps because of how it is portrayed on television. He suggested I look at the TalkCPR website and videos on <http://talkcpr.wales>, and search for the #TalkCPR hashtag he has set up on Twitter, to understand more about CPR in palliative care settings.

So I followed Mark on Twitter and looked at some of the debates and videos that he helped create with patients and carers. The first thing I took in was the low success rates of CPR for patients when the cancer has spread. Then I read what CPR involves.

Changing my mind

At subsequent visits with Mark, I gradually changed my mind. At first I thought that conditional CPR might be acceptable. We terminally ill cancer patients live in hope that a cure for our cancer will be found 'tomorrow'.



But when I discussed it further and reflected on it as 'just one procedure of many' – an invasive and traumatic one which was unlikely to work – I asked to fill in a DNACPR form. I specified my views, stating that I would still be keen to be considered for anti-cancer treatments such as chemotherapy, but if it came to CPR I did not want it. The main influence on my decision was the (low) success rate and the possible damage to my body that would make survival with quality of life almost impossible.

Mark and his colleagues tell me they still see many cases where the absence of a DNACPR or Advance Decision to Refuse Treatment form means that healthcare workers start resuscitation by default, even in patients where a natural, irreversible dying process has begun.

Talking to loved ones

It's not easy to contemplate your own death, but I approach it with some black humour, and my palliative care and oncology team are also good at sharing a laugh about some of the crazy things we discuss. I keep the DNACPR form with me at all times so healthcare professionals can be aware of my wishes, and I've told everyone around me about it. My (grown-up) children were the first to know my decision at each stage and how I had arrived at my final decision of DNACPR.

I'd like doctors and nurses to take the time to talk about the complex issues with patients and their loved ones to create a shared decision-making process. CPR in palliative care is difficult to discuss and some people may find it distressing, but doing so early means patients know the pros and cons and can have an intelligent conversation with their healthcare professional and explain their views to family and friends.

Keith sells tickets to his own funeral

In December 2018, Keith gave an interview to ITV Wales, explaining why he's selling tickets to his own funeral. He said that when he received his cancer diagnosis twelve years ago:

"I thought that's it, my life has gone."

He feared he would never see another birthday or Christmas and that his three-year-old grandson would not remember him.

Now he thinks it was really just the beginning. He set up the [Red Sock campaign](#) in 2007 to help others diagnosed with prostate cancer and their carers. Keith's campaigning has helped thousands of men by raising awareness of the disease.

Now, Keith is preparing for his final goodbye with one last fundraising effort – selling tickets to his own funeral. People who go to the funeral can expect something a bit different.

"I want it to be the best, and the most different, funeral," Keith said. "There'll be a gold room, a silver room and a bronze room. I'm going to pre-record it, so that I can lead the whole thing. I want them to go away sailing. I want them to go away saying, 'Keith made a difference.'"

All the money raised by the funeral will go towards equipment for cancer patients and funding more research.



The National Prostate Cancer Audit 2018

Published February 2019, covering the period 1 April 2016 to 31 March 2017

A report by a patient, Steve Allen, Reading PCSG

The National Prostate Cancer Audit collects clinical information about the treatment and outcomes of all patients newly diagnosed with prostate cancer in England and Wales. It includes information from hospital records and directly from patients, which is then used to help define new standards for diagnosis and treatment outcomes.

The Audit is prepared by clinicians, audit experts and cancer information specialists at the Royal College of Surgeons of England, the British Association of Urological Surgeons and the British Uro-oncology Group. Its findings are entirely independent and are generally regarded as the most recent and reliable source of information on current practice and outcomes relating to the treatment of prostate cancer.

The original report is 62 pages long and very detailed. Fortunately, a Patient Summary is also published.

Below are some of the main facts from the 2018 Report. Comments after each section (in blue boxes) are by Steve Allen personally and don't necessarily represent the opinions of Tackle Prostate Cancer.

Patient characteristics

Data for England quoted; data for Wales similar.

**42,975 men diagnosed with PCa
(41,739 in 2015/16)**

- 12% men aged under 60**
- 33% men aged 60 – 70**
- 37% men aged 70 – 80**
- 17% men over 80**

• Great efforts are being made to raise awareness of PCa in men over 50. These statistics show the numbers of men diagnosed – not how many were actually tested. Possibly, many men under 60 were tested but no cancers were found.

• Overall, prostate cancer remains a cancer of the older man, but one where diagnosis in younger men is increasing – an age group where side-effects of treatment and adverse events can have devastating consequences on quality of life.

• There is still a large number of men being diagnosed over the age of 80 despite the consensus opinion that PSA testing is not always appropriate in this age group.

• The report does not identify the severity of disease diagnosed in each age group. It would be interesting to know if younger men coming for PSA testing were more likely to present with more aggressive disease than other age groups. My perception from involvement with many support groups is exactly that: younger, often asymptomatic, men seem to be diagnosed with more aggressive disease than in older age groups.

Stage of cancer at diagnosis

Data was available in 94% of patients diagnosed.

- 16% had metastatic disease**
- 39% had locally advanced disease**
- 3% mixture of above**
- 35% had intermediate disease**
- 7% had low risk disease**

These figures are similar to the previous year's report.

- It seems men are still not being diagnosed early enough. Only 7% had low-risk disease, 55% had metastatic or locally advanced disease. We cannot afford to reduce efforts at raising awareness of PCa.
- It is estimated that the cost of early 'curative' treatment is €15,000 compared with €300,000 for the long-term treatment of advanced disease.

Multiparametric MRI (mpMRI)

The use of mpMRI continues to increase.

- 58% of all scans performed were mpMRI**
- 80% (England) of scans performed before biopsy (41% in Wales)**

- Tackle, along with other groups, have championed the use of mpMRI earlier in the diagnostic pathway and before biopsy. This is now undoubtedly coming into routine use. It is now supported in the recently updated NICE Guideline for PCa.

Use of prostate biopsy

Trans-rectal ultrasound (TRUS) guided biopsy remains the most common technique used.

Data for England only available for 54% of patients diagnosed. Data for Wales available for 100% of patients, but overall total numbers much lower.

	England	Wales
TRUS	88%	96%
Trans-Perineal	12%	4%

- Template biopsy giving multiple samples is perhaps the commonest reason for using the perineal approach. It normally requires a general anaesthetic, which may explain low uptake.
- Increased use of mpMRI and more accurate localisation of tumour tissue may lead to increased use of trans-perineal for targeted biopsies.
- Trans-perineal biopsy may have a lower incidence of adverse events than the trans-rectal route. The current data for England is split equally between template biopsy and trans-perineal sampling.

Are we improving treatment of patients?

Low-risk disease:

4% men 'over-treated' 2016 /17

8% men 'over-treated' 2015/16

- A major cause for concern in raising awareness of PCa and increasing the uptake of PSA testing has always been the possibility of over-diagnosis and over-treatment. The latest figures show a continuing downward trend, demonstrating the accuracy and efficacy of the diagnostic pathway in current use.

Locally advanced disease:

33% men 'under-treated' 2016/17

27% men 'under-treated' 2015/16

- Under-treatment is suggested here when men with locally advanced disease are treated with ADT (hormone) therapy alone rather than combined with additional radiotherapy or surgery. Under-treatment seems to be more common in older, otherwise healthy, men.

Surgical techniques used

Robotically assisted surgery is now by far the most common type of radical prostatectomy performed.

	England	Wales
Robotic	81%	63%
Laparoscopic	9%	4%
Open	10%	23%

- It is likely that more procedures will be performed using robotic assistance as surgical experience increases. However, there will always be patients who need open surgery for medical or technical reasons.

Radiotherapy

The vast majority of all external beam radiotherapy now uses Intensity Modulated Radiotherapy (IMRT).

90% (England) and 100% (Wales) patients were treated using IMRT

For this Audit, no specific data were recorded for treatment involving brachytherapy.

- The older 3D-conformal technique is likely to disappear as older radiotherapy equipment is phased out. This should further reduce the incidence of short-term adverse events and longer-term ones now being identified from treatment given many years previously.
- The use of shorter courses of treatment which use higher doses at each session (hypo-fractionated radiotherapy) may be increasing but this is not captured in the Audit.

Estimation of quality of life

Information was obtained from a Patient Survey sent by the NPCA to men who were diagnosed with

prostate cancer from 1 April 2015 to 30 September 2016. Of 35,162 surveys sent out, results were obtained from 25,490 men – a response rate of 73%. Estimations of quality of life were measured using Patient Reported Experience Measures (PREMs) and Patient Reported Outcome Measures (PROMs).

Overall experience

90% men said they were given 'the right amount of information' about their condition/treatment

72% men felt they were involved as much as they wanted in decision making

83% given the name of a Clinical Nurse Specialist

89% men rated their overall care as 8/10 or above

- These are good results – and better than some closely involved with support groups and their members might have expected. (But support groups will naturally attract more people who have experienced problems.)
- However, 23% patients did not complete the survey and the figures are incomplete. It is possible that non-responders overall rated their treatment experience highly and that those who had problems were more likely to respond to the survey.

Side-effects/adverse events

No treatment for prostate cancer is without the potential for side-effects or adverse events. Of the 25,490 men who responded:

23% treated with radical prostatectomy (at 56 surgical centres)

44% treated with External Beam Radiotherapy (at 55 Radiotherapy centres)

Outcome measures were scored on a 0–100 scale (0 = bad to 100 = good).

After radical prostatectomy:

Mean continence score 71/100

Mean sexual function score 23/100

After External Beam Radiotherapy:

Mean bowel function score 85/100

Mean sexual function score 17/100

- These are estimates of a few outcome measures in only two treatments. They evaluate the current status of the patient and do not compare it with how patients were prior to treatment. Presumably, some patients would not have scored 100/100 on each measure prior to treatment. However, the Audit uses a well-validated questionnaire giving reliable data, allowing comparison from one Audit to another, and between different forms of treatment.

In conclusion

The full report contains a vast amount of information and only some of the points most relevant for patients are shown here.

The full report for 2018 and previous years may be obtained from: www.npca.org.uk/reports/

The NPCA website also gives further information, such as the performance indicators completed by each NHS Trust involved.

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prostate cancer

www.tackleprostate.org

The National Federation of Prostate Cancer Support Groups

Tackle Prostate Cancer is the campaign name of The National Federation of Prostate Cancer Support Groups. Charity Registration N° 1163152.

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John Burton	London
Brian Jones	Wales
Robin Millman	North East
Sandy Tyndale-Biscoe	Western Counties
Allan Higgin	South East

Our support:

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PR & Marketing	Siobhan Connor

Prostate Matters delivery

Your individual copy of Prostate Matters is delivered to you from your local prostate cancer support group. If you have a change of address or any other notifications, please would you contact your local support group.

Check your details

Unless otherwise requested, your details will appear on the list of groups on our website.

We ask all affiliated groups to check their details on the Tackle website. The information has been updated to include meeting times and places.

See the map at: <http://tinyurl.com/omp6y5e>

If you require any corrections, please contact

Simon Lanyon: simon.lanyon@tackleprostate.org.

Helpline

0800 035 5302

Our telephone helpline
is manned
by prostate cancer patients,
for patients and their
families

365 days per year

9:00am to 9:00pm



PSA testing events

If your group is holding a PSA testing event, we'll add it to the list on the Tackle website. Email info@tackleprostate.org with the date, time, town, postcode, contact name and phone number.

Editor's note

Many of our articles contain links to information on the internet.

The best way to access these is to go to our website: www.tackleprostate.org where you will find the web edition of this and past issues of Prostate Matters with live links.

Contribute to Prostate Matters

Without you, we would not exist! Please keep contributions coming to: editor@tackleprostate.org (send photos separately at high resolution).

Edited by Cheryl Lanyon; Printed by Automedia Limited, Loughborough.

Thank you to everyone who contributed to this edition.



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