

## tackle AGM and Conference 2019

### Prostate cancer: to screen or not to screen?

The AGM and Conference took place on Thursday 13 June 2019 at Horton Grange, Edgbaston, Birmingham.

The day was split into three sessions: the AGM, presentations on the theme of the conference, and news from our partner members.

#### AGM

Roger Wotton welcomed some 80 members from 35 support groups from around the country. He said that Tackle was the best patient-led charity of 2018, helping men locally and increasing media coverage. Although fundraising is still an issue, the charity needs to become more political, influencing the decision-makers.

Awareness is still one of the main aims, signposting men diagnosed to a support group.



**Cycle to the Moon** continues this year with 250 of the 500 gyms approached expressing an interest. Motorcycling clubs are also keen to take part. The **Save a Dad** campaign is trying to raise awareness in schools with a view to getting the topic of prostate cancer into the National Curriculum. The Tackle ManVan (see page 4) is being used by the UNITE Trades Union to raise awareness and for PSA testing. The van was parked outside and open for viewing. Hopefully, support groups will be able to hire it.

The Federation has applied for National Lottery funding to help set up new support groups where there is a shortage.

#### Presentations

**The latest evidence from Europe** Professor Monique Roobol-Bouts, Urology Dept, Erasmus University, Holland

The headlines:

- Across Europe over 2 million men are living with prostate cancer.

- Before the PSA test, survival from prostate cancer was low. Diagnosis incorporating the digital rectal exam (DRE) showed 30-35% already had bone metastases, with one third of patients dying from the disease.

- When PSA testing began there was a 30% reduction in mortality rates, but an increase in biopsies which were often painful procedures.
- Although the PSA test is a useful biomarker it does not always signify the presence of prostate cancer and should be used with risk assessment to eliminate over-diagnosis and over-treatment.
- It is important that the PSA test is not misused.

**The view from a UK study** Jyoti Shah, Consultant Urological Surgeon, Burton Hospitals

Jyoti set up a prostate cancer screening clinic at a local football club in 2016. She anticipated 50 or so men over two days but saw 113, of whom 8 were diagnosed. Since then 11 clinics have been held, with 41 men diagnosed as positive. Jyoti and a colleague run these clinics voluntarily at no cost to the men tested. Everyone tested receives a follow-up phone call and a letter to both the patient and their GP. She gave a couple of example cases from her clinics.

**Case 1:** Man getting up a number of times a night to urinate, requested a PSA test which his GP refused. Found to have a PSA of 565

**Case 2:** Man in his seventies suffering lower-back pain, prescribed painkillers for some while. Finally found to have PSA of 2404

#### What's the problem?

- Poor understanding of both the disease and possible symptoms (which are not always present)
- Fear
- Work patterns and access
- Cultural differences
- Visibility
- The fact that women share and men don't

Jyoti tries to raise awareness at male-dominated events, setting up screening which includes a full consultation with her. She has also targeted Afro-Caribbean men.

#### Her main aims are :

- to raise awareness
- to engage with local communities
- to re-assure men
- to detect cancer!

## The GP's perspective *Dr Ann Williams*

Dr Williams began as a nurse then graduated to become a GP with a special interest in urology.

### As there is no screening, what is there to go on?

- PCRMP (Risk management programme) 17 sections in total!
- Any man over 50 is entitled to a PSA test.
- We know Afro-Caribbean men are more susceptible
- Family history

She feels here needs to be a proper programme as GPs are generalists not specialists and need more time per consultation.

### Statistics

- 1 in 7 men are asymptomatic and a PSA screening will result in an elevated reading.
- 1 in 6 men with a 'normal' PSA reading will have prostate cancer.
- 1 in 50 will have an aggressive cancer.
- 75 out of 100 with an elevated PSA will have a false positive.
- 1 in 3 men will have prostate cancer.

### Pros and Cons of a PSA test

**Pros:** May detect cancer before symptoms appear  
May detect early cancer when cure is possible

**Cons:** Not diagnostic of prostate cancer  
Not tumour specific  
False positives

The PSA test is, however, a predictor. When the result is received, the GP should counsel the patient prior to referral.

### Risk assessment conclusion

- Men need to be properly informed.
- Is screening the correct word?
- Conflicting views – the onus is put upon the GP, when there is lots of advice available from a variety of sources.
- The GP's role is to support the patient and family.
- A 10-minute consultation is not enough for a GP to be effective.

## The Graham Fulford Charitable Trust

*Graham Fulford, Chairman*

Graham spoke about the work continuing with PSA testing events, and about working with many Tackle member support groups. Over 122,000 tests have been done on over 88,000 men since 2004, with over 1,500 known cancers identified that otherwise may not have been discovered.



## Partner members

### Fundraise for Tackle and potentially lower your PSA?

*Professor Tim Oliver, Trustee, ORCHID Male Cancer*

Tim spoke of the impact of puberty on tumours of the prostate and testes, also linking acne to prostate cancer. He emphasised that sunshine gives health benefits such as Vitamin D, and that exercise is very important; he advocates exercising one or two days a week for life, since physical outdoor activity increases the Vitamin D in the body. He suggested golf as a means to engage children and their families in important male health issues.

### Prostate Cancer Research overview

*Oliver Kemp, CEO; Naomi Elster, Research & Communications Manager, Prostate Cancer Research Centre (PCRC)*

PCRC is a small charity set up in 1989 to support research projects. They want to fund more innovative products which improve the survival and quality of life for men with prostate cancer – particularly advanced prostate cancer – while reducing the harmful effects of the treatments.

Their research strategy is to fund a mixture of low- to high-risk projects. The core principles underpinning a wider base are human relationships, reducing the cost of treatments and combining approaches with other organisations to support single outstanding projects. The voice of the patient must be heard to understand their needs, the challenges they face, and to understand where their research centre could make a difference. Currently, PCRC's research strategy is under review by patients, giving them a deeper understanding of patient involvement in the UK.

For the future they see more diverse, empowered and engaged patients, with staff and scientists feeling connected and accountable to those affected by prostate cancer.

### Working to achieve a national screening programme

*Karen Stalbow, Prostate Cancer UK (PCUK)*

PCUK is committed to achieving the earlier diagnosis of prostate cancer. They will do this with a research budget of £7 million, funding new diagnostic tests, genetics research and imaging. This will take time. In the meantime, the aim is:

- to increase the awareness of risk factors among men and educate GPs to counsel men at risk about the pros and cons of the PSA test
- to harness recent changes to diagnostic and treatment pathways and get GPs to reconsider their views of the PSA test.

PCUK want to reduce the rate of late-stage diagnosis, but believe that further research is needed to find a more accurate test than the PSA test.

### The Conference ended with the panel of speakers answering questions from the floor, concluding at 4.30pm.

Our thanks to Terry Garrigan of Purley PCSG for preparing this report.

The presentations are available at:

[www.tackleprostate.org/past-conferences.php](http://www.tackleprostate.org/past-conferences.php)

## What is risk-stratification?

Stratified medicine is based on identifying subgroups of patients with distinct types of disease, or responses to treatments, and developing treatments that are effective specifically for them.

## Current issues?

Current testing for prostate cancer cannot answer many key questions about how aggressive a cancer is, how it might develop and what the likely outcome will be. Many prostate cancers are slow growing, but current testing does a poor job of distinguishing these from more aggressive cancers. There are errors of over-diagnosis, over-treatment, missed-diagnoses and poor risk-stratification. Some men have treatments that have little or no benefit but have significant side-effects.

## Aim of the ReIMAGINE Consortium

The aim of the ReIMAGINE Consortium is to investigate if we can:

- change the method(s) for diagnosing prostate cancer
- better risk-stratify the men who are diagnosed
- better predict prostate cancer progression.

Current risk calculators and models are based on out-of-date assessments. We aim to update these using modern imaging (MRI) combined with advanced blood, urine and prostate tissue bio-marker analyses.



## Prostate cancer screening

There is currently no screening programme for prostate cancer. Prostate-specific antigen (PSA) testing is considered too unreliable for population screening as it can lead to unnecessary invasive biopsies. reIMAGINE will assess whether MRI scans could be used for population screening.

## Future implications

The way in which prostate cancer is diagnosed may forever change. MRI could become a screening method with the ability to detect serious cancers earlier and help to improve survival rates. Imaging (MRI scans) or a new cutting-edge biomarker could in the long term provide a safe and reliable replacement for prostate biopsies for most patients.

## NHS PredictProstate tool



A new online prognostic tool has been developed for men newly diagnosed with non-metastatic prostate cancer.

Known as PredictProstate, it is available on the NHS website at: <https://prostate.predict.nhs.uk>. It is recommended for use in consultation with your doctor.

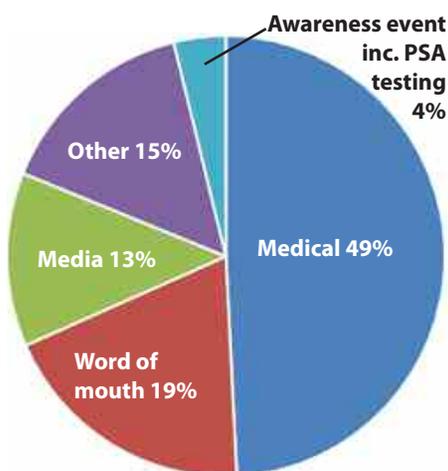
To use it, you enter relevant information about yourself and your prostate cancer, such as your PSA, the clinical T stage of your cancer, your Gleason score and whether biopsy information is available. The tool will then show you how different initial management strategies affect the percentage of men that survive ten and fifteen years after diagnosis – along with the potential harms of each treatment type.

Given the known dangers of both over- and under-treatment, it is critical to make informed decisions at this stage about radical or conservative treatment. The PredictProstate tool has been developed to help you to do this.

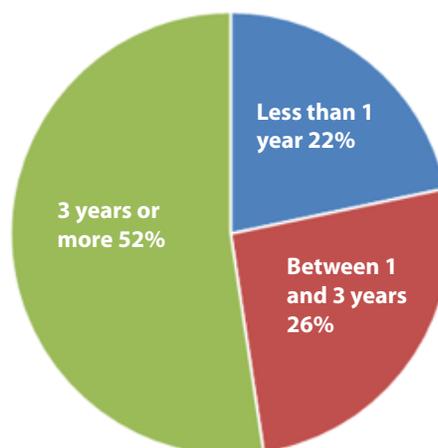
## Lottery survey results

As part of our application to the National Lottery for funding, we asked you to complete a survey. Over 300 of you did and here are the responses, which we can display graphically. Many thanks to all those who completed the survey.

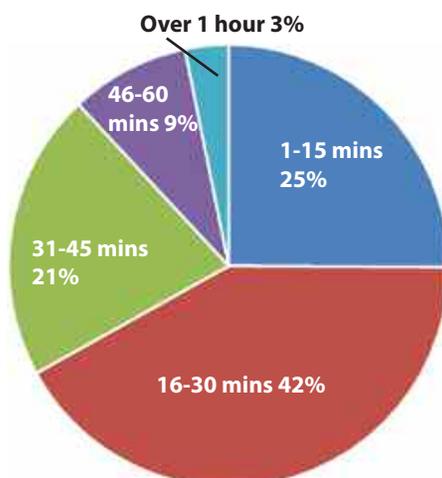
### How did you hear about your group?



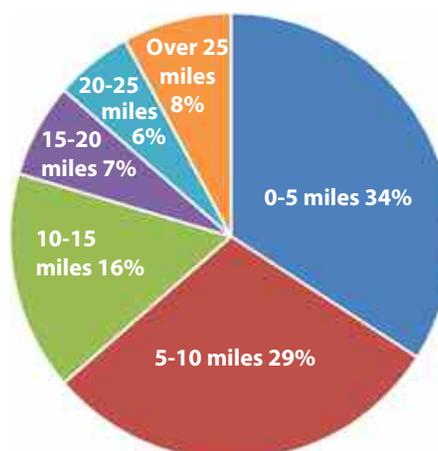
### Length of membership of group



### Average journey time



### Average journey distance



## IoW Group PSA testing success



Outside the Masonic Lodge

On Saturday 18 May at the Masonic Lodge in Cowes, a PSA testing event took place organised by the Isle of Wight Prostate Cancer Support Group and the Cowes 35 Masonic Lodge.

Two hundred and forty men were tested throughout the day with the blood being taken by five phlebotomists

from St Mary's Hospital. Thirty volunteers who had attended a training day the week before turned out to man the event.

The event was supported by a number of Island-based companies, including Pit-stop Training who supplied a courier to take the blood samples to QA Hospital; Wightlink who donated the ferry fare for the courier; Island Environmental Hygiene who disposed of the medical waste; the Women's Institute and People Matter who published the event on their networks; Jewson's (Newport) and Tesco's (Ryde) who allowed us to have a promotional stall in their foyers; Sign Shop of Bembridge worked on banners and posters; and Marvic Packaging & Printing did all the design of flyers and printing of forms and advertising pamphlets. A big thank you to all of them.

With a man dying from prostate cancer every 45 minutes and no screening test available, it was no surprise when this event was oversubscribed, and names were placed on the list to be contacted in September for another event in October.

## Results

The results of our PSA testing day were:

**Red: 10 Amber: 11 Green: 216**  
**Ages of the men we tested:**  
 over 49 yrs 10%  
 over 59 yrs 32%  
 over 69 yrs 31.5 %  
 over 79yrs 21.5 %  
 over 79 yrs 4 %

So 9% needed a follow-up as against 10% from our testing in November last year.



Couriers biking blood samples to hospital

Alan Taylor, Chairman IoW Prostate Cancer Support Group  
[www.isleofwightprostatecancersupportgroup.org.uk](http://www.isleofwightprostatecancersupportgroup.org.uk)

## Salford Group chuffed with train trip

The Salford Prostate Cancer Support Group recently enjoyed a great day out on the East Lancashire Railway, Bury, including a steam train ride to Rawtenstall, a visit to Bury Transport Museum and lunch in the Two Tuns pub in Bury.

This entertaining outing was facilitated by the generous donation of the use of a mini-bus by Booth Charities, a local charity that offers small grants to residents of Salford and the area.. The charity is also helping to support the group's next trip: a narrated river cruise around Salford Quays, plus a meal out.

Pat Millership, Secretary, Salford Prostate Cancer Support Group



## Tackle welcomes new groups

A very warm welcome to three new support groups in Swindon, Millom in Cumbria and Prosper, Harrogate. To see a full list of member groups, go to the [Tackle website](http://www.tackleprostate.org).

## Tackle ManVan



At the Tackle annual conference we were delighted to have the Tackle ManVan on site.

The vehicle you see in the picture is a fully customised 'Wellman' mobile clinic which we hope our support groups can make use of for PSA testing. The initiative is a joint project between Queen Elizabeth Hospital Birmingham (QEHB), UNITE Trades Union and Tackle Prostate Cancer.

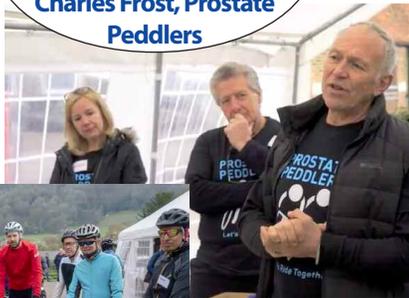
The original idea came from John Hoo, a dear musician friend to the project. Unfortunately, John passed away in April but his legacy lives on.

At the moment the plan is to test the ManVan with local QEHB staff and then have it available for us to use. We are grateful to the QEHB Charity, who funded the purchase and customisation of the vehicle.



Prostate Peddlers are a group of men with prostate cancer who cycle for health and enjoyment. They are based in Ashridge, Herts. and held their first successful Open Day earlier this year.

Cycling is a powerful metaphor for life, with its trials and tribulations.  
**Charles Frost, Prostate Peddlers**



Let's forget about the prostate cancer. Let's get out there. **Dr Shiva Gayadeen, Oncologist**

The group invited several medical professionals along to experience the ride. See their video at: <https://youtu.be/Xb5QK8L8IY8>

They hope to hold events twice a year, in spring and autumn.



**Musette Café road racers and medics**



Talk about what you're going through, talk about support, but talk about other things. Its a really good way to unwind. **Dr Peter Ostler, Consultant clinical oncologist**

You don't have to explain things, do you? You say something and they understand. **Noel Burke, attendee**

Find out more about Prostate Peddlers at: [www.prostatepeddlers.com](http://www.prostatepeddlers.com)

## New Centre of Urology

The Consultant Urologists invited members of the Bolton & Districts PCSG to visit the newly-built Bolton Centre of Urology, which recently opened at the Royal Bolton Hospital.



**Urology Consultants, staff and PCSG members at Bolton Centre of Urology**

The unit offers a diagnostic facility with an integrated theatre suite, and provides a one-stop centre for patients with cancers of the prostate and urinary tract.

We were welcomed by the Consultant Urologists and nursing staff and taken on a fascinating tour of the centre.

The Bolton PCSG group has had a long association with the Bolton Centre for Urology and looks forward to continuing links. As a group it is encouraging to see this level of investment, expertise and experience in our local area.

*Dorothy Sugden, Vice-President Bolton & Districts PCSG*

## Cycle to the Moon event

On Father's Day the South Warwickshire PCSG held a sponsored spin at Stratford Leisure Centre. Doug Badger said,

“ There were 16 of us saddled up at 11am and our instructor, Helena, kept us at it for the next 45 minutes. Collectively, we covered 187 miles so you can see we were working hard – there were hills! ”

Many thanks to all group members and relatives who turned out; to our supporters club, especially the Little Budds!; and to the volunteers from the Leisure Centre for their efforts, participation and contributions.

The total raised is over £1000 via **Virgin Money Giving**.



**The Stratford Spinners**

*Thanks to all of you for a great fundraising effort, helping Tackle to Cycle to the Moon.*

## Fundraising tips



How often do you order things on Amazon? Admit it, it's a convenient way to buy almost anything.

So, why not do your bit for Tackle every time you make a purchase? It doesn't cost you anything. Just search for **Amazon Smile** on your computer, opt to 'pick your own charitable organization' and type **The National Federation of Prostate Cancer Support Groups** in the box.

Now, every time you shop, type Amazon Smile into your computer. It's the same website, the same products, at the same prices, but now Amazon Smile donates up to 0.5% of your eligible purchases to Tackle when you buy. What a great way to contribute!

**Don't forget to sign up all your family, and tell your friends, too!**

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

## Welcome to a new Trustee

Tackle is very pleased to announce the appointment of Alphonso Archer as a Trustee. Alphonso spoke eloquently about his prostate cancer story at the prostate cancer screening discussion we held in the House of Commons earlier this year.

Alphonso is an avid player of Walking Football and reached the final of the People's Cup, 2018.



Alphonso said he was "looking forward to working with the Board and all supporters to keep prostate cancer high on the agenda in all areas until this becomes a disease of less significance".

Chairman, Roger Wotton said, "I am delighted that Alphonso has joined us. No one could fail to be impressed with the passion and commitment he has for earlier diagnosis of prostate cancer!"

# NICE Guideline 2019 – Prostate Cancer

## A review and comments by Steve Allen, patient representative, Tackle Prostate Cancer

NICE is the National Institute for Health Care and Clinical Excellence. Its role is to improve outcomes for people using the NHS across a wide range of healthcare related subjects. Evidence-based and objective guidelines aim to produce effective and good value healthcare. Members of committees assessing each subject are drawn from a variety of clinicians, statisticians and others, including patient representatives.

Tackle is a registered 'stakeholder' with NICE and is asked for comments and feedback on matters relevant to prostate cancer. We aim to represent the opinions and needs of patients and their families. I currently act as a patient representative at NICE for Tackle, in addition to the involvement of some members of the Tackle Clinical Advisory Board.

NICE Guidelines frequently produce considerable comment, both positive and negative, from scientific, financial, philosophical and social viewpoints. It should always be remembered that NICE Guidelines are produced for healthcare professionals and not specifically for patients – although the latter are frequently outspoken about such Guidelines (and quite rightly so!).

### Why write this article now?

An updated Guideline for the diagnosis and management of prostate cancer has just been published. It takes the place of Guidelines published in 2008 and 2014. The process involves producing a draft report, upon which stakeholders are invited to comment. 164 comments were received from 31 different stakeholders in producing this final set of Guidelines.

### What changes have been made?

There are many new recommendations and changes. In the main these are a major step forward in validating and supporting changes that are now in common clinical practice.

Some changes are merely changes in word usage. One example of this is the adoption of the term 'Androgen Deprivation Therapy' (ADT) instead of 'Hormone Therapy'. Although the injection therapy of a drug such as Zoladex is the most common treatment, there are now several different ways of reducing the effect of testosterone on prostate cancer cells. These are all now described by the term 'Androgen Deprivation Therapy'.

One change that produced some negative comments was changing 'men' to 'people' when referring to patients with prostate cancer.

The full report comprises 46 pages and is very detailed. I aim to summarise the main points I see as of greatest relevance to patients. *The purple text on this page reflects my own opinions. These do not officially reflect any policy/opinion of Tackle.*

### Multi-Parametric MRI (mpMRI)

Perhaps the most important recommendation is that mpMRI should now be the first-line investigation for men with suspected localised prostate cancer (PCa), and not a biopsy. The mpMRI should be reported using a 5-point scale (The Likert Scale). Biopsy can be omitted for low-grade disease (Likert 1 & 2) after appropriate discussion with the patient.

The Guideline gives recommendations on the on-going management of those subsequently diagnosed with low-grade disease, e.g. regular repeat PSA assessment, repeat mpMRI and eventual biopsy if needed.

In general, this diagnostic pathway is now in common practice, as indicated by the latest statistics from the National Prostate Cancer Audit (see article in Prostate Matters May 2019 Issue 44).

Early use of mpMRI has been championed by Tackle as well as many others. It is an extremely positive step forward that the early use of mpMRI is now fully supported by NICE.

The concept of 'PSA Density' is barely mentioned. Many clinicians suggest it is a valuable tool for assessing the degree of malignancy in the prostate, particularly in PSA range 4-10 ng/ml.

It is likely that more people will receive a negative diagnosis based on mpMRI findings alone i.e. without biopsy. This group will need effective follow-up. This is not an infallible investigation. It is suggested that there is a 5% risk of a significant cancer developing over the next five years in such patients.

The increased use of mpMRI in active surveillance is stated to be effective clinically and cost-wise. Clinically significant cancers are more likely to be identified and treated earlier – saving on more expensive future treatment costs. However, it will put a further workload on the imaging departments in our hospitals.

### Prostate biopsy

There is increasing use of prostate biopsy using a transperineal approach rather than the trans-rectal ultrasound guided route (TRUS). The data reviewed for this Guideline did not differentiate between these, and the term 'prostate biopsy' encompasses both routes. Template (or mapping) perineal biopsies are increasingly used when more accurate information is needed, but are not included in the generic term 'prostate biopsy'.

### Treatment

- The choice of treatment in low-risk disease (active surveillance, radical surgery and radiotherapy) is discussed in some detail, with particular reference to survival and disease progression at ten years. There is a clear table in the Guideline summarising statistics from the evidence reviewed.

In general the recommendations for low-risk disease are sensible and in line with current clinical practice. However, the table summarising statistics could be used to generate unhelpful 'sound bites' which may negatively influence the number of men coming for PSA testing. Some clinicians may question the research evidence used for this section of the Guideline.

- A protocol for the management of active surveillance is formalised.
- The use of newer, shorter protocols for external beam radiotherapy is supported, where appropriate. However, it is also noted that the higher single-doses used could potentially increase local side effects.

Shorter courses of radiotherapy are now possible. New techniques allow the shape and intensity of the treatment beam to be constantly altered during treatment, to match the shape and size of the prostate pre-programmed into the equipment. Potential increased damage to the rectum should be offset by the more accurate shaping of the treatment beam.

Techniques which physically separate the rectum from the prostate e.g. injection of a gel (SpaceOAR®), are not discussed. These techniques are still undergoing a NICE Technical Appraisal. They may allow even shorter courses of treatment in the future.

- Brachytherapy continues to be a recommended form of more localised radiotherapy. Brachytherapy alone is not recommended for high-risk localised disease. A combination of brachytherapy and external beam radiotherapy may be considered in these patients.

- Chemotherapy (Docetaxel) is discussed in detail. In particular, reference is now made to considering the use of Docetaxel in combination with ADT early in the treatment pathway – particularly where metastases are already present at diagnosis. This is recommended despite there not being a current UK marketing authorisation for Docetaxel in this particular instance, although it is authorised in other contexts of treatment of PCa e.g. hormone refractory metastatic PCa.

The Guideline suggests the use of combination therapy early in the treatment pathway of some patients:

- the combination of brachytherapy and external beam therapy in high-risk localised disease
- the combination of chemotherapy and ADT early in the treatment pathway of patients with metastatic disease at time of diagnosis.

Other drugs could also be used in combination with ADT. Applications for the use of abiraterone, enzalutamide, apalutamide and darolutamide are all at various stages of appraisal by NICE.

- Localised therapies – High Intensity Focused Ultrasound (HIFU) and Cryotherapy are not recommended for general use. Neither form of treatment has yet been approved by NICE. They can continue to be used in the context of controlled clinical trials.

HIFU and Cryotherapy have been given media coverage in recent years. Neither treatment was assessed by NICE as having sufficient evidence on quality-of-life benefits and long-term survival. The lack of support in the Guideline does not imply these therapies are unsafe, only that they are not recommended for general NHS practice. They will still be available in the private sector and research programmes.

- Bone metastases – the older recommendation for the use of Strontium-89 has been withdrawn and replaced by Radium-223 and a reference to the NICE technology appraisal on Radium-223. No other information is given.

Spread to bone is common in advanced PCa. This type of therapy is only relevant if secondary spread is exclusively to bone. This is not made clear in the Guideline, which merely directs the reader to specific NICE appraisal of Radium-223. Radium-223 is very expensive and not in wide use as yet.

#### Side effects

There are multiple recommendations for the optimum management of adverse effects. These are dealt with when the treatment of the specific grade of PCa, or a specific therapy, is being discussed. There is no general section on 'adverse events'. However, considerable positive support is given to the many methods of dealing with such events. Sexual dysfunction, urinary incontinence and radiation-induced bowel problems (enteropathy) are all addressed, but there are no significant changes in the recommendations.

#### Follow-up

There is a specific section on this. There is a trend to increase the amount of follow-up done in a non-hospital-based

setting. This means GPs will have yet more work to do. There are no improved recommendations on the management of non-metastatic, hormone-resistant PCa.

If patients develop confirmed metastases, the treatment pathway is already well established. However, a significant number of men on hormone therapy will develop a so-called 'biochemical' recurrence of their cancer, where the PSA is rising but no metastases can be found with conventional scanning techniques. Docetaxel may be used (off licence) by some clinicians at this stage. Other potential drugs are not yet recognised for this use, although applications are on-going via the relevant NICE appraisal system. Many men with a biochemical recurrence feel lost and angry: "Why do I have to wait until it's too late? Why wait until I get spread? We know it's going to happen..."

#### Further research

Sensible and relevant recommendations are made for further research, including:

- Follow-up protocols during active surveillance and after radical treatments.
- Establishing the most effective diagnostic pathway, both clinically and with regard to cost.
- The natural history of PCa:
  - What happens to those with low-risk disease that are not biopsied?
  - What diagnostic tool should be used to rule out clinically significant disease where there is a negative mpMRI?
  - More research on the prevention of osteoporosis in long-term ADT therapy.

There is no recommendation for the routine use of drugs that help prevent osteoporosis in all patients on ADT. This is established practice in many European countries. Several English clinicians and Patient Charities feel we should adopt a similar practice, but this was not considered to be within the scope of the current update.

#### Additional comments

The media often pick out 'sound bites' for headlines. The public remembers these and does not read any further. This can lead to negative perceptions. We have already seen the headline: '10 year mortality from prostate cancer is unaffected by treatment'. As a bare fact, this may be true, but to get the full picture one needs to read all the research, and also compare effects on quality of life, incidence of adverse events, and how many patients opted for treatment before the study ended. The lack of recommendations about PSA testing could lead to a headline that the latest Guideline does not support it. In fact, it just doesn't mention it!

In the latest Guideline there are a large number of very supportive and positive statements. I hope it is these that reach the general public. Equally, it is up to organisations such as Tackle to ensure the correct information is disseminated.

And finally, rarely does a NICE Guideline get published without both positive and negative responses. Remember that a guideline is just a list of recommendations. Clinicians can still treat a patient as they feel appropriate even if it is not supported in the official Guideline. And occasionally we, as patients, need to challenge treatment and opinions and not just accept that it is/is not in the Guideline. The introduction of mpMRI as a standard investigation is testament to the fact that patients can achieve change.

You can read the full guidelines here:

<https://www.nice.org.uk/guidance/NG131>

# tackle

prostate cancer  
[www.tackleprostate.org](http://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.

Registered Office: Kemp House, 152 City Road, London, EC1V 2NX.

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Registered in England N° 9672970

### Ambassadors

David Gower OBE  
Damian Hopley  
Lord Rose  
Captain Julian Burgess

### Supporter

Jason Leonard OBE

### Honorary President

Sandy Tyndale-Biscoe

### Our volunteers

#### Trustees:

Roger Wotton, Chairman  
Ken Mastris, Secretary  
Professor Frank Chinegwundoh MBE,  
Clinical Advisor  
Erik Friis-Scheel, Finance  
Rob Banner

John Coleman, Help Line Coordinator  
Alphonso Archer

**Helpline coordinator:** John Coleman

**Information officer:** Alan Ashmole

**NICE coordinator:** Steve Allen

#### Regional coordinators:

Roger Wotton	Midshires
John Coleman	North West
John Burton	London
Brian Jones	Wales
Robin Millman	North East
Sandy Tyndale-Biscoe	Western Counties
Allan Higgin	South East

#### Our support:

Group Liaison	Simon Lanyon
PR & Marketing	Siobhan Connor

## WANTED! Wives or Partners

We would like to strengthen our Board by appointing the wife or partner of a man with prostate cancer. For an informal discussion, please call our Chairman Roger Wotton on 07818 404004 or email him at [roger.wotton@tackleprostate.org](mailto:roger.wotton@tackleprostate.org)

## 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, contact Simon Lanyon: [simon.lanyon@tackleprostate.org](mailto:simon.lanyon@tackleprostate.org).

## Keith Cass obituary



Keith Cass with his MBE

We were all saddened to learn of the passing of Keith Cass MBE on 18 April. Keith finally succumbed to prostate cancer, surrounded by his family, after a long and valiant fight.

We owe a debt of gratitude to Keith, not just as a Tackle Board member and Trustee, but for his relentless campaigning on behalf of men everywhere who were suffering from prostate cancer.

His Red Sock campaign, which he set up in 2007, was a beacon of awareness and support for many men, for which he was awarded an MBE by Prince Charles, something Keith was rightly proud of. His funeral at the Manor Parc Hotel in Cardiff was as he had wished, a mix of humour, good music, good company and a celebration of his life.

He will be sorely missed.

Roger Wotton



## 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](mailto: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](http://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](mailto: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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