I was pleased to represent TACKLE at this meeting attended by 47 delegates from around the EU and North America. The delegates came from a wide variety of backgrounds representing expert patient opinion, specialists in urology, oncology, radiotherapy and imaging, public health, research, pharma, technology and the European Commission. Eleven professors were present and the UK was represented by myself and Angela Culhane, Interim CEO of Prostate Cancer UK.

The delegates' brief was potentially enormous: to cover all aspects of prostate cancer from screening and early detection through the patient’s pathway to all potential treatment modalities culminating in future predictions and recommendations for policy makers and governments.

The morning session was dominated by the PSA screening question. Eloquent and expert opinions were given by two patients, both long term survivors following screen detection in their 50's and radical treatment. I followed this with TACKLE's opinion in support of risk based screening. A Belgian representative said that following the US Preventive Services Task Force’s opinion against screening, the Belgian Health Service was no longer reimbursing PSA tests. The Austrian representative showed figures demonstrating that the percentage of men presenting in the USA with advanced disease was already rising following the USPSTF's report. I pointed that there was no urologist on the USPSTF's panel and that their advice conflicted with that from the American Urological Association. A Belgian oncologist supported this criticism of the USPSTF stating that there wasn’t a radiotherapist or oncologist on the panel either! Nobody in the room opposed PSA screening and the WHO representative said that “unofficially” the WHO supported early detection. The discussion then moved on to the importance of MRI
before biopsy, its better utilisation, its quality standardisation and its reducing cost. An American delegate reported the potential benefit of a new high frequency ultrasound scan giving allegedly superior imaging to MRI; watch this space.

Second line markers were discussed but the conclusion was that nothing yet was good enough or cheap enough for universal use and PSA remained the only useful frontline tool.

An interesting debate then occurred on the value of randomised clinical trials, how difficult it was to conduct them, their inherent delays and cost and how they frequently failed to provide answers or even reflect best practice.

The European Association of Urology (EAU) Secretary General gave an overview of the EAU as, arguably, the most influential and best connected urological association in the world and a pragmatic way forward would simply be to adopt all its recommendations. This would iron out most of the service variations that disadvantage patients. This was followed by a number of excellent points stressing the value of multidisciplinary team work, counselling, informed decision making, the value of multimodality treatments in cancer centres and the growth in active surveillance for low stage, low grade PCa.

The question of the psychological impact of screening and a positive diagnosis was raised but I don’t recall a conclusion. However, a strong point was made that if screening was only directed at men “at risk”, most men with PCa would not be detected.

There did not appear to be any clear messages on the direction of research and scepticism was evident on the utility of new markers and gene testing.

The afternoon concluded with all delegates being asked to state one or two of their key opinions and I was able to listen to 75% of the delegates before having to leave. The “votes” can be summarised thus:

- Promote (PSA) Screening: 9
- Multidisciplinary Team Decisions: 5
- Increase education and awareness for men and primary care physicians: 4
- Implement existing (EAU) guidelines: 4
- Implement best practice and transparency of (surgical) results: 3
- Better/more use of MRI imaging: 3
- More active surveillance: 1
- Map the differences between the 28 EU countries: 1

Chris Booth, MBBS, FRCS
Clinical Director, CHAPS Men’s Health Charity & member of Tackle Clinical Advisory board.

### Prostate Cancer Screening and Misleading Statistics

The British Medical Journal is a respected publication whose editorials and articles are considered to be authoritative. In so far as prostate cancer (PCa) is concerned and with the BMJ’s power to influence opinion, its latest editorial “Full Disclosure About Cancer Screening”[1] and analysis entitled “Cancer Screening Has Never Been Shown To Save Lives”[2] are highly misleading due to outdated references used by the authors to support their case.

Prostate cancer is the commonest cancer in UK men and second commonest cause of cancer deaths with 47,000 new registrations and 11,000 deaths each year. Despite this there is no national screening programme and although screening using the Prostate Specific Antigen (PSA) blood test is available via the NHS, only 8% of UK men avail themselves of the test. The reasons for this low uptake are lack of awareness amongst men and a negative attitude from the medical establishment based on perceived inaccuracy of PSA and the concepts of “over-diagnosis” and “over-treatment” of non-aggressive cancer based largely on outdated clinical practice.

In countries where PSA screening is extensive, the percentage of men presenting with advanced, incurable, metastatic PCa had dropped from 60-80% in the pre-PSA era to 20% or less now. Since the biggest international PSA screening trials commenced in Europe, cancer specific mortality has fallen consistently by approximately 30% with best trial results reporting a 50% drop! [3]

Regarding “over-diagnosis” and “over-treatment”, UK specialists are fully familiar with these historical problems and are working successfully to eliminate them as judged by the consistent rise in the proportion of men with apparent non-aggressive PCa who go onto active surveillance programmes.

In the BMJ articles emphasis is given to the differences between cancer specific and overall mortality but it is unacceptable to use a reference that is 13 years old [4]. It is equally misleading to quote references comparing PCa mortality statistics from the pre-PSA era and present these as if the data was current [5].

Regarding death from either metastatic PCa or locally advanced PCa, this is almost always thoroughly unpleasant and to be avoided if at all possible; screening almost always achieves this.

The editorial suggests the facilitation of Informed Decision Making (IDM). In the UK early PCa was used as the model for the introduction of IDM almost 10 years ago and its practice is standard in UK urology cancer practice.

So far as PCa and PSA screening is concerned, these BMJ articles from foreign authors, who are not urologists, are outdated, unbalanced, do not reflect current UK practice, do not reflect the international consensus [6] that advocates PCa screening based on an individual assessment of risk and informed decision making and do nothing to help men at risk, particularly those with a family history and black African and African Caribbean men, from this serious and frequently fatal disease.

References:
1. Gigerenzer G, BMJ, 2016; 352, 8
2. Prasad V et al, BMJ, 2016; 352, 22-23

Tackle Clinical Advisory Board

- Chris Booth, MBBS, FRCS, Clinical Director, CHAPS Men’s Health Charity
- Professor Nick James BSc (Hons) MBBS PhD FRCP FRCS: Director of the Cancer Research Unit, University of Warwick
- Professor Frank Chinegwundoh MBE Consultant Urological Surgeon
- Professor Stephen Langley IVS FRCS Urol; Professor of Urology & Clinical Director Royal Surrey County Hospital, Guildford
- Professor Heather Payne: Professor of Prostate Oncology University College Hospitals, London
- Dr Jonathan Rees, GP Backwell and Nailsea Medical Group Chair of the Primary Care Urology Society
- Keith Cass, Patient Representative, and Trustee of Tackle Prostate Cancer
- Bruce Turner BA MSc urological nurse Nurse Practitioner Homerton university hospital and Barts health hospitals.

Free Help Line - 0800 035 5302
Every year, over 47,000 men are diagnosed with prostate cancer across the UK. This is a cause close to the hearts of many Freemasons and since 2006 the Grand Charity has donated over £240,000 towards research into the detection and treatment of prostate cancer. Last year, The Freemasons’ Grand Charity awarded a grant of £100,000 to the Cancer Genetics team at the University of East Anglia (UEA) to help fund research that will focus on distinguishing between aggressive and non-aggressive forms of the disease.

A critical problem in clinical management is that at the time of diagnosis it is not possible to reliably distinguish aggressive, from non-aggressive disease. The Grand Charity award will allow us to tackle this critical question head-on through the analysis of large amounts of information that have been already obtained from prostate cancer patients.

The highly variable nature of prostate cancer can be problematic for its management and a high proportion of cases are over treated, leading to unnecessary impotence, while some are under-treated, leaving potentially aggressive cancers untreated. It is therefore vital that techniques are developed which allow men with aggressive cancers to be targeted and the remainder to be spared the side effects of such treatment. This research will focus on examining biomarkers secreted into urine by prostate cancer cells.

Professor Colin Cooper, lead researcher This most recent grant will support part of an ongoing study that was previously funded by the Grand Charity in 2011 and 2013 with grants of £50,000, bringing the total donated to this project up to an impressive £200,000. This previous research generated large amounts of data which, with this recent grant, can now be analysed using sophisticated techniques to further develop and refine tests that aid diagnosis.

Prostate cancer is the most common form of cancer in men in the UK, resulting in 11,000 deaths each year. Therefore, we believe strongly in assisting medical research that will focus on identifying which patients are most at risk of dying. We are very happy to give this grant to ensure further insight into this awful disease is achieved.

Laura Chapman, Chief Executive of The Freemasons’ Grand Charity

Local Men Raise Over £1100 For Rory The Robot Prostate Cancer Appeal Fund

Paul Markell, Treasurer, Kidderminster & Worcestershire Prostate Cancer Support Group.

Three local men have raised over £1100 through a collection at local supermarkets to help Worcestershire men with prostate cancer in future.

£1171 was raised over two days by Brian Wilkes, Ian Jukes and Paul Markall, all part of local appeal Rory the Robot.

The Rory the Robot appeal is a campaign to raise £1.6 million to buy a state of the art surgical robot to treat Worcestershire men with prostate cancer. With Rory’s assistance, patients will benefit from less pain, minimal blood loss, quicker recovery and reduced complications.

The collection was held at the Morrison’s store in Hereford on Friday 12 and Saturday 13 February with local shoppers digging deep to donate.

Many of the customers who contributed had stories to tell themselves of friends or family who have been affected by prostate cancer.

Mr Wilkes, who works at Morrison’s in Bromsgrove has also organised other collections and bag packing events covering 11 stores over Herefordshire and Worcestershire this year.

Ian Jukes, Chairman of the Rory the Robot appeal said: “The appeal is very close to our hearts and of many others in the county too. We’re very grateful for the public’s generosity and all those who have supported us so far. We’re very excited for the upcoming events and hope that they will be as successful as this first one!”

Pictured from Left to right Brian Wilkes, Ian Jukes and Paul Markall
Revised PSA Guidelines – A step forward

Roger Wotton

Prostate Cancer UK recently published a revised set of PSA guidelines. Tackle has been involved in the development of these and we see them as a step forward in achieving earlier diagnosis and better outcomes for men. They may not be perfect, but they do provide some much needed advice. It is good to see a greater emphasis on identifying men who are in higher risk categories and testing these men earlier. There is also a welcome guideline on baseline testing for all men in their 40’s who do not have any symptoms.

Professor Frank Chinegwundoh MBE, Chair of Tackle’s Clinical Advisory Board, had this to say: “These revised guidelines on PSA testing may not satisfy those who think screening should be introduced, but by recommending a risk based assessment and a more informed approach to PSA testing I believe this will contribute to improving early diagnosis. It is a step in the right direction”. Dr Jon Rees, a GP and another member of our Clinical Advisory Board - said “The controversy that surrounds PSA testing for asymptomatic men means that most GPs face constant uncertainty in how to offer a sensible, evidence-based approach to this problem. This approach, however, also needs to be based on pragmatism – men are understandably concerned about prostate cancer, and a ‘no-testing’ policy is utterly unrealistic in real life primary care”.

You can read more about the guidelines in an article below from Prostate Cancer UK. There is also an opportunity for men to provide feedback on discussions about PSA testing they might have had with their GP.

You can find the PSA guidelines on Tackle’s website at www.tackleprostate.org/psa-consensus.php

Prostate Cancer UK call for men to share experiences of the PSA Test

Martin Abrams

Last month Prostate Cancer UK released a set of 13 statements, representing the consensus view of hundreds of health professionals in order to support primary health care professionals to use the Prostate Specific Antigen (PSA) test more effectively for men without symptoms of prostate cancer. Prostate Cancer UK’s Change Delivery Manager Martin Abrams explains what this means and why we need your help to build a picture of PSA testing across the country.

Men give us mixed reports about the PSA test conversation they have with their GP. Some men say it helped them to make an informed choice about whether a PSA test was right for them or not. Other men have told us that they were put off having a test or were denied a test after requesting one. We want all GPs to discuss the pros and cons of a PSA test with men aged 40 or over who ask about it. We’re asking men to share their story to help build a picture of access to PSA testing across the country. We’ll use this to campaign for all men to have a better experience.

The new PSA consensus

Until we develop a better test, the PSA test is the best means of achieving early prostate cancer detection in men without symptoms.

Public Health England’s current guidelines under the Prostate Cancer Risk Management programme (PCRMP) state that only men over 50 are entitled to a PSA test after discussion with their GP. In a concerted effort to plug gaps in these guidelines, Prostate Cancer UK convened a powerful group, which included doctors, nurses, consultants and professional bodies, to agree recommendations for using the PSA test more effectively. The purpose is to save more lives by helping GPs detect cancer before men get the symptoms that mean the disease is advanced.

The new advice encourages GPs to proactively discuss the test with men aged 45 or over who are at higher than average risk of prostate cancer – because of Black ethnicity or a family history of the disease.

It also recommends that men in their 40s who are concerned about prostate cancer should now consider a ‘baseline’ PSA test in order to help predict their future risk of developing the disease. At present, a switched-on GP might test a man under 50 on the NHS but the new consensus highlights to all doctors that earlier baseline testing should be an option for men across the UK.

We released the 13 ‘consensus statements’ on 29th March, which build on the advice from the PCRMP but can cover additional areas as they are based on clinical consensus, rather than the published evidence from lengthy clinical trials. These statements along with much more information on the PSA Test can be found on our website http://prostatecanceruk.org/about-us/what-we-think-and-do/consensus-on-PSA-testing and of course you can contact our specialist nurses Monday to Friday on 0800 074 8383.

Tell us about your experience of the PSA test

If you have discussed the PSA test with your GP over the last few years we would love to hear about your experience. Please visit bit.ly/psa-survey and fill out our short and confidential questionnaire.

We need you!

Raise vital funds for free when you shop online with easyfundraising.org.uk

It costs you nothing to raise money for Tackle - sign up to Easy Fundraising now!

Turn your online shopping into donations for Tackle Prostate Cancer

Do you shop online? Did you know that every time you buy something you could be raising money for Tackle Prostate Cancer?

That’s right, over 2,700 well known retailers, including Amazon, John Lewis, eBay and Tesco will donate a small percentage of what you spend to Tackle Prostate Cancer to thank you for shopping with them.

Just visit: http://tinyurl.com/qaxl9ny and follow the simple steps to sign up.

Easyfundraising has already raised over £7 million for over 55,000 good causes across the UK. So what are you waiting for? Head to: http://tinyurl.com/qaxl9ny now.

Already registered? Spread the word to family and friends to let them know just how easy it is!
Prospect Bristol Support Group – Making a difference locally

Prospect Bristol support group has been busy and has added extra informal meetings to its calendar. At these meetings there is no speaker so that members can discuss problems and get help in fellowship and talking to each other. The first such meeting was a success and attracted praise from new members. It has been suggested we invite a urologist to these meetings not to speak but to be there to answer members’ questions. The urologist would get to know us and perhaps be more inclined to recommend us to patients. The chairman was contacting a consultant for help/information on this.

We had a successful stand at the Weston-super-Mare beer festival and two members arranged an awareness stand at Bristol Haematology and Oncology Centre. An excellent awareness talk was also given at Ashfield Prison and a stand was set up in Newport for a company event. This corporate side of health and wellbeing seems to be a growing area and could be a fertile ground for us. Two members put up a stand at a second event in Bristol and spread the word about prostate cancer to a number of builders.

Mike Broxton attended a Living Well and Beyond evaluation focus group where the future make-up of the Living Well Days was discussed. Two members attended a Living Well Day at which the speaker failed to turn up so Mike Broxton stepped up to the plate and it is hoped he will get a regular slot at these events.

A successful Christmas meal was held and a visit to the Penny Brohn cancer centre near Bristol attracted a good turn-out.

We had a productive meeting with the Macmillan administrator about regular drop-in coffee meetings for PCA sufferers at their centre at Southmead Hospital and there was a successful turn-out at the first one.

We gave a talk to Fishponds Probus group, which earned us £25. Two members attended a Macmillan centre Tree of Life event at Southmead and this will probably be an annual event too.

The group’s own helpline was underused so arrangement were made to use the Federation’s free service.

Our website (http://www.prostatecancerbristol.org.uk/) is kept up to date and attracts a lot of visitors from all over the world. We also got a page on a Streetlife social network website and articles about our group in two local Voice magazines.

The group has bought a hands-free mic for meetings and presentations.

Bernard Smyth, Prospect Committee Member
It's been a busy year for the STAMPEDE team, with new results shared and plans for future changes.

**Docetaxel and/or zoledronic acid results**

The results from groups looking at adding to the standard treatment either:

- the chemotherapy drug, docetaxel
- or the bone drug, zoledronic acid
- or both

were published in The Lancet journal just before Christmas 2015.

The standard of treatment was long-term hormone therapy for everyone plus radiotherapy for some men whose disease had not spread far.

The new results showed that adding docetaxel improved survival for these men starting long-term hormone therapy for the first time.

Men who had standard treatment plus docetaxel lived on average for 10 months longer than men who had just standard treatment. Among the subgroup of men whose disease had already spread to distant parts of their body, the benefit was even bigger: 15 months.

Adding zoledronic acid to standard treatment did not improve survival. Men who had both docetaxel and zoledronic acid did better than men who just had standard treatment, but no better than men who had just docetaxel and standard treatment without zoledronic acid.

The unwanted side-effects from standard hormone therapy are already well known and many men have them. Men who also had docetaxel were more likely to experience more unwanted side-effects compared to men on hormone therapy alone. The most common extra side-effects with docetaxel were a low number of white blood cells (call “neutropenia”), which increases the risk of infection. However, these side-effects were usually manageable and were generally short-term. Indeed, by one year there was no difference in the numbers of men reporting severe side-effects in any of the groups. Very few men had to stop their docetaxel treatment due to side-effects.

The researchers have made a short film that explores these results [https://vimeo.com/149626704](https://vimeo.com/149626704).

In January 2016, just four weeks after the STAMPEDE paper in The Lancet, NHS England started to offer docetaxel to men starting long-term hormone therapy for the first time. It is also available on the NHS in Scotland.

**Celecoxib (and zoledronic acid) results**

In January 2016, the STAMPEDE researchers presented results from two more of STAMPEDE's original groups looking at adding to the standard treatment either:

- the anti-inflammatory drug, celecoxib
- or both celecoxib and zoledronic acid

Men who had celecoxib were no more likely to have severe side-effects than men treated with just standard treatment. Adding both celecoxib and zoledronic acid to standard treatment did not appear to improve how long men lived for, on average. However, for men whose disease had already spread to distant parts of their body when they joined the trial, there was some evidence that this combination may help them live longer.

This is the first trial to suggest that a combination of celecoxib and zoledronic acid may improve survival in these men. There is not enough information to change the standard treatment for prostate cancer at the moment, but it does raise some interesting questions. There may, perhaps, be a role for adding celecoxib to zoledronic acid where zoledronic acid is already used such as in the later stages of prostate cancer or in people with breast cancer or multiple myeloma. Further research is needed to investigate this.

**What next for STAMPEDE?**

More than 8,000 men have agreed to join STAMPEDE now, making it the biggest ever prostate cancer treatment trial. Follow-up to all the arms is continuing and it is really important that all people in the trial keep going with the trial appointments. There are nearly enough men in the questions looking at radiotherapy for men whose cancer had already spread elsewhere and in the question looking at adding both enzalutamide and abiraterone to the standard treatment.

This year, the team will to start looking at whether the diabetes drug metformin helps non-diabetic men with prostate cancer. This question will be asked at all hospitals.

The team would like to thank all the men taking part in STAMPEDE for their extremely valued contribution to this research. The results from STAMPEDE are already helping men with prostate cancer.

**Further information**

- Short film about the docetaxel and zoledronic acid results [https://vimeo.com/149626704](https://vimeo.com/149626704)
PATCH trial: Can transdermal oestradiol work as well as standard hormone therapy but with fewer side-effects?

What is the PATCH trial about?
The trial is looking at whether giving oestradiol (a type of hormone) through the skin can work as well as, or better than, standard hormone therapy for treating prostate cancer, but with fewer side-effects. This may offer patients better quality of life. In the trial, oestradiol is given transdermally using patches which stick on the skin, and gradually release the hormone into the body. A picture of a patch is shown below.

Why is this important to look at?
Over half of men diagnosed with prostate cancer are treated with hormone therapy at some point. Prostate cancer relies on the male hormone testosterone to grow. Hormone therapy is used to lower the level of testosterone in the male body, which will hopefully control the cancer. This is usually done by giving hormone injections.

Patients may be treated with hormone injections for a long time, many for a decade or longer. Unfortunately these injections can cause a range of side-effects which may become serious. For example, they can cause bones to thin which might lead to them becoming fragile (osteoporosis) and more likely to break. They might also increase the chance of developing diabetes or heart disease. For some patients the side-effects of hormone injections can have a big impact on their quality of life.

Transdermal oestradiol (Te2) is another form of hormone therapy which might be able to treat the cancer in a similar way to standard hormone injections without causing some of these side-effects. A clinical trial is the best way to answer this question. So far, 1000 men have already joined PATCH. We need 1000 more men to take part.

What happens in the trial?
Men who take part in the trial are divided into two groups, at random. One group will be treated with hormone injections as this is standard NHS treatment and the other group will be treated with Te2. The outcomes between the two groups will then be compared to assess the benefits and the side-effects of Te2 versus hormone injections.

Participants in PATCH can still receive other cancer treatments that are already part of routine clinical management, such as radiotherapy and chemotherapy. They can also come off the trial treatment they have been assigned to (ie. hormone injections or Te2) at any time, as they wish or following the advice of their doctor.

As well as monitoring the cancer, doctors will also regularly monitor the patient’s hormone levels, side-effects and how the treatment is affecting their daily life.

How does PATCH compare with the STAMPEDE trial?
STAMPEDE is assessing whether using certain treatment(s) in combination with hormone injections is better than standard of care with injections alone. Some of these treatments are normally only given to patients with cancer still growing despite being on hormone treatment, and STAMPEDE is seeing if there is a benefit in using them earlier in the course of the disease. PATCH is primarily interested in seeing if there is a long-term alternative hormone treatment approach that works as well as hormone injections but with fewer side-effects.

Who can take part in PATCH?
Men who have advanced prostate cancer, or cancer that has spread to other parts of their body (metastatic), who would normally be treated with hormone injections can join the trial. This includes patients whose cancer has come back after surgery or radiotherapy.

Many hospitals across the UK are taking part in PATCH. If you are interested in joining the trial, it is best to talk to your doctor. You can also find further information at http://tinyurl.com/hvuufww

Data from the ongoing PATCH trial have already shown the following:

Patients quotes

“I find it easy taking part in the trial….because of the support I have received from the oncology team... I'm sure all other participants find the same.” – PATCH participant

“I know quite a few men who struggle on the LHRH drugs with unpleasant side effects….By comparison, patches would be a breeze!” - Patient representative on the NCRI Prostate Cancer Clinical Study Group
Our printer, Automedia, had a Christmas present returned to them. It was in an envelope which had previously been used for Prostate Matters and recycled. The addressee had not responded to Post Office requests to collect the parcel and by a process of elimination it was returned to Automedia.

After ascertaining who sent the parcel and in fact that the addressee had been on holiday, Automedia put on the address and posted off the present.

Santa came late, but he came in the end and a big thank you to Automedia!

---

Cancer Research UK and the MRC Clinical Trials Unit at UCL are hosting a series of free events around the UK for men affected by prostate cancer and their loved ones.

The events will provide an opportunity to hear from experts in the field and gain insight into recent developments in research that are improving the way the disease is treated.

Two of the clinical trials we’re focusing on include the STAMPEDE and the CHHiP trials. STAMPEDE is looking at adding new treatments to hormone therapy for men with advanced, locally advanced or high risk disease. The CHHiP trial tested giving radiotherapy in fewer, larger doses for men with early stages of the disease.

Join us to find out how recent clinical trials are finding more effective ways to treat prostate cancer.

- London: Tuesday 3rd May, 6-9pm
- Glasgow: Wednesday 11th May, 2-5pm
- Belfast: Tuesday 14th June, 6-9pm
- Manchester: Friday 17th June, 6-9pm
- Shrewsbury: Thursday 30th June, 1-4pm
- Southampton: Thursday 28th July, 2-5pm

To find out more and register for an event, visit our event page: http://po.st/1t4Bss or call 0203 469 8777.

---

Our printer, Automedia, had a Christmas present returned to them. It was in an envelope which had previously been used for Prostate Matters and recycled. The addressee had not responded to Post Office requests to collect the parcel and by a process of elimination it was returned to Automedia.

After ascertaining who sent the parcel and in fact that the addressee had been on holiday, Automedia put on the address and posted off the present.

Santa came late, but he came in the end and a big thank you to Automedia!