Prostate cancer is the most common cancer in men in the UK, accounting for a quarter of all male cancers. Approximately 37,000 new cases are diagnosed each year, which is approximately 100 new cases per day. It affects mainly men in late middle age and old age. In the UK a man has a 1 in 9 chance of being diagnosed with prostate cancer. In the region of 10,000 men a year will succumb to prostate cancer. The outlook for a man with prostate cancer is good if the disease is caught early before it has spread.

Unfortunately, in the UK approximately 22% of prostate cancer is diagnosed when the illness cannot be cured, although there are treatments that will prolong life.

In 2006, I published a paper, which has subsequently been confirmed in larger studies, showing that black men in the UK had a three-fold greater risk of being diagnosed with prostate cancer than their white counterparts. This echoed data from the USA. The reason for the racial disparity which holds all over the world is currently unknown. Research is concentrating on genetic factors. Whether higher rates of prostate cancer translate into a higher death rate is the subject of debate. American data would suggest that black men are more likely to die of their prostate cancer than white men, but UK data does not support this. In the UK proportionate numbers of black men die from their prostate cancer. Of course the health systems are different. Studies have shown that on average black men will be diagnosed with prostate cancer five years earlier than white or Asian men. Again the reason for earlier presentation is unknown.

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This earlier presentation does suggest a different biology to prostate cancer by ethnicity. It is important to appreciate that prostate cancer may be present even if there are no urinary symptoms. Or it can be linked with urinary troubles, such as a poor urinary flow, passing urine frequently or at night, or having to reach a toilet in a hurry. Recent onset of erection difficulties may also herald prostate cancer. Most men with urinary symptoms will not have prostate cancer, but only by seeking expert medical advice can prostate cancer be excluded.

Crucial to the diagnosis is the blood test PSA, which stands for prostate specific antigen. This is a chemical made by the prostate gland and extruded into the bloodstream. The
normal PSA should be below 4 ug/l. A level above that suggests that prostate cancer may be present. Prostate cancer is also suggested by the prostate feeling “hard” on digital rectal examination as opposed to the normal “rubbery” feel.

Whilst in the UK there is no national screening programme in the UK at present (under review at the Department of Health), this does not mean that men should not take responsibility for their prostate health. A good diet is important; fresh fruit and vegetables, low fat intake, less red meat, more fish and white meat and avoiding obesity are thought to be of value in reducing the risk of prostate cancer. There is an argument that screening would be of particular benefit to high risk groups, which would include black men and those with a family history of prostate cancer. It is unfortunate that to date major funds have not supported screening studies for black men.

Every man over the age of 50 years is entitled to a PSA blood test on request to their GP. This is something I would encourage. The earlier prostate cancer is diagnosed the more the treatment options and the greater the likelihood of cure. Waiting for symptoms may be too late. As black men generally develop prostate cancer at a younger age than white men, I would suggest starting PSA testing at age 45 years. Prostate cancer can run in families. Therefore prostate cancer in the family should lead to a request for PSA testing from the GP. It is up to the man to make the GP aware of the family history.

If the PSA is raised or the prostate feels abnormal, the GP will refer the man to an urologist, who is a specialist in urinary system disorders. There is an obligation on the NHS to be seen by the specialist within two weeks.

The urologist will organise a biopsy of the prostate. That is called a transrectal ultrasound guided biopsy (or TRUS biopsy for short). Commonly 12 samples (cores) of prostate tissue obtained are sent to the pathologist for analysis. If prostate cancer is confirmed, further tests are done to gauge the extent of the disease. The tests may include a MRI scan or CT scan or bone scan. These will determine if the disease is confined to the prostate or not. Each case is discussed by a multidisciplinary team, comprising urologists, nurse specialists, oncologists (cancer experts), radiologists (imaging specialists) and pathologists, in order to recommend a treatment plan for the patient. These deliberations are fed back to the man and inform the consultation as to how to deal with the cancer. Treatment is usually under the care of the cancer centre, which may be distant from the local hospital. In the cancer centre, there is a critical mass of human expertise and equipment which leads to better outcomes.

Not all prostate cancers need treating. It is a truism that many men die with their prostate cancer rather than from it. Especially where the cancer is small and the PSA relatively low, there is a good chance that the cancer may lie dormant and never cause a problem. Thus some cancers can be kept an eye on (active surveillance). Monitoring is by PSA and repeat prostate biopsy at intervals. A more detailed biopsy, called a transperineal template biopsy, gives more information as to whether it is safe to observe the cancer.

Voluntary organisations such as Cancer Black Care (CB) provide a valuable source of information and support. Such groups are an adjunct to the statutory services and are worthy of support from the community. Awareness needs to be raised in the black community about prostate cancer. Men should be encouraged to get themselves tested annually.

In November 2014 Public Health England, supported by PCUK and Cancer Black Care, ran an awareness campaign in London. The message was that 1 in 4 black men will develop prostate cancer; therefore it is worth having a discussion with your GP if you are over 45 years.

Further information is available from:
Cancer Black Care http://www.cancerblackcare.org.uk/
Professor Frank Chinegwundoh
http://www.urologyconsultant.co.uk

Professor Frank Chinegwundoh, Consultant Urologist & Chairman of Cancer Black Care.
Look who’s helping us Tackle prostate cancer…..

David Gower, OBE

One of the most capped and high scoring players, David captained England during the 1980’s. He also played for Leicestershire and Hampshire. He is now a sports commentator for Sky TV.

Damian Hopley

A graduate of St Andrews and Cambridge University, Damian played for Wasps and England but was forced to retire from professional rugby in 1998 after a series of knee operations. The lack of support available to professional players led Damian to found the RPA later that same year. He is the driving force behind the RPA and his influence ensures that players’ rights are protected and represented at all levels within the sport. Damian has been the principal negotiator for both the England and British & Irish Lions players’ contracts since 2001. He is currently Chairman of the International Rugby Players’ Association (IRPA).

Lord Rose

Stuart has worked all his life in retail having joined Marks & Spencer in 1971. After leaving Marks & Spencer in 1989 he successively managed the multiple retail chains at The Burton Group, Argos, Booker, Arcadia and subsequently returned to Marks & Spencer in 2004 as Chief Executive, becoming Chairman in 2008. He left M&S in 2011. He is a Non-Executive Director of Woolworths (South Africa). In May 2013 he joined Ocado as Chairman. He is also Chairman of Fat Face, Oasis Healthcare Group and The Healing Foundation, a medical charity. He was knighted in 2008 and made a life peer in September 2014.

And our newest supporter, Jason Leonard, OBE

“I think the work that Tackle Prostate Cancer is doing is extremely important. They need all the support they can get to tackle the effects of this dreadful disease”.

Jason is President of the Rugby Football Union for the 2015 World Cup season. A former Rugby Union prop forward, Jason held the world record for winning the most international caps. He played for England and the British and Irish Lions, Saracens and Harlequins.

Gift Aid

Did you know, if your group is a registered charity, you can claim GiftAid from HMRC on personal donations given to the charity. This will increase their value by 25% at no cost to the charity or the donor. To register or to find out more, go to:

www.hmrc.gov.uk/charities/gift-aid-toolkit.htm

We are extremely grateful to our supporters. Having them involved helps to raise awareness of the disease and the need for support.
Have you ever wondered why you developed prostate cancer, what does it mean for you and your family and can your treatment be personalised towards the genetic changes occurring in your body? Genomic medicine may start to have the answers, writes Dr Julian Barwell.

Prostate cancer occurs when mistakes occur in a number of critical genes which control the balance of cell growth and cell death. These are not usually inherited and these changes in our DNA (genetic code) occur in the prostate over a man’s life-time. Occasionally prostate cancer can have an inherited component and is linked to breast, ovarian or bowel cancer. Identifying and understanding these inherited traits can help target screening, resulting in earlier diagnosis and treatment; both crucial to improving long term survival.

The mapping of the genetic changes in the blood which makes a man susceptible to prostate cancer and the genetic alterations in his tumour, which have caused this loss of control, is being studied in a new NHS service development project. Led by Genomics England Limited, this so-called ’100,000 Genome Project’ signals the dawn of the genomic era and aims to mainstream the use of genomic medicine into standard NHS care by 2018. University Hospitals of Leicester have joined with Cambridge, Nottingham, Norfolk and Norwich University Hospital Trusts to create the East of England Genomic Medicine Centre.

The project aims to carry out full sequencing of the DNA code from the blood of 20,000 patients (with one of 100 rare diseases) and their parents and blood and tumours of 20,000 patients with one of five tumours (breast, bowel, lung, ovarian and prostate cancer). The project will involve consenting for a blood test and a tissue biopsy (taken alongside NHS tests) to be sent to Genomics England for full DNA sequencing and on-going medical records being uploaded onto an anonymous national database.

Dr Julian Barwell, consultant in clinical genetics at the Leicester Royal Infirmary, is the rare disease lead for Leicester and leading PPI (Public Patient Involvement) activities for the East of England. Alongside consultant urologist and cancer lead, Mr Roger Kockelbergh, and Prostaid, Dr Barwell aims to improve understanding of the project in our community to ensure men affected with a new prostate cancer diagnosis are given an opportunity to participate and are given appropriate support through the consent, blood and biopsy sampling process.

There are major challenges ahead in extracting DNA of high enough quality and quantity from prostate biopsy samples and the project is likely to be open to prostate cancer patients in the autumn. Results will be reported back to clinicians who have recruited the patients and relevant findings about the causes of their disease, potential treatment and future health will be explained to patients and in turn, their wider families. This provides opportunities to start developing treatments for tumours based on specific genetic pathways that have been altered in an individual’s tumour rather than generic chemotherapy for all.

We want to stop hearing ‘it is one of those things’ and move onto ‘Mr Smith, we are going to treat you and YOUR tumour’. The journey starts now....

Richard Clark, a 48 year old carpenter from Beccles in Suffolk, really took our strap line ‘Action for Patients’ seriously when he ran the London Marathon for Tackle on Sunday 26th April. He entered the ballot in October and was lucky enough to be given a place. He was deliberating as to who to raise money for but when his father-in-law was diagnosed with prostate cancer in January, in Richard’s words, “Tackle was the obvious choice and I am pleased to do this so you are able to continue your good work”.

Richard has run the London Marathon on three other occasions, training for months beforehand. His longest training run was 22 miles in the rain which he ran on two separate occasions. He is a running coach for the Saxons running club in Saxmundham so, as he says, “no excuses!” Well he didn’t need any excuses for his performance this time around, completing the course in an incredible time of 3 hours 48 minutes, beating his previous best of 4 hours 9 minutes. Congratulations Richard!
York Hospital Prostate Cancer Awareness and Information
Stand Week commencing Monday 2nd March

The York & Selby Prostate Cancer Support Group recently held a very successful event after being asked by the Urinary Department at York Teaching Hospital, to promote greater awareness about prostate cancer, by offering information to hospital patients, relatives and visitors, during the week commencing Monday 2nd March.

The request for us to help was received during our quarterly meeting at York Hospital on Monday 23rd February. Despite the rather short notice, we were able to provide a number of enthusiastic support group members who willingly offered their time, to support this important hospital initiative. During much of the week we were able to relieve Departmental Co-ordinator Koran Atkinson and Carolyn Bedford - Macmillan Urology Nurse Specialist, who both needed to continue their normal daily hospital work duties. By making good use of our own personal experiences, the knowledge we ourselves have acquired about prostate cancer and the wide range of leaflets and booklets at our disposal, we were able to confidently answer all of the questions asked of us, by both male and female visitors to the stand.

The event was judged by the hospital staff (and I am sure by the visitors also) to have been very successful. A lot of interest was generated by the presence of the stand, strategically placed at the entrance to the main passageway from the large hospital entrance foyer to the wide corridor, leading to wards, theatres and clinics. A large number of people passed our stand in both directions, during each day of the week we were there.

In addition to our principle aims of answering questions and informing people about prostate cancer, we were very pleased to learn that around £200 of voluntary donations for York hospital funds had been collected from the visitors to our stand and from other people who had passed by.

Our Support Group members who took part were: Vernon and Julie Janes, Ken George, Graham Clift, Gerry Cunningham and Gerald Gilpin.

Post-Radiotherapy Treatment
Roy Sowersby

I thought readers might like to know about treatment for the after-effects of radiotherapy. I recently came across this by accident, and felt that there must be other men in a similar situation who are unaware of this fact.

My prostate journey started in October 2000 when I was diagnosed with prostate cancer with a psa of 6, Gleason 3+3, at the age of 55. I quickly decided that I wanted surgery so had a conventional radical prostatectomy on 6th December 2000.

Afterwards, my psa settled at 0.01 for six months and then rose slightly to 0.13, where it stayed until the end of 2002. Over the next 2 years, it again rose slightly to 0.17 and, over the next 5 years, showed signs of increasing at every six-monthly check-up. In 2007 it was 0.50 and so it was decided that I should have some ‘salvage treatment’.

This included a further MRI and bone scan, and in September 2008 (psa now 0.67) I had 37 sessions of radiotherapy. The result was that my psa dropped below ‘recordable’ and (I am pleased to say) has remained at 0.01 ever since.

Post-Radiotherapy Treatment
Roy Sowersby

A good result you might say. Well, yes, to a degree. The after-effects of the radiotherapy have caused me uncomfortable (but liveable) problems such as bloating, urgency to go to the toilet with numerous visits each day. I have managed this issue and adapted my lifestyle accordingly.

At a ‘Tackle’ prostate cancer meeting in London in November, I luckily met up with Dr Ajay Aggarwal who told me that this was probably a condition known as Pelvic Radiation Disease (PRD) and that treatment is available at the Royal Marsden in London. He suggested I asked my GP for a referral to the Gastroenteritis Clinic run by Dr Andreyev at the Marsden.

I attended my first consultation on 27 February where I discussed my situation with Dr Katerina Klimova (a fellow in gastric problems). She started by explaining the rudiments of the food passage through the alimentary canal, and diagnosed that I probably had bacteria leaking through the ilium which had probably become weakened by the radiotherapy treatment.

I also had to complete a ‘fibre quiz’ and my score suggested that I am eating too much fibre! I now have to change my diet somewhat to reduce fibre intake. I was given a booklet to help me do this. I am now due to revisit the hospital at the end of April 2015 at which time I shall have the following tests:

- Glucose hydrogen methane breath test
- Gastric endoscopy
- Colonoscopy
- Stool samples.

Whilst I do not absolutely need these treatments, I do feel that it is worthwhile to pursue this route, since it will undoubtedly improve my condition and enable these experts to give me advice and/or medication to make life more comfortable.

Further progress reports to follow!

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Our Support Group members who took part were: Vernon and Julie Janes, Ken George, Graham Clift, Gerry Cunningham and Gerald Gilpin.
We talk about “life after prostate cancer” as if we are all survivors. There are cases where this adage is not true and where the impact on a family is sudden, profound and heart-wrenching. At Tackle we recognise it is important to tell these stories, to help others and share some of the realities of dealing with this awful disease. Here is one such story, which I wanted to share with other readers.

**TEARFUL AND VULNERABLE - A very personal view**

Carole Williams

When my husband died from advanced prostate cancer nearly a year ago, I was totally unprepared for the avalanche of despair, grief and vulnerability, which swept over me like a huge crashing wave.

Even now almost a year on, I sometimes wake to what Churchill described as his ‘black dog’ and then I find the only remedy is vigorous physical exercise, or doing domestic tasks which focus my mind. This unpredictability is quite un-nerving and one simply has to learn not to worry about it and to accept each day as it comes.

I have nothing but praise for our local GP services and for the local hospital during the eight and a half years my husband was under their care and support. We were lucky to have no problems with accessing drugs funding and for the local integrated health team in the last few weeks. My husband died in a local palliative care unit and again their care and support was superb.

However, what did surprise me was the time I had to wait for bereavement support, which I felt I needed early on in the few weeks immediately following his death.

Exhausted and disorientated by grief, I knew I needed help, but felt I could not walk into the palliative care unit again, which was where most of this counselling was offered. This would have been too painful. I requested a home visit, but I had to wait several months for this to happen. Perhaps it is assumed that most people will have close family and/or children to help the bereaved in the early weeks: one organisation told me I had to wait three months to ‘qualify’ for this support, which I found quite cold and unfeeling.

By then, with the help of close friends, I had worked through many of the early issues and had started to feel a bit more ‘normal’ and when a kind counsellor did visit me at home, it was more to reassure me that what I had undergone and the way I was coping with it was something she had seen before. There is no pattern to coping with grief: there is no blueprint, so to simply accept what your mind and body want to do is the best way.

Without close family or children, grief can be a difficult path to navigate: one does not wish to overburden friends or to seem too needy of their time.

People who have not experienced the loss of a close family member may not understand the sudden and possibly seemingly irrational changes of mood and physical energy. One day you feel fine, the next as though you could hide from the world. I was totally unprepared for this, being a mostly outgoing, confident person, used to public speaking, sometimes to large audiences and to handling difficult situations.

What I have discovered in this bereavement journey is that you have to create your own path through it. Anything is ‘normal’ if it helps: having photographs of my husband in every room, talking to him when in the house and to visit the grave with flowers each week. Some people find moving house a help. This for me would be a nightmare, since we bought our current home to retire to. I am so glad we had the time to furnish it and plan and execute the garden together, so the lovely memories are here, with the growing plants and garden features. These all help me to remember a lovely man, who too late, discovered he probably had inherited a faulty gene, but who stoically determined to fight as long as he could and to live life to the full.

We did many holidays, many trips and visits while we could. This is also something I would strongly advise all those approaching retirement. You simply do not know what the future may hold. At least I have happy memories, full photograph albums and many mementoes.

To all my friends, to the local medical services, a huge thank you and to all those men who think they will know when they have prostate problems, go and have the test as soon as you are 50. You may get the chance to live a longer life.
We held a PSA blood testing event on Saturday 31st January. The event took place at Burnley FC, Turf Moor, 9am till 12 noon. The testing was carried by Gary Steele and his ‘team’ including 8 Phlebotomists. The response was beyond our wildest expectations, 273 men turned up during the morning! They started arriving 8.40am and by 9am we had to ask the Football Club if we could use an extra adjacent room. Men came from all parts of East Lancashire and continued arriving right up to 12 noon!

Out of the 273 tested, 14 were Red (above the accepted threshold), 15 were Amber (borderline abnormal), the rest were Green (within normal range). Of the Reds one showed a PSA of 268 and one of 800.

To have a successful event like this does in fact need a lot of promoting and advertising, via local newspapers, pubs, clubs, health centres, leafleting around town, local radio stations, in fact yours truly was interviewed on Radio Lancashire at 7.20am on the morning just prior to the event. Quite a number of men had then heard it on the half hour news bulletins throughout the morning.

East Lancashire PCSG holds a PSA Testing session
Stuart Marshall

Tackle welcomes new members

Tackle would like to welcome three new groups to our organisation. They are: The Bedford Prostate Support Group, The Milton Keynes Prostate Cancer Support and The Metro Walnut Group from Manchester. We look forward to meeting our newest Members at our AGM, Regional Workshops and other events.

Please Check Your Details

Unless otherwise requested, your details will appear on the list of groups on our website. Please would all affiliated members check on the PCSF website, that their details are correct on both the map: (Please note, this information has been updated to include meeting places and times of meetings)
http://tinyurl.com/429ee7f

and the contact web page:
www.tackleprostate.org/member-organisations.php
If there are any alterations, please contact: Simon Lanyon
Email simon.lanyon@tackleprostate.org

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

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

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 say 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!
It is with deep sorrow that we have to announce the passing of our Hon. Secretary David Smith. He fought his prostate cancer with great bravery and forbearance, never showing that it was getting the better of him. David had been on the PCaSO Executives Committee since 2007 and he became a Trustee of The Prostate Cancer Support Federation in 2009. He succeeded Mike Lockett as Hon. Secretary in 2011. Apart from being Secretary on the Board of Trustees, David was the Tackle Patients’ Representative on NICE Appraisal Committees for new prostate cancer drugs, including pre-chemotherapy Abiraterone and Radium 223. He was also very much involved in helping to formulate all of the responses to NICE Appraisal Committees. His input was always constructive, measured and extremely valuable. For this alone, he will be deeply missed.

He took on the role of coordinating the Riskman Trial with Professor Ken Muir. This was his great passion with Tackle and took up a lot of his time. His knowledge and work in this area was of the utmost importance. He was a great friend to us all, with a wicked sense of humour. A man of great integrity, drive and principle who could always be relied upon to give help and advice on an infinite number of subjects.

His funeral was held at a packed Chichester Crematorium on 24th March 2015. David asked for contributions to be made to Tackle and we send our thanks to those who donated so generously to help us to continue David’s work.

Our thoughts and best wishes go out to his wife Linda and his family.