Why is Bone Health so important for advanced prostate cancer patients and why is it such a ‘forbidden subject’?

The only treatment option for advanced prostate cancer is hormone treatment (ADT). This stops the body from producing the testosterone which drives the prostate cancer. This works very well indeed, but over time, causes osteoporosis. Up to 8% of bone density can be lost from the lumber region in the first year. This in turn can lead to Skeletal Related Events (SRE) and ultimately Catastrophic Spinal Compression.

Zoladronic Acid is a very good treatment for bone health and is given as standard practice in all metastatic cancers apart from prostate cancer.

Evidence from trials and use in the clinical setting, show that zoladronic acid, given intravenously on a monthly basis, greatly reduces SREs, bone pain and the time to the first SRE.

Having been on the receiving end of zoladronic for over four years, I have found little or no side affects.

Dental hygiene is of the utmost importance because zoladronic acid, in rare cases, can cause a serious condition called osteonecrosis of the jaw. To help guard against this, it is possible to obtain, on prescription from your dentist, a very high fluoride toothpaste called Duraphat 5000.

There is a newer and even more successful treatment for bone health called denosumab. This is a new class of osteoporosis treatment called a human monoclonal...
antibody. Denosumab is an anti-resorptive therapy that inhibits the development and activation of osteoclasts (the cells that eat away bone). It is administered by a six monthly injection, just under the skin, in your GP’s surgery. This is much more convenient than a monthly trip to the hospital.

Denosumab has been passed for use in all metastatic cancers apart from prostate cancer. WHY? When NICE looked at denosumab. The comparator used was zoladronic acid, as zoladronic acid is not in the NICE treatment pathway for prostate cancer, there was no comparator and therefore it was refused.

With the advent of new life prolonging drugs and treatments, it is even more important to make sure that the patient receives treatment for bone heath, because if not treated, as patients live longer the chances of SREs and spinal cord compression increase and can have a serious impact on quality of life and even death.

I wonder how many patients have been told all of this? It seems to be a forbidden subject. NICE guidelines state that neither zoladronic acid nor denosumab can be given routinely for advanced prostate cancer. However, if you develop osteoporosis, then you can then be treated under the guidelines for osteoporosis. Therefore, please make sure that if you are receiving long term ADT treatment, that you are given a DEXA (bone density) scan to measure your bone density at regular intervals.

So what of “Riskman”.

As long standing members will recall, Riskman is the program of work that followed the debate organized and hosted by the Federation in 2008.

The debate featured arguments for and against population based screening for prostate cancer based on the PSA test. Whilst there was good agreement around the potential of setting up population based screening for PCA there were doubts raised at the debate around the use of the single PSA test. The result was that members agreed to support the build up of a series of pilots to establish the case for a combined risk based approach. This would assess prostate cancer risk and determine which men should undergo a prostate cancer biopsy. In the words of the Chairman at the time (Sandy Tyndale Biscoe) the aim of the Federation was to “kick off” a program of work that potentially would ultimately look at the case for population wide screening in the UK.

So what has been happening since those days back in 2008? Equally importantly what have the funds that the Federation members generously raised been spent on? Well to answer both questions posed above – we believe quite a lot!

We have carried out a series of surveys and pilot studies to inform the best approach going forward. These have included:

- Two attitudinal surveys to assess men’s and GPs’ attitudes to a risk-based approach to prostate cancer screening. These two important feasibility studies were conducted in partnership with the Graham Fulford Charitable Trust. The studies were conducted separately with the general public and with General Practitioners. We developed two short surveys which were completed by more than 1000 men from the general public who voluntarily attended PSA test sessions organised by the Graham Fulford Charitable Trust and by more than 100 GPs around the country. The results indicate that both men and GPs are very supportive of the risk-based approach. Over 80% of men expressed strong support; 77% of GPs were supportive, though the survey indicated an understandable demand for more evidence.

- A pilot study collecting and utilising a risk-based approach in Primary Care. Dr Jon Rees helped run this pilot which demonstrated that both the clinical investigation require and data collection procedures involved were simple and practical to achieve in the General Practice setting.

- We have been working with Dr Ian Lewis and Claudia McVie from The Tenovus Cancer Charity supported by Professor Malcolm Mason to look at collection practices and recruitment through mobile health units.

- In collaboration with Dr Cezary Cybulski and Prof Jan Lubinski at The International Hereditary Cancer Center in Poland – we have undertaken an analysis based on over 2800 biopsies from men who have been assessed for risk factor characterisation. The results confirm that using a risk threshold of 12.5%-15% would indeed save between 27%-34% of disease-free men needing to have a biopsy.

- The Riskman program has been presented to a number of important committees including the Prostate Cancer Advisory Group and the NIHR Prostate Cancer Clinical Studies Group and the pilot work has been very well received.

Thus, since our relatively small beginnings back in 2008 it has been a somewhat long and slow process to get to where we are now but inspired throughout by the Federation’s support. We have continued to work towards our agreed joint aim at the original debate of seeing whether the case for risk based screening continues to build and the pilot works above all support the program pushed on by David Smith, Hugh Gunn and Sandy in particular since the start.

Continued on Page 3
Two important developments have occurred recently that have the potential to move us even further forwards. Firstly, the Swedish group led by Prof Henrik Gronberg have completed the “STHLM3” trial - a trial of a new algorithm based diagnostic for aggressive prostate cancer in Sweden. Both the Riskman and STHLM3 groups exchanged protocols at the start and we have been involved in the STHLM3 work as Prof Muir was a member of the external scientific advisory group to STHLM3.

In summary, the Swedish study “screened” nearly 50,000 men using 2 “molecular chips” – one based on a biomarker panel and one based on a panel of 120 informative genetic markers. The study, which recently reported, has been very successful and has shown the following: Using the same sensitivity as PSA≥3 ng/ml to diagnose Gleason Score ≥7 prostate cancer, the STHLM3 model reduced the number of biopsies by 32% and avoided 44% of the negative biopsies. Furthermore, the number of Gleason Score 6 cancers was reduced by 17%.

Thus, the STHLM3 model reduces unnecessary biopsies without compromising the ability to diagnose Gleason Score ≥7 prostate cancer, and is a significant step towards personalized risk-based prostate cancer diagnostic programs. For the UK setting though there is still important work to do, that is:

- It has yet to be assessed in a different multi-ethnic population such as the UK. Approx 10-1500 men would be ideal to prove its comparable performance in such a setting.
- To determine its relative costs.
- To look at its use in the NHS setting. To define its precise role in wider systematic population based testing.

Through our ongoing strong collaboration with the STHLM3 group we have a great opportunity within the Riskman program of work going forwards to validate its use for the UK multi-ethnic population. UK based commissioners and clinicians require this vital validation to quantify the performance of this approach for the British population and have confirmed this to us.

To achieve a UK based validation therefore Prof Gronberg and Fisher Sciences (who manufacture the chips) have agreed to make the chips available to us together with testing capabilities at cost. We have already run pilot samples through these testing procedures and confirmed their comparability and reproducibility and are able to scale up rapidly to full validation within our recruited study population.

Thus, as part of the Riskman program going forwards we plan to include allows a validation for UK multi-ethnic population.

The second key development is “Devo Manc” – that is, from April 1st 2016 Greater Manchester will take responsibility for its entire health and social care budget – some 8 Billion pounds to commission and provide its own healthcare service, referred to locally as “Devo Manc”. Whilst not providing funds for research per se it does provide a platform for much more flexibly testing, alongside existing cancer pathways new models for the improved delivery. As such it also effectively provides greater clinical support for assessing new approaches that potentially dramatically change the way healthcare for a particular disease may be delivered in the future. We have presented the Riskman program of work to seek approval for running risk based assessment in parallel to the existing clinical urology pathway and the case is being considered.

In summary, going forward we can provide and take advantage of unique opportunities for the delivery of significant impact of proven new technologies and approaches to improving the prostate cancer diagnostic pathway. To do this we, as ever, need to attract further funding to continue the work but we continue to explore all possible routes for this and remain optimistic that given the kick start of the Federation’s funding at the start we can carry on the work independently assessing the case for better and more systematically diagnosing prostate cancer reliably in the community.

Ken Muir and Li Lophatananon in loving memory of Mr David Smith (Federation Riskman lead) who continues to inspire us...
We are delighted to welcome two new members to Tackle’s Clinical Advisory Board:

Nick James BSc (Hons) MBBS PhD FRCP FRCR
Founding Director of the University of Warwick Cancer Research Centre and Consultant in Clinical Oncology at the Queen Elizabeth Hospital Birmingham. previously Professor of Clinical Oncology at the University of Birmingham until his move to Warwick in 2013. Nick qualified in 1983 from St Bartholomew’s with the principal class medical prize and a First in Immunology. He undertook postgraduate training in London, Brussels and Tokyo as well as a PhD at Imperial College, London.

Nick co-founded the leading website CancerHelp UK in 1994. The website was one of the first to focus exclusively on patient information and was underpinned by a programme of educational research. It featured the first searchable database of clinical trials for patients seeking to enter a study. In 2002 it became the main patient resource on the Cancer Research UK website until being recently absorbed into their main site.

He led the first UK trial of gene therapy in prostate cancer and was UK chief investigator on the TAX327, which led to the licensing of docetaxel for prostate cancer. He has subsequently led a range of trials in prostate cancer most notably the STAMPEDE trial. This novel multi-arm multi-stage trial has formed a platform for testing, in parallel, a range of different therapies and has now recruited over 7000 men. The recent analysis of the docetaxel data from this study has demonstrated that use of docetaxel at diagnosis of advanced disease improves overall survival by over 20%.

He has also led a series of trials of chemoradiotherapy for bladder cancer culminating in the phase III BC2001 trial, published in the New England Journal of Medicine in 2012 with an accompanying editorial describing the work as “ground-breaking” and “practice changing”.

Stephen Langley MBBS(Hons) MS FRCS Urol
Consultant Urological Surgeon at the Royal Surrey County Hospital and the St Luke’s Cancer Centre in Guildford. Stephen became a Consultant in 1998 and then after 6 years was appointed as Professor of Urology at the Post Graduate Medical School of the University of Surrey, where he co-lead a major research programme in the field of prostate cancer.

Educated at St Paul’s School London before studying medicine at St Bartholomew’s Medical School, London. He graduated with honours in 1988 and then began his surgical training. In 1996 he passed his Specialist Consultant exams in Urology in which he was awarded the Keith Yates Gold medal for outstanding performance.

He has an international reputation as an expert in the diagnosis and treatment of early prostate cancer. In 1999 he pioneered the treatment of early prostate cancer by brachytherapy in the UK. This technique uses tiny radioactive seeds implanted into the prostate gland which treats the prostate cancer sparing the surrounding tissue. To date he and his large team have successfully treated over 3000 men with this treatment. The excellent clinical results have been widely published and presented.

In 2012 he published and presented the technique of 4D Brachytherapy, a novel method to perform prostate brachytherapy using both stranded and loose seeds in a one-stage procedure with real-time dosimetry. This technique delivers an improved radiation dose to the prostate whilst reducing the side effects compared to earlier techniques. 4D Brachytherapy is quick to perform, reducing the anaesthetic time and allowing patients a quicker recovery.

Stephen's passion to improve the care for prostate cancer patients led him in 2003 to invent the technique of prostate template biopsy. This new method allows the surgeon to diagnose and monitor cancerous changes within the prostate in a more detailed and specific way. This technique, developed in Guildford, has been NICE approved and is now used throughout Europe. He is a pioneering clinician and in recent years has trained as a robotic surgeon. He uses a Da Vinci robot to surgically remove cancerous prostate glands from patients as another tool in his armamentarium to treat prostate cancer patients. He is the Chairman of the UK Prostate Brachytherapy Advisory Group and sits on the Department of Health’s Prostate Cancer Advisory Group, influencing national policy. In 2005 he received Karl Stortz Golden Cystoscope awarded from the British Association of Urological Surgeons for an outstanding contribution to British Urology. In 2013 he received a Silver Clinical Excellence award. He has recently spearheaded a successful campaign to raise £4m from Charitable and NHS funds to build a prestigious new Centre of Urology at the Royal Surrey Hospital due for completion in 2017.
Dear Hugh,

I have read Tackle and Updates for several years now but have yet to see anything on two matters I have been involved with.

One is rectal bleeding post radiation, frightening when it occurs, and quite common I believe.

The other is the frequency of radiation. I refused a daily hospital visit over seven weeks so was offered a weekly one at three times the daily dose.

Did I do right? My PSA is now minimal, so why is this not offered to everyone?

Yours Sincerely,
Robin Kent

Below is a letter from Robin Kent who is a member of PCaSO. If you have any views, please reply to: hugh.gunn@tackleprostate.org
Room Seven is one of eight radiotherapy suites at the Cancer Centre at the Old Queen Elizabeth Hospital in Birmingham. I have now completed 20 of my 33 sessions so the journey from Stratford-on-Avon to the QE is now becoming routine. I cycle to the station, take the train to Moor Street and then walk over to New Street to catch the train out to the University stop. From there it is a short walk to the hospital. I have afternoon appointments and like all prostate cancer patients being treated need to arrive an hour before the appointed hour to allow time for a self administered mini-enema and the drinking of at least 4 cups of water.

An empty bowel and a full bladder is everyone's aim. The waiting area serves all eight suites and is a large airy room with a central section that has a glassed roof. It can get hot but still many of us sit in this central area as it is close to Room Seven and we like to keep an eye out for any notices of delays or advances in treatment times. Like Las Vegas gambling halls this is a room without clocks but time and timing is very important to all of us men as we seek to present with the required full bladder. There are patients here with all sorts of cancers but we have no trouble identifying which of us have prostate cancer. We are the ones with the plastic cups filled with water in front of us.

When you come to be measured up for radiotherapy you have to do the enema and the drinking routine and they tattoo a spot on each hip and one low down on the abdomen. The scan of your bladder on that day is the benchmark that the radiographers use before each treatment to see if you are full enough to be treated. They will not treat you if they do not think it is safe to do so. This can mean starting again with the drinking routine or having another enema. Occasionally the repeat does not hit the mark so the day can end without success.

All these matters are clearly set out in a leaflet that guides you through the treatment process. I arrived early for my first appointment and clocked in by dropping my appointment card into the slot outside Room Seven.

I felt alone as I sat and re-read my leaflet, observing my fellow patients and no doubt being observed by them. However within a couple of days I discovered that I had joined an exclusive club of those whose appointment times fell towards the end of the afternoon. Except that it was a very inclusive type of exclusive club with everyone greeted and made welcome by a core group of about 6 people including one wife who came along every day. I soon felt comfortable drawing my chair up to the round table where we usually congregated. The conversations varied from the test match scores to the state of the car industry but the recurrent themes were and are your time of treatment and any delays, any side effects and any travel complications. I have found myself discussing bowel and bladder issues with complete strangers in the confident expectation that we were in the same boat. Quite how unusual this is was brought home to me when I met a fellow patient at New Street who had just completed his treatment after a number of unsuccessful days due to constipation, a not uncommon side effect of radiotherapy. I wondered what other passengers made of our enthusiastic celebrations of his empty bowel!

Travel arrangements and delays were not just a matter of moaning about getting home and having a late meal. The process of achieving a full bladder requires the patient to be fully hydrated and this is not something that is achieved quickly nor are its effects rapidly dissipated. For myself I make sure that a couple of pints of decaffeinated tea and non-carbonated water had been downed before I leave home but then I am sure of comfort stops at the railway stations and on the trains. Even with these stops I am often very relieved to reach the Cancer Centre. It may be called urgency and frequency by the medics but its desperation for many of us.

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**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 say thank you for shopping with them.

**Just visit:** [http://tinyurl.com/qaxl9ny](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](http://tinyurl.com/qaxl9ny) now.

Already registered? Spread the word to family and friends to let them know just how easy it is!

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Doug Badger - Chairman South Warwickshire PCSG.

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Free Help Line - 0800 035 5302
And this desperation can occur on the return journey too so those travelling by car or bus are usually timing their runs in and home very carefully.

When you are called for treatment the radiographer checks the first line of your address and your date of birth address before you enter the room as the previous person leaves. A rapid turnaround is achieved by asking all prostate cancer patients to wear slip-on shoes or slippers and joggers. Trousers and footwear off and action stations! The actual treatment takes about ten minutes and involves lying very still on a metal bed with your head cupped in a half-helmet and ankles lying in slots. You are asked to ease down your underpants to the point where your tattoos are visible as this is how they target the rays. The bed lifts when you are in position and retracts towards the wall where some white pieces of equipment are attached to a sort of wheel. Once all the measurements are confirmed the radiographers (there are always two) withdraw and you are alone. After a while there is some whirring and the wheel starts to turn in an anti-clockwise direction and the pieces of equipment revolve around you for a full rotation. This is when the scan is taking place. There is then a pause as they make the decision if all is good to go. The height of the bed is remotely adjusted minutely at this point which indicates that the scan was OK and treatment is about to start. Then the kit rotates in a clockwise direction and treatment is in process. After a while it goes back in the other direction. When it stops your treatment is over and the radiographers come back into the room and slide your bed away from the wall and lower you so that you can get off safely. Sometimes this exit is pretty fast and in extremis a bottle is on hand for immediate relief!

The staff have a demanding and responsible job. The first treatment starts at 8am and the last one ends about 6pm. On a busy day they will see about 40 patients. Despite all the technology and the pressure of time they manage to retain the human touch and chat for a bit before and after treatment. The prostate cancer patients are a big group in the Room Seven clientele but there are other patients too and for them the treatment room has to be arranged differently so changeover time can be busy. And they fit in an occasional in-patient who will arrive on a trolley. This will bring delays but no one is complaining because we wouldn't want to change places with those patients on the trolleys.

For many of the men this radiotherapy is at the start of their prostate cancer journey and naturally they hope all will be well when they have their PSA tests after the treatment. This is probably why I get a lot of questions about why I am having radiotherapy when I had a prostatectomy 11 years ago. I have to explain that though I no longer have a prostate gland I do still have prostate cancer in my body as my PSA level is rising, having been suppressed by Zoladex injections over the last 6 years. On the other hand the scans suggest that the cancer has not spread to other organs so that is good news. And so I find myself having 33 sessions of radiotherapy to the prostate bed while most of them have 37 sessions targeting the prostate gland.

And so we educate each other about this disease that threatens our wellbeing and gain strength from the sharing. But this is a shifting group, a conveyor belt of patients, and I know that some of those who have made me so welcome will be finishing next week. And I am glad for them but it will not be the same without their company. I know that when I complete my 33 sessions that I will miss these conversations and shared laughter and even Room Seven.

PROSTaid Awareness Evening at Leicester Racecourse

How many doctors does it take to make a good event into an excellent one? The answer is two. At the prostate cancer awareness evening held by the Leicester Group PROSTaid, Dr. Jon Rees, who gave a talk on “A GP’s Perspective” and Dr. David Boocock, Senior Research Fellow at Nottingham Trent University, who spoke about looking for Biomarkers in prostate cancer.

Before an audience of over one hundred people, Dr. Rees spoke about good practice in dealing with prostate cancer patients and pointed out that most GPs will only diagnose one new patient a year and consequently it is possible that well informed patients frequently have more knowledge in the treatment of the disease than they do.

To help GPs to be better informed, Dr. Rees, who is also a partner in a busy practice in the Backwell & Nailsea Medical Group, travels around the country giving talks to provide a better understanding of the disease. He is also on the Clinical Advisory Board of Tackle Prostate Cancer.

Dr. David Boocock, who is based at the John van Geest Centre at Nottingham Trent University, gave a talk about the development of a new vaccine which utilises the body’s own immune system and would be given to advanced prostate cancer patients. A small successful phase one trial has already been carried out and they are looking to raise four million pounds to start a phase two trial. He made a very complex subject completely compelling and understandable.

For a little light relief Leicester Tigers’ players, Greg Bateman and Lawrence Pierce gave a very entertaining insight into their lives as professional sportsmen.

The whole evening was fascinating and PROSTaid is very grateful for the use of the venue and the staff who gave up their free time to help.
It is with great sadness that we announce the passing of Colin Peach. Colin, you will remember, bought a racehorse and called it ‘Prostate Awareness’. Although it never won any races, he was able to use it to raise awareness of prostate cancer at racecourses all over the country. Colin also had the satisfaction of indulging his lifelong passion and doing valuable work at the same time.

Members of our group and our former MP were extremely privileged to be invited by our local Urology Surgeon Mr Mohan Pillai, to view a new da Vinci Surgical Robot sited at the Royal Blackburn Hospital, Lancashire. This hi-tech equipment will benefit many people in the Lancashire area (from North Manchester to the Cumbrian border).

We spent just over two hours in the company of Mr. Pillai who first of all talked to us about this fantastic machine, the funding and its uses. He then took us to meet some of the staff in the theatre, where we were given an amazing insight into how the Robot operates, including being allowed to operate the Robotic arms from the console ‘at the other end of the operating theatre’. ( Needless to say none of us got the job!). The surgery is carried out using the screen in the console, where the whole operation is greatly magnified and in 3D. It is quite incredible! We are extremely thankful to Mr. Pillai as nothing was too much trouble to him!

The £1.3 million da Vinci Robot is the first in the Lancashire area. It is now installed, with a number of successful Prostatectomy operations having already been performed.

It with great pleasure we welcome the following groups to Tackle:
Isle of Wight Prostate & Urology Cancer Support Group
Contact: Mr Dave Kiely
davekielyiow@aol.com
Mr Norman Harriss
stormingn@hotmail.com
Website: www.isleofwighturologycancersupportgroup.org.uk

Please Check Your Details
Unless otherwise requested, your details will appear on the list of groups on our website.
We are asking 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/429ee7f
And the contact details at: http://tinyurl.com/omp6y5e
If there are any corrections required please contact Simon Lanyon by email: simon.lanyon@tackleprostate.org

Don’t forget, the National Help Line is now Free of charge: 0800 035 5302

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