East Lancashire Prostate Cancer Support Group Newsletter

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What's Inside

New genetic variations identify men at higher risk of prostate cancer

NHS Choices Tuesday June 12 2018

"Prostate cancer spit test is trialled," reports BBC Online. They say that this test looks at men's DNA to see if they have "high-risk [prostate cancer] genes that are thought to affect 1 in every 100 men". The BBC reports that the test has started to be trialled in 3 London GP surgeries.

As yet, however, no results of this test have been published. Instead, the news has been prompted by the publication of a new international study that identified 63 new genetic variations associated with an increased risk of prostate cancer.

The researchers in this study compared DNA from about 80,000 men with prostate cancer and 60,000 men without the disease. They identified 63 single genetic variations in the DNA code that increase the risk of prostate cancer. These add to the 85 genetic markers already identified in previous studies.

Overall these variations were estimated to account for just over a quarter of the genetic risk for prostate cancer.

The researchers hope the findings could help to identify which men are at higher risk of prostate cancer and could therefore benefit from closer monitoring.

Although the media report that trials of such a test have started, this study did not give any details of this. We will need to wait for the results of this subsequent trial to know whether such a test does improve detection and management of the condition.

Where did the story come from?

The study was carried out by an international consortium of researchers from several countries including the UK, US and Australia. The authors reported various sources of external funding from different institutions around the globe, such as the US National Institutes of Health, European Re-

search Council, Cancer Research UK and Prostate Cancer UK.

The study was published in the peer-reviewed medical journal Nature Genetics. The abstract can be read for free online.
Although the media focus their headlines on a potential prostate cancer "spit test" being used as a form of screening to identify men at high risk, this study did not look into any such test.

However, a press release published by the Institute of Cancer Research covering the study did include details of the plan to trial the DNA "spit test" in a sample of GP practices.

The study focused on the identification of genetic variations associated with prostate cancer, but does not describe development of this into a test or give details of any trials of such a test. The reporting of the findings of the actual research was generally accurate.

What kind of research was this?

This was a genome-wide association study, a type of case-control study, which aimed to identify genetic variations associated with a man's prostate cancer risk.

Prostate cancer is the most common cancer in men in the UK. The causes are not clear cut, but a few factors are known to increase risk. These include being older or of certain ethnicities (for example black-African ethnicity), and also genetic factors.

Many different genes are likely to each contribute a small amount to a man's risk. This study aimed to identify more genetic variations associated with prostate cancer. To do this the researchers compared the DNA of men with prostate cancer (cases) with the DNA of men without the disease (controls) to see if they could find differences.

Studies like this are useful for digging a little deeper into how a person's genetic makeup may influence the onset of medical conditions. They can also in some cases pave the way for new ways of assessing a person's risk of disease.

But with this type of complex disease it's important to bear in mind that genetic studies are at a very early stage so further research is nearly always needed before better diagnostic tests – and treatments – can be developed.

What did the research involve?

The researchers combined both new and existing data on men of European descent. They compared the DNA of 79,194 men with prostate cancer and 61,112 men without the disease.

The researchers were specifically looking at single "letter" differences (variations) in the men's DNA – called single-nucleotide polymorphisms (SNPs), pronounced "snips". They looked at hundreds of thousands of SNPs across the DNA, looking for variations that were more common in men with the disease than men without the disease. Researchers already know about 85 SNP variations that are linked to an increased risk of prostate cancer.

Not all of these SNP variations will lie within genes. (Genes are the parts of the DNA that are known to contain instructions for the cell to make proteins). Sometimes they are just near to genes that are having an effect on a person's risk. The researchers therefore looked at any SNPs that were more common in men with prostate cancer to see whether they were within or near to genes that could be important in prostate cancer.

The researchers also estimated how much of the genetic risk of prostate cancer could be explained by the 85 known, and any new, SNP variations they identified as being linked to the disease.

What were the basic results?

The researchers identified 62 SNP variations that were more common in men with prostate cancer and had not been linked to the disease before. They also identified 1 SNP associated specifically with early-onset prostate cancer.

They estimated that overall the 63 SNPs they identified as being linked to the disease, plus the 85 already known to be linked to the disease, accounted for about 28% of the genetic risk of prostate cancer.

How did the researchers interpret the results?

The researchers concluded: "In summary, we identified 63 novel prostate cancer-susceptibility variants." They say that a "risk score" based on all the known SNPs "can be used to improve the identification of men at high risk for [prostate cancer]" who are more likely to benefit from screening using the Prostate Specific Antigen [PSA] test. This could help to "reduce the burden of over-testing".

Conclusion

This international study has identified more than 60 new genetic variations that are associated with an increased risk of prostate cancer, bringing the total known to almost 150.

These findings increase our understanding of the genetic risk factors for the disease. Researchers will now look more closely at the specific genes that may be causing these differences in risk.

The researchers have also suggested these results could be used as a way of finding men who are at increased risk of prostate cancer, and who could therefore benefit from closer monitoring.

At present, the only way to screen for prostate cancer is to have a blood test to look for raised levels of the PSA protein. Unfortunately, PSA levels can be raised for reasons other than prostate cancer. So not only may the PSA test miss some men with the disease, it can also lead to unnecessary interventions in men who do not have prostate cancer.

These limitations mean that the PSA test is not used for screening for prostate cancer in the UK. Theoretically, a new DNA-based test could identify those men at highest risk, who might then be targeted for screening using the PSA and other diagnostic tests, rather than offering PSA testing to all men.

One point to note is that a test based on these findings won't be able to definitively identify all men who will develop prostate cancer, nor guarantee that men won't develop the disease. Also, because the findings are in men with European ancestry, the results may not apply to other ethnic groups.

The media have reported that a trial looking at the use of such a test has started in London. The current research paper gives no details of this so it is not clear how it is being used. We will need to wait to see the results of this or other trials to determine whether such a test could improve prostate cancer care.

Analysis by Bazian
Edited by NHS Choices

Life isn’t about waiting for the storm to pass… It’s about learning to dance in the rain.

By **philosiblog** on 31 July 2013 in **courage**, **decision**, **motivation**, **perseverance**, **procrastination**, **risk**

Life isn’t about waiting for the storm to pass… It’s about learning to dance in the rain. – Anonymous, more recently attributed to Vivian Greene

What does that mean?

This quote is about living our lives, not simply waiting around for a good time to start. Too many people wait for the right moment before starting to live their life. To me, that’s just too much wasted time.
The quote starts by saying what life is **not**. It is not about waiting. It is not about avoiding the storm. And it is most definitely not about waiting for the storm to pass.
Waiting just allows time to pass. What gets done while you wait? Time has gone by, and you have nothing to show for it.
he quote concludes by saying that life is about learning to dance in the rain. It’s about learning to live with, and even enjoy the inevitable storms of life. Sing or dance, enjoy your life, no matter what the weather might be.
We all will face storms in our lives. It is up to us to determine how we will respond to these disruptions. Will we hide inside, waiting for it to pass, or will we continue with our lives, enjoying even the roughest of weather? It is our choice.

Why is not waiting important?

Whether you call it waiting, procrastinating, or just wasting time, what is happening is… nothing. However, time isn’t standing still, is it? It, like your life, is moving forward. If you are just waiting, you are really drifting while you wait. What will that gain for you?
Another problem with waiting is that it can be much harder to learn when you aren’t doing anything. I differentiate between doing nothing and cerebral exercises, such as reading or planning. One can learn and do, even if you aren’t out dancing.
Yet, eventually, we must take action. Sometimes there is no possible way to do anything without getting wet. That is when we must learn to dance in the rain. Or to do whatever we need to get done.Rain or shine,

life must go on.
The implication of dancing is that we are enjoying it. If you have to do something, the least you could do is learn how to enjoy doing it. Even if it might be the best time, or perfect weather, we still must do, so let's have some fun while we're doing it, right?

Where can I apply this in my life?

We all go through rough weather at various points in our lives. Sometimes we sit down, to wait for the storm to pass, and then forget to get back up. Take a moment to consider where in your life you might have paused for a break in the weather, and never gotten back to it.
What about the storms presently in your life? They are the things which this quote is specifically focused. Take a moment to consider what, where, and how severe are your storms at this moment in time.
Are there storms in your family life? Are there storms with or between your friends? Are there storms at work, between co-workers, or even between your company and the customer? What about your social groups, are there any storms there? Weather can come up fast from any direction, can't it?
But the question remains, what will you do? It's easier to restart the things placed on hold due to rough weather, once the weather is passed. But what about things which you have put on hold where the weather is still less than great?
Are you going to get back to it? Are you going to learn to dance in the rain? Are you going to learn to enjoy the extra challenge? Will you revel in the chance to see if you are good enough to make it happen despite the weather? At least for some of them?
If you choose to wait for the storm to pass, what are you missing? Are there opportunities slipping by? Are there people to meet, whom you will not be able to meet because you aren't out there? Yes, there are costs to waiting, just like there are costs associated with dancing in the rain.
How many of those storms are you hiding from? While we all have our reasons or excuses, in the end, we either are doing things in the weather or we are not. That is our choice; to do or to do not. It is also our choice to enjoy it or to be miserable. Which will you choose, dancing in the rain, or waiting?

MEN WITH PROSTATE CANCER COULD BENEFIT FROM NEW RADIOTHERAPY TECHNIQUES

8/08/2018

The leading edge 'SPORT trial' (A Study Evaluating Stereotactic Prostate Radiotherapy in High-Risk Localised Prostate Cancer) is the first if its kind in the UK and uses an advanced treatment called 'SABR' (Stereotactic Ablative Body Radiotherapy). SABR is highly accurate in targeting certain cancers and delivers large doses per treatment, allowing men to have their full course of radiotherapy in only five hospital visits instead of the typical 37.

In addition, patients in the study have SpaceOAR, a minimally invasive hydrogel technology, inserted prior to radiotherapy treatment. In previous studies, SpaceOAR has been shown to significantly decrease unwanted radiotherapy side effects for patients.

The trial is led by Dr Suneil Jain, Clinical Reader at Queen's University Belfast and senior oncologist at Friends of the Cancer Centre alongside Dr Ciaran Fairmichael, Clinical Research Fellow at Queen's University Belfast. Dr Fairmichael explains: "One of the complications from using radiotherapy is the potential damage that can be inflicted on neighbouring tissues.

"In this trial, we are evaluating the performance of the SpaceOAR hydrogel which is inserted between the prostate gland and the rectum of the patient. This creates a greater distance between the prostate tumour and other tissues, which allows us to concentrate the radiotherapy dosage provided to the tumour and thus reducing the chance of radiation harming other tissues close to the tumour such as the bowel."

Mr Gordon Robinson, aged 70, took part in the trial. He said: "If it wasn't for this research, I simply would not be here. My family and I are so thankful to the doctors who have helped us. This treatment has allowed me to live my life again."

Using the new hydrogel allows clinicians to treat the prostate with a higher dose of radiation, potentially without increasing the risk of side-effects, including impotence, bowel and bladder problems.

Mr Robinson continues: "Taking part in this trial meant I was offered a high-dose five treatment course instead of enduring two months of treatment. The treatment was really successful in getting rid of my tumour.

"I knew about the side effects of treatment, and they really frightened me, but this trial meant I had very little discomfort or complications and can return to normal life, for that I am very grateful."

The preliminary results from the first patients treated in the trial with SpaceOAR and SABR have recently been published in the British Journal of Radiology.

The trial is still open and in the future there are hopes to be able to offer this treatment to a wider range

of men.

The SPORT study is conducted in collaboration with the Northern Ireland Cancer Centre and is being supported/funded by Friends of the Cancer Centre and Augmenix UK Ltd. Queen's University Belfast is a Prostate Cancer UK/Movember Foundation Centre of Excellence.

MEDIA INQUIRIES

Media inquiries to Sian Devlin, Communications Officer at Queen's University Belfast at s.devlin@qub.ac.uk or tel: 028 9097 5840.

Deadly form of advanced prostate cancer is common, calls for distinct treatment

Date:

July 9, 2018

Source:

University of California - San Francisco

Summary:

A new study of prostate cancer in 202 men, whose cancers had spread and were resistant to standard treatment, found that a surprisingly large number of these cancers -- about 17 percent -- belong to a deadlier subtype of metastatic prostate cancer.

A new study of prostate cancer in 202 men, whose cancers had spread and were resistant to standard treatment, found that a surprisingly large number of these cancers -- about 17 percent -- belong to a deadlier subtype of metastatic prostate cancer.

Previously, it was thought that these cancers constituted less than 1 percent of all prostate cancers.

The study, which was led by researchers at UC San Francisco and published online July 9 in the *Journal of Clinical Oncology*, suggests that this prostate cancer subtype, called treatment-emergent small cell neuroendocrine prostate cancer (t-SCNC), might in the future be routinely and more successfully treated with targeted drugs that already are being developed or tested in clinical trials.

"Think of advanced, hormone-treatment-resistant prostate cancers as a pie," said Rahul Aggarwal, MD, assistant professor of medicine in the UCSF Division of Hematology and Oncology and the study's corresponding author. "Instead of treating these advanced cases homogenously as we do with today's standard treatments, we want to split the pie according to tumor characteristics, and develop treatment protocols tailored to individual slices, based on the cancers' distinctive growth-driving genetic mutations and gene expression patterns."

The research team identified specific genetic mutations and patterns of gene expression that are found in t-SCNC, but are distinct from the more common type of prostate cancer known as adenocarcinoma. Among the patterns identified in t-SCNC was higher activity of specific "transcription factor" proteins -- proteins that switch on production of other proteins that drive cancer

Two of the transcription factors over-activated in t-SCNC are targets of drugs already in clinical trials, Aggarwal said, with several more in pre-clinical testing. Aggarwal is a member of the UCSF Helen Diller Family Comprehensive Cancer Center.

In contrast, mutations that previously have been discovered to play a role in many adenocarcinomas were almost never present in t-SCNC, the researchers found.

Treatments targeting specific mutations in prostate cancer are not yet available in standard practice, which relies on hormonal treatment and chemotherapy as the mainstays of treatment. However, as the number of targeted treatments available for cancer grows, genetic analysis of tumors is expected to become increasingly valuable in helping to guide treatment. "Obtaining tumor biopsies in metastatic cancer has not in the past been the standard of care, but it is being done more often, in part to look for neuroendocrine tumor cells, but more generally to get an idea for what mutations are driving cancer growth," Aggarwal said. "This trend has lagged in prostate cancer because most metastasis occurs in bone, and it is more difficult to do biopsies in bone in comparison to other tissues."

The American Cancer Society estimates that 29,430 men will die from prostate cancer in 2018, making it second only to lung cancer as a cause of cancer death among U.S. men. About one in 10 prostate cancers has spread beyond the prostate at the time of initial diagnosis and is more difficult to treat successfully.

In these advanced cancers, additional mutations and alterations in gene expression patterns give rise to treatment-resistant tumor cells. These treatment-resistant cells and the clones they generate through cell division live on and enable the tumor to grow again, according to Aggarwal. The pattern of gene mutations observed in the study suggests that t-SCNC in these advanced cases of treatment-resistant prostate cancer arises from a pre-existing adenocarcinoma, he said.

"It is important to provide hormonal therapy in metastatic prostate cancer, because these hormonal treatments prolong survival," Aggarwal said. "But they are not curative. In nearly every patient the cancer will become resistant to these treatments. It's just a matter of when. We want to know why prostate cancer becomes resistant, and we believe the emergence of t-SCNC is one important mechanism through which they evolve and evade treatment."

The study, which was undertaken by a consortium of five different academic medical centers, enrolled patients at the time their cancers were discovered to have become resistant to conventional hormonal treatment, known as androgen deprivation therapy.

Among patients who had previously stopped responding to second-line hormonal treatment with abiraterone or enzalutamide -- drugs usually administered when initial hormone therapy fails -- men with the t-SCNC subtype survived on average just 36.6 months, compared to 44.5 months for men without t-SCNC. Three-quarters of men in the study had received one or both these drugs.

"An understanding of the biology of this important mechanism of resistance is essential to our developing novel therapeutics designed to prevent the development of this lethal prostate cancer subtype, or, once developed, to effectively treat it," said senior author Eric Small, MD, professor of medicine and chief of the Division of Hematology and Oncology at UCSF. Small is also deputy director of the UCSF Helen Diller Family Comprehensive Cancer Center.

In 160 of the men, there was enough tumor in biopsy specimens to classify the cancer, which was done independently by three different pathologists blinded to clinical and genetic characteristics of the cancers. They found t-SCNC in specimens from 27 of these men. The researchers surveyed genetic mutations and gene activation within tumor cells and identified patterns of genetic mutations that were associated with t-SCNC and with worse survival.

The study was funded by the Prostate Cancer Foundation, Movember, and Stand Up To Cancer through a Stand Up To Cancer Dream Team Award, which Small led.

Other study authors from UCSF are Li Zhang, Felix Feng, Paul Lloyd, Jack Youngren, Adam Foye, Denise Playdle, and Charles Ryan. Authors from UC Santa Cruz are Alana S. Weinstein, Verena Friedl, Can Zhang, Chris Wong, Vlado Uzunangelov, Artem Sokolov, and Joshua Stuart. Authors from UCLA are Owen Witte and Matthew Rettig. Authors from UC Davis are Christopher Evans and Primo Lara. Authors from Oregon Health Sciences University are Joshi Alumkal, George Thomas, and Tomasz Beer. Authors from the University of British Columbia are Martin Gleave and Kim Chi. Authors from Weill Cornell Medicine are Himisha Beltran and Mark A. Rubin. Additional authors include Jiaoti Huang from Duke University, Lawrence True from the University of Washington, and Francesca Demichelis, from the University of Trento, in Italy.

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Proposed afternoon tea at the Ribchester Arms Ribchester. All past and present members are invited to an informal group get together for Afternoon Tea on Wednesday 12th September 2-4pm.

Would all interested parties please send their details to Dave Riley at -- riley.d7@sky.com -- or ring on 01282 451852 . The cost will be free for group members and Ten pounds for partners.

Please give Names, Email address, Contact number along with Places required.

Regards Dave R.

From Left to Right Hazel Goulding (Treasurer) Leon D Wright (IT Admin) Stuart Marshall (Secretary) Steve Laird (Vice Chairman) Dave Riley (Chairman)

Contact Information

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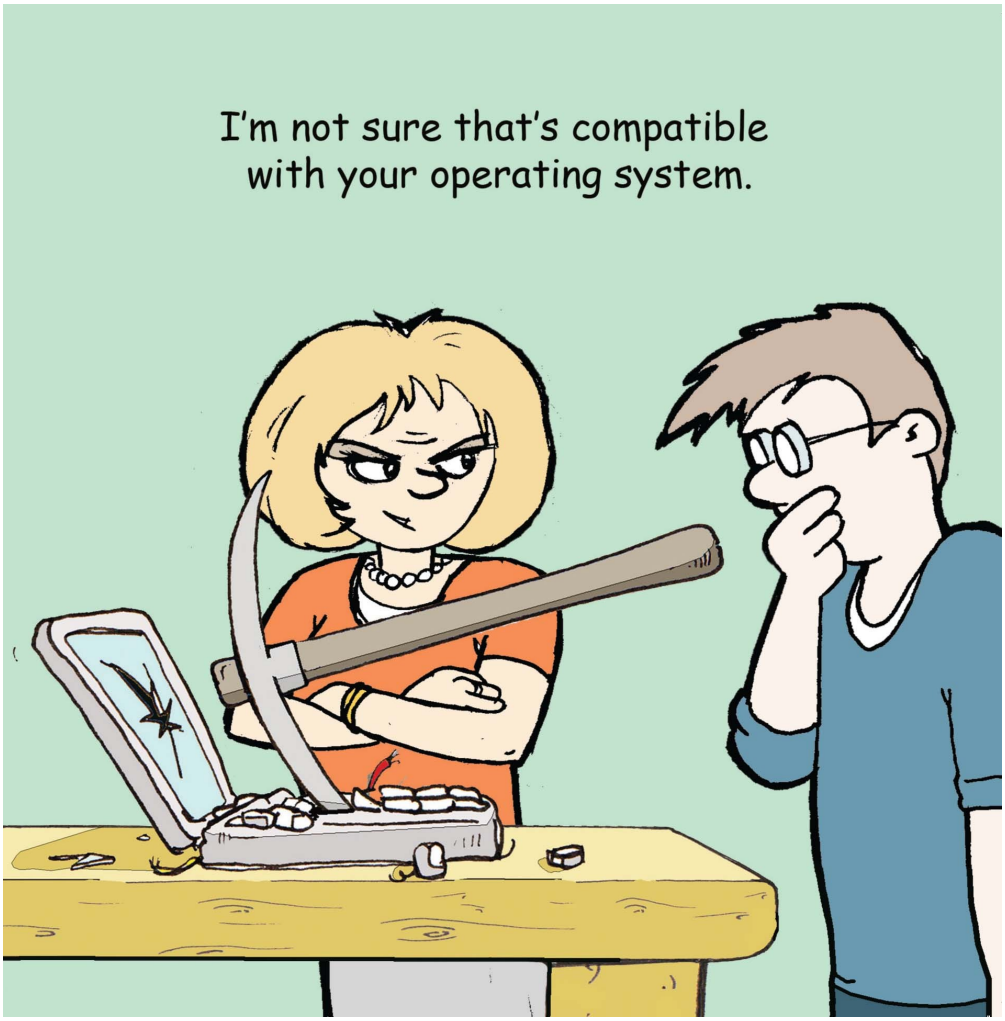
We are a group of local people who know about prostate cancer. We are a friendly organisation dedicated to offering support to men who have had or who are experiencing the effects of this potentially life threatening disease.

The East Lanc's Prostate Cancer Support Group offers a place for free exchange of information and help for local men and their supporters (family and friends) who may be affected by this increasingly common form of male cancer.

At each meeting we strive to be a happy, supportive and upbeat group of people; encouraging open discussion on what can be a very difficult and perhaps for some an

Technophobia



From: Darrell at Prostate Cancer Support <darrell@prostatecancersupport.org>
Date: Monday, 13 August 2018
Subject: FW: Research about memory changes and hormone treatment for prostate cancer at Coventry University
To: Darrell at Prostate Cancer Support <darrell@prostatecancersupport.org>

From: stephen wilson [mailto:wil8769@hotmail.co.uk]
Sent: 13 August 2018 11:58
To: darrell@prostatecancersupport.org
Subject: Fwd: Research about memory changes and hormone treatment for prostate cancer at Coventry University

Hi darrell could please seen this email out to members . Stephen wilson

From: Marya Mobeen <mobeenm@uni.coventry.ac.uk>
Date: 8 August 2018 at 11:57:52 BST
To: "wil8769@hotmail.co.uk" <wil8769@hotmail.co.uk>
Subject: Research about memory changes and hormone treatment for prostate cancer at Coventry University

Hi Steve,

Re our telephone conversation. I would be grateful if you could circulate this email to members of the support group.

At Coventry University , we are doing some research about memory changes and hormone treatment for prostate cancer.

Background: Some people experience memory changes when they have hormone treatment (Androgen Deprivation Therapy) for prostate cancer and this can affect their quality of life. We developed a booklet, which includes information and advice to help manage memory changes related to hormone treatment. As part of a study we are asking people to share their views on a section of the booklet. The study involves a single telephone contact. Everyone will be offered a £10 Love2shop voucher as a thank you.

If you are currently having hormone treatment (or have had hormone treatment in the past 18 months) and are aged under 70, then we would like to hear from you. If you are interested in taking part, **please get in touch before 31st August 2018** (Email: mobeenm@uni.coventry.ac.uk; Tel: 0746 560 7702).

Best Wishes

Marya Mobeen

Doctoral Researcher

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