P-05-849 All men in Wales should have access through the NHS to the best possible diagnostic tests for prostate cancer - Correspondence from the Petitioner to the Committee, 1.12.18

To the Petitions Committee. Stuart Davies Petition

My reply to the Cab Secs evidence.

I have used the Cab Secs letter and my words are in red.

"Dear David.

Thank you for your letter of 19 October regarding Petition P-05-849: access to diagnostic tests for suspected prostate cancer.

Patients in Wales should have access to investigations for cancer in line with clinical guidance and this should be delivered consistently across Wales.

So why is it given free in your ward and two others in South Wales but not in North Wales and has done so for nearly two years that I know of! Ken Skates when I approached him said, NOT EQUITABLE. The stock answers that have come from your dept about NICE, about them being trials in South Wales etc ring hollow, one of the initial studies by NICE was done in the Maelor in Wrexham. So why did you not continue by offering the "free trials" in Wrexham?

Why have I and 15 other men had to pay £900 for each for scans privately, here in N Wales (recommended by the NHS pros by the way!)

The introduction of new tests and procedures need to be fully understood and planned for by Health Boards. In terms of pre-biopsy mpMRI, evidence has emerged from at least one clinical trial that pre- biopsy mpMRI may have advantages over the current recommendations from the National Institute for Health and Care (NICE) for the investigation of suspected prostate cancer.

We know that, the pros know that, I have spoken to quite a few on this journey, they want it, it takes out that horrible mechanical dangerous biopsy treatment.

For info, first hand knowledge.

Antibiotic pessaries are shoved up your bottom first, antibiotics are given orally as well

before and after. Then a cigar shaped instrument is pushed up your bottom and wriggled around as the doctor looks with the built in ultrasound for where to fire it. First comes the needle with the stuff to numb you, then the sample collector needles are fired at your prostate. It hurts! Some one asked what it was like? My reply, like someone sticking an airgun up your backside and then pulling the trigger! It works on compressed air I believe.

The procedure misses some tumours and a negative result can occur even though tumours are there. It is a dangerous procedure because of the instruments environment and the fact that the needle pierces the bowel wall and can infect the prostate. One of the reasons that doctors don't like giving PSA tests as a general rule as a well man thing is that it can lead to more dangerous things as outlined above. Mp mri scans have the potential to do away with these biopsies. It sees all!

However, the issues are broader than whether or not mpMRI is conducted pre or post– biopsy. It is also about the standard of the test, the equipment specifications, the training requirement for the reporting and the potential to rule out the need for a biopsy in some patients. There will also be implications for other cancer and disease pathways if a significant element of demand shifts from histopathology to radiology, while there are already significant pressures on radiology, therefore any pathway changes must be planned for and managed.

What are we waiting for, England went down the route months ago of saying mp mri as first line stuff! You yourself say you want to have more one stop diagnosis for cancer in Wales (not just S Wales!) If as believed mp mri scanning is superior to mechanical biopsy then the streamlining done by mri scanning could be cost neutral. Extra mri scanners can be utilised by other parts of the NHS anyway.

My expectation is that Health Boards deliver high quality and consistent care by providing services in line with guidance from bodies such as NICE. As mentioned above, NICE does not currently recommend pre-biopsy mpMRI but it is undertaking a review of the guideline for prostate cancer diagnosis and management, which is due to be published in April 2019. Details on the scope and progress of this update can be found at:

https://www.nice.org.uk/guidance/indevelopment/gid-ng10057/documents

The Wales Urology Board has discussed this matter on a number of occasions in the past twelve months and at its last meeting agreed to establish a consensus building workshop to support health board planning in advance of the decision from NICE. This workshop is taking place on 12 November, with involvement from Prostate Cancer UK.

Past twelve months, what has taken so long, Ive been asking the questions for longer than that! NICE made noises previous to that and a trial was conducted in the Maelor in Wrexham. Why was it rolled out in South Wales and not North wales, and purleeese! don't keep giving me the official line that it was trials, that line came later when you realised that I was being serious and questions were being asked in the Senedd.

If NICE recommends pre-biopsy mpMRI then I will expect all Health Boards to amend their pathways accordingly. However, what the Welsh Government cannot do is make a decision on what is the most clinically appropriate pathway to investigate suspected prostate cancer.

You put the Betsi in to special measures, it still is, the buck stops with you, This must be the responsibility of Health Boards and clinical leaders, based on the evidence available. I expect there to be greater consistency in service provision You seem to accept that there has been INEQUITABLE TREATMENT across Wales with this statement after the NICE guidelines have been updated.

Can we now trust you to get a grip and make sure that treatment across the whole of Wales is now Equitable and that MP MRI scanning is made available, FREE to ALL men in Wales?

Thank you again for writing to me on this matter.

Yours sincerely,

Vaughan Gething AC/AM Ysgrifennydd y Cabinet dros Iechyd a Gwasanaethau Cymdeithasol Cabinet Secretary for Health and Social Services"

To Sum up:

Nealy 6000 people signed the petition online, nearly 400 have signed a manual one in Llangollen.

In October I note that you gave a Press Release that 3 new scanners are being paid for by the WG, 1 in N Wales. 1 in S Wales and one in Aberystwyth Mid Wales

Why has it taken so long?

We need it doing sooner rather than later!

We want to see funds allocated now so that the rollout of scanners, staff and infrastructure is not held up by lack of funding.

To help the process to go further faster, can the committee do as it says on its front page on the internet and get a debate scheduled as in "seek time to debate the issue in the Assembly" please?

Finally, I know of at least one guy in Wrexham who is holding out to have a scan rather than mechanical biopsy.

Will he die before we get this initiative up and running OR will you do the right thing and tell the Betsi to do what they are doing in South Wales and offer free scans NOW using the Spire equipment as an interim measure. As I have found out, the NHS only pays £300 for these scans as a "trade" rate and you do have an excellent radiographer in the Maelor who can and did interpret my paid for scan.

The Betsi is in Special Measures, the WG is in charge, the buck stops with you.

Stuart Davies