



# All-Party Parliamentary Group on Prostate Cancer

## Minutes of meeting including Extraordinary General Meeting (EGM): Monday 24<sup>th</sup> February 2025

Committee Room 17

### Attendees

- **Calvin Bailey MBE MP** (*chair*)
- **Ben Obese-Jecty MP** (*officer*)
- **Paul Davies MP**
- **Clive Jones MP**
- **Iqbal Mohamed MP**
- **Peter Prinsley MP**

### Speakers

- **Dr Aoife Molloy** (Senior Clinical Advisor Health Inequalities Improvement at NHS England)
- **Professor Frank Chinegwundoh MBE** (Consultant Urologist at Bart's Health NHS Trust)
- **Professor Ros Eeles** (Professor of Oncogenetics, The Institute of Cancer Research and The Royal Marsden NHS Foundation Trust)
- **Jeff Thompson** (Patient Advocate, Founder of Cancer Don't Let It Win)

### 1. Approval of motions – EGM

The APPG held an EGM for a new Officer where Dr Peter Prinsley MP was nominated and successfully elected, following Clive Efford MP's decision to stand down from his role in the Group. Dr Prinsley was selected as a Vice Chair for this session.

### 2. Chair's welcome and introductory remarks

The chair Calvin Bailey MP welcomed MPs and attendees to the first meeting of the APPG on Prostate Cancer. He outlined the importance of bringing together parliamentarians, charities, clinicians with a common goal. He highlighted that this is pertinent in light of upcoming Government strategies including the new Cancer Plan, Men's Health Strategy and consultation from the National Screening Committee.

He provided an overview of the meeting which focused on **identifying men at highest risk of prostate cancer**, recognising that many men could be treated earlier, and this is particularly important given that prostate cancer is now the most common cause of cancer in England. He also referred to recent findings from the National Prostate Cancer Audit (NPCA) which found that black men have higher rates of stage three prostate cancer and are four times as likely to die as white men - setting the scene for today's discussion.

### 3. Dr Aoife Molloy – prostate cancer, inequalities and the NHS

Dr Molloy provided an overview of the strategic priorities in the NHS – highlighting that this is with a view to providing exceptional quality care for all. Dr Molloy then explained the **Core20PLUS5** work and how it sets the framework for addressing both different experiences of care; and different levels of access to care experienced by the Core20PLUS5 populations. She used data from the NPCA to set out what this means for prostate cancer. It was noted that one of the five areas of clinical focus is on **early cancer diagnosis** and that this is vital for prostate cancer as we are seeing huge disparities between different cohorts of men. Dr Molloy highlighted that targeted rather than general approaches are needed. She stated that Core20PLUS5 has laid the foundation, and we are soon to welcome the NHS 10-Year Health Plan but to see change, we will need community buy-in. The example of vaccine uptake during COVID-19 was used to highlight how this worked well. Dr Molloy reiterated key recommendations made by the NPCA to help improve experiences.

### 4. Professor Frank Chinegwundoh – case finding and black men

Professor Chinegwundoh highlighted where his interest began in understanding the numbers of Black men being diagnosed with prostate cancer. He noted that where he practiced in East London, he saw many Black men being diagnosed and noted that there were no official stats exploring how widespread of an issue it was. He explained that he led a team in Barts to look into this and noticed that Black men were twice as likely to get prostate cancer, in his area in East London. With funding from Prostate Cancer UK, he was able to carry out additional research on a larger scale and noticed that the issue was also prevalent in other populations. Professor Chinegwundoh noted that despite the increased risk, there was work that needed to be done to **make Black men aware of their risk**. He stated that he has been making the case for a national screening programme to the National Screening Committee for several years – including arguments around a **targeted programme** for Black men, men with a family history or known genetic disposition. He noted that in the absence of this, targeted interventions can happen at GP level, but current guidance does not enable GPs to have proactive conversations with men about their risk. Professor Chinegwundoh also noted that **case finding can occur through community events** with charities raising awareness. He provided an example from several years ago in Newham where drop-in clinics were held in the community rather than healthcare settings (which can be a barrier) – this meant that men could turn up and get a PSA test. Professor Chinegwundoh stated that his one key ask was for the National Screening Committee to review up-to-date metrics on the reasons for screening.

### 5. Professor Ros Eeles – case finding and family history

Professor Eeles began by highlighting that the risk of prostate cancer is higher in certain groups of men – Black men, men with a family history and men with certain genetic variants. The question is how we find these men without leading to overdiagnosis. Professor Eeles referred to the ‘Family History of Prostate Cancer and Survival Outcomes in the UK Genetic Prostate Cancer Study which looked at men who had a family history of prostate cancer who had been diagnosed with prostate cancer and those without a family history. This showed that men aware of a family history had a better survival and those diagnosed as the first affected member of the family did not demonstrate this indicating that this is an awareness effect. Professor Eeles also

mentioned the importance of looking at the genome. She mentioned that men with BRCA2 mutations are at a higher risk of getting prostate cancer. The cancer is **more likely to be aggressive** and men are more likely to relapse or present with metastatic disease. Results from the international IMPACT studies of targeted PSA screening in BRCA1/2 mutation carriers were discussed, whereby it was highlighted that there should be **yearly PSA tests in carriers of BRCA2 mutations from age 40**. It was noted that this is reflected in European Association of Urology guidelines, so why hasn't this been addressed in the UK? Professor Eeles highlighted that there are genetic tests currently available in the NHS for limited criteria (men with very young onset prostate cancer or very strong family history only) whereas in the private sector and in the USA, men are offered genetic screening and asked whether this is something we should look at in the UK. She mentioned that it is still unknown whether men should have an MRI then a PSA test or not and referred to the BARCODE1 study that is in press in New England Journal of Medicine which screened men according to their genetic risk of prostate cancer using a polygenic risk score. She highlighted that there is a genetic arm of the TRANSFORM trial that will explore different approaches to screening men at higher risk.

## **6. Jeff Thompson – patient voice**

Mr Thompson spoke to the APPG about his **personal experience of prostate cancer**, highlighting the impact on his family, friends, sexual relationships and the psychological impact – particularly when factoring in concerns around family history. He explained that the Doctor spoke to him and did a PSA test followed by a digital rectal exam (DRE). He noted that he hadn't thought about prostate cancer before and didn't know what a prostate was or its purpose. This led him to think about what the experiences are for men more generally, especially Black men. He set up support groups to help and started during COVID-19 with around 5 men, this increased to 10, 15 and 50. He now has around 17 support groups with a database of around 3,000 men. He highlighted that his goal is to see **prostate cancer included in everyday conversation**.

## **7. Questions**

Peter Prinsley MP reflected on Mr Thompson's experience and that many men may not know what a prostate is. He asked whether this is common? Mr Thompson believed it was and also felt that few boys are taught about this in schools. On educating boys, Professor Chinegwundoh highlighted that he had approached the Department of Health and Social Care a few years ago about educating boys in schools and was told to speak to the Department for Education. Between the two Departments there was a lack of clarity around where responsibility for this education sits. Professor Eeles also highlighted that testicular examinations are already incorporated into this type of education in schools so could the knowledge about the prostate be given at the same teaching session.

Chris Booth, Urologist and founder of the CHAPS men's health charity mentioned that he believed there are political barriers to a national screening programme and how can the target to diagnose 75% of cancer at Stages 1 and 2 [in Core20PLUS5] be met without it? He felt that there was no other mechanism that can achieve this other than a screening programme. He also referred to GP education and having initial baseline PSAs. He felt it was negligible for men

without increased risk. Professor Eeles mentioned that the issue is overdiagnosis – PSAs can be raised for prostatitis, urine infections etc not just prostate cancer.

Iqbal Mohamed MP asked whether the speakers had any information on risk for men in the South Asian community. Is it the same as Black men and is there anything he can do in his community to raise awareness? Professor Chinewundoh highlighted prostate cancer is less common in South Asian communities and we currently don't know why. In response to the question about what can be done in local communities, Professor Chinewundoh said that he strongly felt that this should be taught in schools. Professor Eeles also highlighted that whilst South Asian men have a lower risk, they also can have more aggressive prostate cancer.

Ben Obese-Jecty MP stated his interest in prostate cancer stems from his own father's experience with the disease and the connection with ethnic minorities. He reflected on his own experience of getting tested in light of his family history. He highlighted the stigma around DREs, when in fact they are rare and in some instance a PSA is more the norm. He felt education within different communities was vital. Professor Chinewundoh agreed and that there is work to do within the community to make this known. He also commented that the DRE can now be omitted especially when undertaking targeted PSA screening.

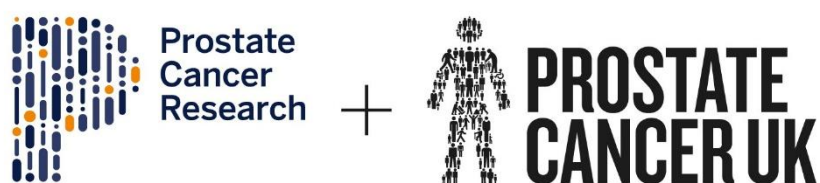
Mr Thompson asked a question about why he's hearing of younger men (<40 years) going underdiagnosed. Professor Eeles highlighted that this is rare but does happen. She stated that it's not currently known why this occurs.

Vishwanath Hanchanale, Chair of Section of Oncology at the British Association of Urological Surgeons (BAUS) agreed that DREs are often barriers and that educating men is key. He also mentioned that different clinicians use different levels when it comes to PSA testing and this must be unified. He said that BAUS feels that a national integrated earlier screening programme is needed for targeted groups. He also pointed to the fact we need more strong family history data to support earlier diagnosis.

Bhavan Rai, BAUS Vice Chair of Oncology, said that he believed overdiagnosis/overtreatment is always an issue, but this is less so now.

Peter Prinsley MP thanked everyone for their contributions and provided an overview of the conversation, which centred around the need to improve data, the importance of a screening programme (whatever this looks like), and education for communities. He reiterated the importance of political power in achieving this.

**Secretariat provided by:**



Contact: [contact@appgprostatecancer.org](mailto:contact@appgprostatecancer.org)

Joseph Clift – Prostate Cancer Research

Joe Woollcott – Prostate Cancer UK