APPG on Black Health & APPG on Prostate Cancer Meeting Minutes

Meeting Title: Increasing Representation of Black Men in Prostate Cancer Research

Date: Tuesday 27th October 2026

Time: 17:15 -18:30

Location: Committee Room 14, House of Commons

Co-Chairs: Dr Paulette Hamilton MP & Dr Peter Prinsley MP

APPG Secretariat: Caribbean & African Health Network (CAHN), Prostate Cancer UK & Prostate Cancer Research

Minutes Prepared By: Caribbean & African Health Network (CAHN)

Welcome & Opening Remarks

Paulette Hamilton MP (PH) and Dr Peter Prinsley MP (PP) co-chaired the joint session of the APPG on Black Health and APPG on Prostate Cancer, held during Black History Month to examine how researchers, charities and community organisations are working to increase the representation of Black men in prostate cancer research and clinical trials.

Dr Peter Prinsley MP welcomed attendees and highlighted the disproportionate burden of prostate cancer among Black men, who face approximately twice the risk of diagnosis and death compared with the wider UK population. The importance of ensuring that advances in early detection, screening and treatment reflect the needs of this high-risk group was emphasised.

The Chair referenced the recent Westminster Hall debate on prostate cancer screening and the growing cross-party attention to developing an effective screening programme. The meeting then proceeded to the speaker's presentations.

Dr Veline L'Esperance (VL'E)

Senior Clinical Lecturer and Co-Lead, Black Health Legacy, Queen Mary University of London

VL'E outlined the work of Black Health Legacy, a genomic research programme established to improve understanding of health conditions that disproportionately affect people of Black African and Black Caribbean ancestry. VL'E emphasised that the programme is built around conducting research with communities rather than doing research on them.

Underrepresentation in Genomic Research

VL'E reported that people of African ancestry make up approximately 16% of the global population but account for only 1.1% of participants in genomic studies, compared with around 89% of European ancestry. She explained that these datasets inform the development of new diagnostic tools, medicines, and treatments, and that limited representation can and often lead to interventions that do not serve different populations equitably.

VL'E identified historical mistrust, systemic and structural barriers, a lack of diversity among researchers, cultural and language barriers, difficulties taking time away from work and limited awareness of research opportunities as important factors contributing to unequal participation.

Clinical Implications: G6PD Deficiency and Diabetes Diagnosis

To illustrate the consequences of underrepresentation, VL'E discussed research concerning glucose-6-phosphate dehydrogenase (G6PD) deficiency, a genetic condition more common in populations from regions where malaria has been endemic. The condition can affect the lifespan of red blood cells and produce artificially lower HbA1c readings, a test routinely used to diagnose and monitor diabetes.

The findings suggest that a relevant genetic variant affects approximately 1 in 7 Black men, compared with around one in 10,000 people of White European ancestry. VL'E explained that the resulting reduction in HbA1c readings could contribute to missed or delayed diabetes diagnoses, in some cases by several years, with significant consequences for complications affecting the eyes and kidneys.

VL'E stressed that this example showed how even widely considered reliable tests can produce unequal outcomes when research does not adequately population differences.

Black Health Legacy: Recruitment and Community Engagement

VL'E reported that Black Health Legacy had recruited approximately **2,700 participants** in under 12 months, with more than 90% having no previous experience of research participation. She argued that this challenged the description of Black communities as "hard to reach" and demonstrated the effectiveness of approaching research through trusted relationships.

Recruitment had included engagement through churches, libraries, community health fairs and other local events, supported by community organisations and researchers able to explain the purpose of the study and respond to questions. VL'E emphasised that engagement should not be measured solely by participant numbers but also by the value of wider conversations, awareness-raising and feedback to participating communities.

VL'E summarised this approach:

"it's really about relationships, purpose and transparency."

Preliminary Findings on Black Men's Attitudes to Genomic Research

Despite the programme's overall recruitment success, VL'E acknowledged a gender disparity, with men accounting for approximately 30% of participants. To understand this further, the team conducted a preliminary survey involving 36 Black men.

VL'E cautioned that the findings were exploratory and based on a small, self-selected sample, but suggested that they offered useful indications for future recruitment strategies.

The findings suggested that many respondents were familiar with genetic research and used online sources for health information, but familiarity did not necessarily translate into trust or willingness to participate.

Respondents particularly valued:

- Personal invitations and encouragement from people they trusted. rather than relying only on written or digital invitations.
- Live opportunities to ask researchers questions and hear from previous participants.
- Visible involvement of Black clinicians and researchers.
- Clear explanations of both individual and community benefits.
- Assurance about data privacy, the use of genetic information and whether it might be shared beyond the original research.
- Recognition of participants' time and practical costs, including appropriate support for travel.

VL'E concluded by noting that messaging focused on community benefit, ownership and the value of participants' contributions resonated more strongly than abstract descriptions of genetic research. She concluded that trust must be earned through ongoing, face-to-face engagement, transparency and a willingness to share power with the communities researchers seek to involve.

Dr Ann-Britt Jones (ABJ)

Genetics Researcher, The Institute of Cancer Research and The Royal Marsden - PRODICT

ABJ introduced **PRODICT**, a prostate cancer risk prediction study investigating how genetic testing might support more targeted approaches to screening. The study seeks to improve understanding of inherited risk among men from different ancestry groups, particularly those historically underrepresented in cancer genetics research.

Prostate Cancer Risk and Polygenic Risk Scores

ABJ outlined established prostate cancer risk factors, including increasing age, family history, ancestry and inherited genetic variants. She noted that men of Black African and Black Caribbean ancestry experience an increased risk of developing and dying from prostate cancer, while much of the genetic evidence currently available has been from participants of European ancestry.

ABJ explained that a polygenic risk score combines the small effects of many common genetic variants to estimate a person's inherited susceptibility to a condition. She emphasised that the score is **not a diagnosis** and cannot establish whether an individual will develop prostate cancer. Environmental, lifestyle and other factors also contribute to risk. However, PRS may help identify those who could benefit from more intensive screening.

ABJ clarified:

"it doesn't predict that a person will get the disease"

Earlier research suggests that genetic risk stratification, combined with PSA testing, MRI and biopsy where appropriate, could improve the detection of clinically significant prostate cancer. However, ABJ emphasised that genetic scores and imaging should be considered complementary tools rather than standalone solutions.

PRODICT Study Design and Eligibility

The study aims to recruit **1,000 men aged 40-55** from several ancestry groups, including Black African and Black Caribbean, White European, South Asian and East Asian participants. ABJ explained that the current study criteria require all four grandparents to be from the same ancestry group, meaning that individuals of mixed heritage are not eligible under the present protocol.

Participants provide a saliva sample, which is analysed for more than 400 common variants associated with prostate cancer risk, alongside a panel of rare variants in genes linked to higher prostate cancer risk.

Those found to have a higher genetic risk, including individuals within the upper portion of the polygenic risk distribution or carrying relevant rare variants, may be invited for PSA testing. Depending on the result, further assessment may include MRI and biopsy through established NHS pathways. Participants without findings requiring further investigation are followed up through the study's monitoring arrangements.

ABJ also highlighted work with collaborators at Imperial College London to examine the practical and behavioural challenges involved in implementing genetic testing within communities. This includes understanding the barriers that may arise when approaches developed in research settings are introduced into routine care.

Recruitment Challenges and Adaptations

ABJ reported that recruitment began in June 2025 and that initial responses were strongest among White European men. Participation from other groups, including Black communities, had been lower than anticipated, in spite of the importance of gathering more representative data.

The original recruitment model relied largely on GP practices sending invitations to eligible patients. Following community events, stakeholder meetings and workshops, the researchers expanded their approach to allow additional recruitment through community pharmacies and other local networks.

ABJ stressed that interventions developed within academic settings must also be workable and acceptable in practice. Understanding why people participate, where they access healthcare information and which settings feel accessible would be central to the study's wider implementation work.

Keith Morgan (KM)

Associate Director of Black Health Equity, Prostate Cancer UK - TRANSFORM

KM discussed the relationship between trust, health inequalities and participation in prostate cancer research, before outlining Prostate Cancer UK's work to support more inclusive recruitment to the **TRANSFORM trial**.

Trust and Historical Exclusion

KM emphasised that mistrust of health research does not arise in a vacuum. He linked it to historical mistreatment, discrimination, experiences of exclusion and continuing disparities in access to care.

As KM explained:

"Mistrust does not exist in a vacuum."

KM also noted the cyclical nature of underrepresentation. When Black patients are excluded from studies, there is less evidence about whether new treatments or interventions work effectively for them. This can, in turn, reinforce concerns about the relevance and fairness of research and further discourage participation.

KM referred to examples from cardiovascular disease, COVID-19 and breast cancer research to illustrate the wider consequences of low representation. He stressed that Black men face approximately twice the lifetime risk of prostate cancer and prostate cancer mortality compared with White men, despite remaining underrepresented in the research needed to improve outcomes.

KM argued that rebuilding trust requires an acknowledgement by healthcare and research institutions of their role in creating these inequalities. He stressed that responsibility should not be placed solely on individuals or communities who may be reluctant to engage.

TRANSFORM: Recruitment and Black Community Representation

KM introduced TRANSFORM as a major trial seeking to establish the safest and most effective approaches to diagnosing prostate cancer earlier. He noted that the UK does not currently have a national prostate cancer screening programme, including a targeted programme for Black men, despite their higher risk.

KM reported that the first stage of TRANSFORM included a commitment for at least **10% of those invited** to be Black men. He also referred to an additional **£18 million in Government funding** to support the second stage of the trial and create an opportunity to invite eligible Black men aged 45-74 across the UK.

KM emphasised that this represented a significant opportunity to gather the evidence needed to inform screening policy. However, the value of that evidence would depend on recruiting enough Black participants and ensuring that their experiences were meaningfully reflected in the trial.

He noted that the absence of an established national prostate cancer screening programme for Black men made it especially important that new research reflected their experiences and risks.

Patient Involvement and Community Engagement

KM explained that patient and public representation had been incorporated into TRANSFORM governance and that feedback from engagement groups, including Prostate Cancer UK's Black Men's Health Advisory Group, had already informed the trial.

Changes and planned measures included:

- Involvement of Black patient representatives in trial decision-making.
- Establishing a Black Clinical Advisory Group and increasing the visibility of Black clinicians in communications.
- Revising invitation letters to explain the purpose of the study more clearly.
- Co-designing invitation materials with community representatives.
- Investing in a more integrated programme of recruitment, engagement and participant support.

KM noted that more than 10% of people invited at that stage were Black men and that participation was increasing. However, he emphasised that further work was necessary to maximise the opportunity created by the trial's expansion.

KM concluded that underrepresentation is widespread but not inevitable. He stressed that meaningful participation depends on inclusive research design, sustained community involvement and the trust established through these relationships.

KM concluded:

"under representation is widespread, but it's preventable, it's not inevitable"

Professor Caroline Moore (CM)

TRANSFORM Trial - Prostate Cancer Screening and Early Detection

CM provided an overview of the clinical rationale and research underpinning TRANSFORM, focusing on the need to detect cancers that are likely to cause harm while reducing unnecessary investigations and treatment.

Limitations of Current Screening Approaches

CM explained that conventional screening based on PSA testing and clinical examination can reduce prostate cancer deaths but also generates false-positive results, unnecessary biopsies and diagnoses of low-risk cancers that may never have caused symptoms. These diagnoses can expose patients to treatments associated with lasting urinary, bowel and sexual side effects.

CM stressed that a screening programme must demonstrate benefit through robust clinical evidence, including randomised comparisons, and must deliver the greatest possible reduction in mortality with the least avoidable harm.

Evidence from Earlier Studies

CM outlined findings from previous studies including **PROSTAGRAM**, **ReIMAGINE** and **LIMIT**, which explored MRI, PSA and ultrasound approaches to screening.

She reported that Black men had accounted for approximately 33% of participants in PROSTAGRAM, demonstrating the potential for more inclusive recruitment. By contrast, work using traditional GP invitations in ReIMAGINE had generated a low response from Black men, highlighting the limits of standard recruitment methods.

CM described efforts to adapt both the invitation process and how testing was delivered, including partnerships with community representatives, targeted materials and mobile MRI facilities. She highlighted the value of bringing screening to community settings and, where feasible, enabling participants to undergo blood tests, MRI scans and receive results on the same day.

The earlier studies also suggested that relying on PSA thresholds alone could miss a proportion of clinically significant cancers, supporting the examination of combinations of imaging and risk assessment.

Three Stages of TRANSFORM

CM outlined the three-stage design of the trial:

- Stage 1: Compare different screening strategies and methods of inviting men, using combinations of PSA testing, MRI and polygenic risk scores.
- Stage 2: Conduct a larger randomised trial of the most promising approaches, supported by additional investment and expanded invitations.
- Stage 3: Evaluate longer-term primary outcomes through linkage of national databases to determine whether screening leads to a measurable reduction in prostate cancer mortality.

CM explained that the need for randomisation creates additional communication challenges. Potential participants may be invited to consent to future follow-up and to data being retained before knowing what screening pathway they will be allocated to. She acknowledged that this can raise questions about data use, uncertainty and fairness.

CM highlighted a forthcoming roundtable & world cafe with community groups in November to discuss how invitations and participation could be improved. She concluded that TRANSFORM offered an important opportunity to understand both the most effective screening tests and the most successful ways of engaging men at higher risk.

Dr Jayne Spink (JS) and Rupert Aikman (RA)

Prostate Cancer Research - Prostate Progress

JS introduced **Prostate Progress**, a research initiative led by Prostate Cancer Research to bring together clinical records and patient-reported experiences in order to improve prostate cancer diagnosis, treatment and care.

Using Existing Data and Patient Experience

JS noted that valuable information about the prostate cancer journey is spread across hospital systems, general practice records and cancer registries. Although large quantities of data already exist, they are not always connected in ways that allow researchers to identify patterns, evaluate outcomes or understand people's experiences over time.

Prostate Progress invites people who have or have had prostate cancer to provide information about their diagnosis, treatment, quality of life and experiences of care, and to consent to the secure linkage of this information with their NHS health records. Participants can take part whether they are currently receiving treatment or were diagnosed several years ago.

Data Security, Research Access and Participation

JS explained that participation is voluntary and that the programme operates within a secure data environment. Applications to use the data are reviewed for scientific quality, suitability and ethical acceptability, while approved researchers are provided with only the information needed to address their research questions and not with unnecessary personally identifying information.

The initiative had attracted strong interest 31,039 **participants** had enrolled at the time of 12th October 2026. However, JS acknowledged that participation among Black communities remained low, at **1.4%,** and that this needed to increase to reflect the disproportionate burden of prostate cancer among Black men.

Supporting Other Studies and Community Outreach

JS described how Prostate Progress can support other research teams by helping them reach eligible patients for additional studies. Examples discussed included BALANCE, a global study by the European Association of Urology (EAU) on the quality of life and care experiences among Black men of African and Caribbean ancestry and men of missed black ancestry and FRAME-PCa which is a

community-driven study by a King's College London addressing ethnic and socio-economic inequalities in care.

Then RA went on to outline engagement activities with community organisations and local partners in Birmingham, Manchester and London, including opportunities for patients and community members to speak directly with researchers and ask questions about taking part in research.

RA concluded that Black men's participation was essential to creating a more representative evidence base and ensuring that research findings could inform improvements for those experiencing the greatest risks.

Patient Voice - Patrick Williams

Lived Experience of Prostate Cancer Diagnosis and Treatment

PW shared his experience of being diagnosed with prostate cancer in **January 2020** and undergoing treatment during the COVID-19 pandemic. He described receiving limited information during the initial stages of his diagnosis and undergoing a series of investigations without fully understanding what they meant for his prognosis.

Reflecting on his early experiences of care, PW stated:

"I did not get the full information"

PW explained that he subsequently received his results by email while alone at home. He was informed that he had advanced, stage 4 prostate cancer and had been given an estimated life expectancy of 18 months to two years. PW reflected on the distress of receiving this information without immediate personal support, particularly as a father of five sons.

PW emphasised the seriousness of his diagnosis, stating:

"This is a nasty disease"

PW emphasised that the information available to him at the time had not adequately communicated the seriousness of his condition. He noted that commonly repeated assurances about prostate cancer being a disease that men do not necessarily die from were difficult to reconcile with his own experience of being told that his cancer was terminal.

PW also discussed the challenges of treatment during the pandemic, including chemotherapy, the effects of treatment on his appearance and the difficulty of navigating care while coming to terms with his diagnosis.

Reflecting on attitudes towards prostate cancer within his community, PW described encountering misinformation and the culturally rooted beliefs following his diagnosis, including an unsolicited proposal for an unproven alternative remedy. His account illustrated how misinformation can compound uncertainty and why patients and families need accessible, evidence-based support. He emphasised the importance of accurate information and clinical support, particularly for patients who may be vulnerable to misleading advice following a serious diagnosis.

PW reflected that earlier testing might have led to a different outcome for him, while recognising that others with similar diagnoses had not survived. Having lived beyond his original prognosis, he stressed the importance of early detection, clearer communication and ensuring that patients are adequately supported throughout their diagnosis and treatment.

Closing Remarks

Dr Paulette Hamilton MP thanked the speakers, co-chair (Peter Prinsley MP) and attendees for their contributions, and acknowledged the importance of bringing together research evidence and patient experience to address inequalities in prostate cancer.

Due to time constraints, the scheduled Q&A could not take place. Attendees were invited to direct any outstanding questions to the APPG on Prostate Cancer or the APPG on Black Health for follow-up.