**The G Word Transcript**

**The Errol McKellar Foundation and Friends of Caswell Thompson**

**Marie:** Hello, I'm Marie Nugent, Community Manager for diverse data at Genomics England, and you're listening to the G word.

Through the conversations we have on this podcast, we hope to bring the benefits of genomic medicine to everyone. Today we'll be hearing about the work of two fantastic organisations. The Errol McKellar Foundation, and friends of Caswell Thompson, and the impact they're having in raising awareness of prostate cancer risk in the communities. I will be asking them what health research organisations can do to learn from their experience, and better connect into community groups and improve health outcomes for those people. We are joined by Errol McKellar, MBE, founder of the Errol McKellar Foundation, and the MOT yourself campaign and Errol Thompson and Errol Campbell, Directors of Friends of Caswell Thompson, who are dedicated to supporting families affected by prostate cancer in and around Bristol. Welcome to the G Word.

**Marie: H**ello, and welcome Erroll, Erroll, and Erroll, you have given me quite a challenge today. It is a genuine pleasure to have you here with me today and this is my first ever podcast so I'm very excited. We are here to discuss the brilliant work that you're doing and obviously take an opportunity to see what we can learn from the extensive experience that you've got and doing this really important work. So, I just wanted to take a moment actually to recognise this it's going to be a slightly different kind of conversation for the G Word as I don't have a genomics background and my real interest in this sort of work is the engagement work. How you really connect meaningfully with communities, importantly I'm always looking for ways in which we can better centre around that lived experience to improve things and really make a difference. So, this is a slightly different sort of take on the kind of conversation we're having here for the G Word, but one, I think, nonetheless is still very important to have.

We are always trying to look at ways of engaging with communities to develop and benefit health and research it's part of the work that we're currently looking at in Genomics England, but there are a lot of different organisations looking at this now. So, it's great to have you here to enlighten us a bit more on this topic I think there's lots to learn. So, I'm going to come to you first Errol McKellar, I might call you LM, to make the distinction. So, who are you and what do you do?

**Errol M:** Right, well, my name is Errol Mikayla, MB, prostate cancer survivor and founder of the Errol McKellar Foundation. And our aim, and the reasons why I set up the charity, is for us to raise much-needed awareness issues to do with prostate cancer and to bring knowledge and information to lots of people in the communities, particularly in the African Caribbean Community, which is a deep education that needs to be brought to the table

**Marie:** Am I right in saying that in a past life you were a football coach mention with some mention of David Beckham?

**Errol M:** Well, in my past life, I was a fully qualified football coach, and I had the privilege of working with people like David Beckham, Sol Campbell, Ashley Cole, Ledley King, Jermain Defoe, Lee Bowyer - quite a few professional footballers. I'm probably known more for my football coaching than my prostate cancer campaign, but it was a privileged time. I was very fortunate to work with some very, very good youngsters who went on to represent the country. So that was a proud moment for me. I wanted to be a professional footballer when I grew up, didn't quite happen, but kind of payback really because I've got satisfaction from going into coaching and helping those to fulfil their dreams. I've worked with a lot of others that, you know, probably didn't get the mention that they should get - people like Ade Akinbiyi, who you've always known from Bristol. So, I've worked with a lot of good footballers, but it's easy when they're talented and gifted and they're determined - you know, you've got to steer them in the right direction as a coach.

**Marie:** And it sounds to me like that’s something you've really brought into this kind of prostate awareness.

**Errol M:** I think it is, yes. It is helped. It is my passion. It's interesting because, as the other guys will tell you, this is not something that we planned to do. It just happened to us, and collectively, I applaud the guys alongside me here because it's "We" who are going to make a difference with this issue. It's a big problem and it needs to be addressed, and we three are a number of great people out there that are really championing to do something about this issue.

**Marie:** So, we will come to Errol and Errol in a moment. I just wanted to ask, how did you first come across their work? Because I remember first bringing you into a call - yes, with Errol Thompson here - and I must say the bromance in the online room was real.

**Errol M:** I think the first thing that always attracts you is when you've got the same name as somebody else! To have the same name as two very popular people means you've got to look at what they do, and I'm really proud to say, you know, that's why I will always use the phrase “We” because, you know, these two guys on my right and my left have done a lot of fantastic work in this issue, and it shouldn't go unrecognized because we're all championing for the same cause. Special mention has to go to what they're doing because if you go anywhere in Bristol, I'm proud to say I'm Errol because I get confused with these two, which is brilliant really as I've known about them through my journeys in doing what I do. And it's great because it just makes me realize why we are the ones who are going to make this real big change with this issue.

**Marie:** Absolutely, thank you. Obviously, we have got friends of Caswell Thompson with us too. So, I will come to Errol Campbell first: Who are you, and what do you do?

**Errol C:** Well, obviously, my name is Errol Campbell. Perhaps I ought to just simply say that it is a privilege doing what we're doing. I got into this, not because of a great desire, but because of circumstance. My uncle died of prostate cancer in 2005 - the first time I actually heard about prostate. I was too busy with life and work and so forth to attend to the necessaries. And of course, the journey started with me because, as far as the medics were concerned, if it's in the family, that train's already left the station. So, I made sure I got myself tested and, in 2008, I decided to have an awareness day in Bath, where I was ministering at the time. And we had an awareness, Dave had a doctrine, and spoke to the guys about prostate cancer and their wives and family.

But to cut a long story short, 2014, I was diagnosed, and then that's when reality really hit that this thing can take your life. And Caswell came to see me - Errol's brother came to see me at home. It just happened. I was at home on my own that day. And we sat around my dining table and spoke about the situation. And he made it known to me that his was terminal, that he was there to try and encourage me to do something about my diagnosis, which I just wanted to think it through and come up with the right plan. And I did say to him at the time, because we were thinking about how we're going to get this out to people, given the situation with him - because he came to see me on the walking stick, it broke my heart - and I did promise him that we would do something, I would do something. And I did not know what, I was going to do something.

And it was the day of his funeral. At the wake, it just came up in my head, you know, "Friends of Caswell Thompson," because all his friends were there at the funeral. And I asked a couple of people there if they would join me, and they said yes, and that's where it actually started. But I really don't want to talk about me, it's talking about the work. That is what we're doing. And we're applying some of those disciplines that I learned to what we're doing, to bring the message because the message was, if we can save one life, one life, you know, what we do? The expense, the effort, it'd be worth it.

So, it is a journey. It's a journey where we're into this journey we're learning, and we're going to make a difference.

**Marie:** Yes, I think you are already by the sounds of it, completely. Now to you Errol Thompson

**Errol T:** My journey is a bit different. I first got involved in 2006. I got approached by someone who told me about prostate cancer and asked me if I realised that it is the thing that affects mainly black men or predominantly black men. And there was an event going on because we're all footballers, there were 12 of us. He said they've got an event called Run for Life, which is to raise funds for prostate cancer research. So, we did the event, and the doctor there was saying men need to be tested when they're 50. As I was approaching 50, I thought, "Oh, I better get myself checked out." And I had a word with my older brother, awkwardly, my older brother had prostate problems at the time, but he wasn't sure what it was. I mean, he could not really explain. So, in 2009, I actually went to the doctor and got some information on what prostate cancer was because although I knew about it, and as both Errol’s said you didn't really understand and until you actually see it around you, or you had it yourself. We all got ourselves tested, but Caswell was a bit unfortunate because, although he was getting tested, it's a bit blurred whether he missed a test or not. When he actually went to get a test, because he had a show, within a few months, they told him it was terminal, it's too late. And he was 58 at the time, just before his 59th birthday. I watched him, my oldest brother, who had it long-term, and Caswell my youngest brother for 2 years suffering, who tried everything because he was determined to beat it, but it got the better of him on his 61st birthday. Unfortunately, I lost my oldest brother the following January. To make a long story short, I ended up getting it in lockdown in 2020. So, yes, I know a lot more then obviously, because you read stuff, and things that we've been doing with Errol. I've also logged into Errol McKellar's online thing during lockdown. Football is my thing. I love football. I mean, I love sport, but football is the main thing. I've been involved with football for well, my life, organizing and running. It's difficult because it's prevalent within my family. After my oldest brother's death, both his sons tested. I believe it was the same year that we did the first event, and he was 46. He wasn't sure, but because we did the event, and he learned a bit more, he decided to have a test. His other brother did the same. My eldest brother had three sons, so they all had tests, and two of them had cancer at that particular time.

**Errol M:** And this was this was a month after the Glandels death because we had the awareness day in February. So, if you think if you take August 15th, my birthday, well, that's when Caswell died, and I was 10th of August, to February, all that happened: two deaths, those diagnosis, and so forth, in that compressed in that short space. Now you're going through all the emotions of losing people, and then after having to decline again to deal with giving advice to those others. Well, that's the difficult part, isn't it? You know, like, when this happens, you know, that's one thing, and you've tried to digest that, but it's the effect that it leaves the emotional effect. And that is not one that you're trained to cope with. You know, the physical side of it is one thing you have to deal with, but the emotional side is a really tough one. And we've seen hardened men that we know, the three of us. This has broken them. You know, I mean, one of the things I used to do, I used to do some door work back in the days I did 10 years of door work. So, you face everything doing that kind of job. But nothing prepared me for this cancer, nothing.

I mean, you know, my story, briefly, is my wife was complaining about my snoring. And I said that story because snoring has got nothing to do with prostate cancer. But as the guys will tell you, nine times out of 10 we found out by accident that we have this problem. And I said to her, "Look, if it bothers you that much, you know, make an appointment with a doctor, and I will go." She made the appointment, went to the doctors, sat in the reception room, picked up a leaflet, read it: prostate cancer information for black men. I thought, "Okay, let me go through." So, I went through it. Thought I'll go to the reception and make an appointment to come back and do the test. I got to the reception, the young lady said, "Mr. McKellar, you don't need to make an appointment. This is a simple blood test, takes less than 10 minutes." Little did I think that that 10 minutes was going to change the rest of my life.

So, to move the story on, a week after that first blood test, I get a phone call. Can I do another blood test? I did that. A week after that second blood test, I get a phone call, and they said, "Mr. McKellar, we booked you in for a biopsy." I said, "When have you done this?" And they said, "Well, actually, we booked you in this morning." I said, "Okay," so I put the phone down. I rang my wife, and I said, "Sharon, doctors just called me, they want me to go in and have a biopsy." And she said, "Well, when did they want to do that?" So, we'll actually they want to do it this morning. And I think she obviously knew, because she said straight away, "Well, listen, don't worry, don't drive, get a cab, and I'll meet you at the hospital." And I remember before I put the phone down, I turned to her, and I said, "By the way, what's a biopsy?" Because it wasn't something that I was related to, I'm a football person. So, you tell me about Achilles or ankle sprains and knees and that sort of injury, then I get it. But no, you know, and she said, it's something routine that we women have to go through that's how she described it?

Well, to be honest, I'm glad she didn't go into detail because it was probably the most frightening experience of my life. And, you know, I've been through some things, but nothing prepared you for that biopsy. But it is something that is needed. Then, a week after that biopsy, I had to have the MRI scan, and one week after that scan, they called me and my wife in, sat us down, and said, "Mr. McKenna, your prostate is covered in cancer." Well, guys, I got up and I walked out of the room. You know, I walked out of the building and went and sat in my car. And I think the fear of that word "cancer" then hit me. I'm not ashamed to admit it in front of all of us here. I just burst into tears, and I felt lost, helpless. I remember my wife coming in, and she sat there. And she said, "All the years I've been with you, I've never ever seen you quit on anything that you've ever done." I had to stop and man up and wipe the tears from my eyes. I looked at her, and I thought, "Is she having a go at me? Was this her way of motivating me to do something?" I took the latter, that's what she was doing. So, we went back in, and I said to the doctor, "Right, what do I need to do to deal with this problem?" He said, "Mr. McKellar, if we don't remove your prostate, you could be dead in six months." I said, "Okay, well, let's do it," just like that. He said, "Look, there'll be some issues you have to deal with, there'll be some side effects you have to come to terms with." I said, "Doctor, if I have a chance to stay alive, I'll take that.

I had the operation to remove the prostate, but by then the cancer had already come out of the perimeter walls, as we call it. So, I had to have nearly three months of radiotherapy. The guys will tell you that it is brutal because it burns away not just what it burns away, it burns everything else away that it gets into contact with. So, this was a tough period for me and, you know, I sat down with my wife, and I said, "Listen," I said, "you know, because of my faith, I have to thank God that I'm still alive here. If I have the amount of cancer that they're telling me and I'm still alive, I have to thank Him for that. But I really now think I need to find some way of doing something about this issue because this is all new to me." You know, and women are very inspirational. When they're not nagging, they're very inspirational, right? And my wife turned to me, and she said, "Listen," she said, "this cancer is only knocked you down. It has not knocked you out. But what you're going to do, you're going to go 12 rounds with it, but you will take everybody in the ring with you to give yourself a fighting chance." And that's my inspiration when I get up every morning.

I was out of work for six months, you know, and I used to be a mechanic servicing, repairing, and MOT cars. And the first day I went back to work, a guy walked into my garage, and we got into a pleasant conversation. He said, "you know what, I'm really glad to see you back. I heard you were going through a really tough time. You know, good to see you back on your feet and so forth." And I do not know where it came from. I looked at him and I said to him, "when was the last time you had your prostate checked?" And a pleasant conversation stopped. And now he's undoing his jacket, and I think he wants to fight me now. Right? And he says to me, "What the Bleep Bleep Bleep has that got to do with my gearbox not working on my car?" So, without thinking about it, I just turned him and said, "I'll tell you what, I'll give you 20% discount on the work I'm going to do on your car if you get your prostate checked by the time you come back." Well, guys, clearly, I didn't think this one through right. He came back in two weeks later and he goes, "I took your advice." He was waving his bit of paper in his hand, and I looked at him, and I said, "Jesus Christ, this has just cost me 200 quid." He obviously saw the look on my face because he said, "listen, don't worry about the money." And I looked up there again, and I said, "Thank you, God." But he said to me, he said, "Listen, I think you'd better read this piece of paper." And I've got to tell you the shock is still there with me today. When I opened his letter, he had 25% cancer in his prostate. He didn't even know he went to do that test because I offered him a 20% discount.

What was frightening was he was the first of 48 guys that walked into my little garage in the East End of London that were diagnosed with prostate cancer. Twenty-eight of those guys were African Caribbean men. Two of them are no longer here. One was 42 years of age when he found out, and he lasted 10 months. He was the unlucky one for me. The other gentleman was 36 years of age, and it is not a common thing. The history of this young man is that when I spoke to him, he said, "I can't go through all of that because my two brothers have had prostate cancer. My dad's had it, and my uncle's had it." And I thought I needed to ask him the question and hope that I didn't hear what he said. And he said it again. And I said, "Okay," took his keys, gave them to one of my mechanics, put him in a car, and drove him to Homerton Hospital because they knew I was doing the campaign. They said, "If you refer anybody to us, we'll look at them there and then." They did a test on him. Two weeks later, when he came back, he stood outside of the garage. He had tears running down his eyes and he said to me, "It's too late. It's already reached my bones." Six months he lasted. So, what we are trying to do as a group of people is to try not to get to that stage. I'm a mechanic, so if you've got a problem with your car, you're going to bring it for me to fix it, or you're going to bring it for me to MOT. Yet, we don't have that same attitude to our bodies and that's what we are collectively trying to do.

**Errol:** I don't want to interrupt you, but you said it there. It is a pre-test. So, you're bringing you bring car in for an MOT and a test to check to see how it is and it's no different when you take your car for a service, because you want to make sure it lasts longer. It's no good taking it when it's broken because it might cost you a lot of money.

**Errol M:** I just want to add something what the guys were saying, and it's very important to get this conversation right. When I spoke to my dad about this issue my dad said Son, I had that five years ago and I was so shocked I couldn't speak to him for six months. I said, Dad, you've got four sons, five grandsons don't you think we should have had this conversation? But since I've been doing this campaign, the guys will back me on this is very common, particularly in in our culture. They do not talk about this issue in our culture. Back home, where we come from, is complications, waterworks, all of those sorts of languages never prostrate.

**Errol C:** I think the PSA test is one of those that causes people a problem. I look at it this way: It's the start of the conversation. You might go and have a prostate test and it becomes a positive negative, but a start of the conversation, because perhaps the prostate might have been enlarged. But at least what's happened now, you've started the journey. Without that initial kickstart, you probably would have gone on with life, and like those two guys when they presented, it was too late. And that's one of the reasons why on our website, Friends of Caswell website (if I can plug it a bit, foct.uk), we've got a video made by Orchid, which is very, very good. It speaks about presenting a letter to your unprecedented self, which is a rebuke.

I think the fight, I'll put it as, because we are fighting this, we're fighting ignorance, we're fighting reluctance, and we are in an economic war as well, believe it or not. You know, we're dealing with prostate cancer, but there are economics attached to that as well. So, the work that Errol M is doing is great, and we're just part of the puzzle. Okay, you know, we do our bit, he does his bits, and what we found with Friends of Caswell Thompson, which was a shock to me, was that there was nothing happening in our community. The statutory bodies that were responsible for our health were not visible, not large, not known in the community. You will have to fend for yourself. Some people don't know how to fend for themselves. They have no one to speak to.

So, the work of raising awareness is not enough, just to raise awareness. We have to change policies. So, the journey, first of all, I need to make men aware and so they get themselves sorted out, then we have to address the issues. Why didn't I know about prostate cancer? Why didn't I know about the statutory bodies? Your Council is responsible for the health of the community, why haven't we heard from them? Why was nothing done? So, when we had the very first awareness in Bristol, which was the first time it's ever been done. Nobody knew about it. I'm thinking, hang on a minute, somebody's being paid to look after my health, and I've not seen them. So, we have to have the mindset that if we don't do it for ourselves, it probably won't get done now.

**Marie:** What does that look like? You mentioned that there's, an issue of raising awareness, getting the conversation going from the community side, these are scary things to talk about, but you need to start, and you need to sort of get those messages across.

**Errol M:** I think the blunt truth is that our community, at the moment, is not trusting of the health service, and the reason being is because, as Errol C is saying, no one has told us what needs to be told, no one has advised us what needs to be advised. We are having to seek this information. It should not be that way.

They've told us that prostate cancer is the biggest killer of mankind in the country, but it's curable if caught early. So, our question is, what are we doing about this then if it's curable? Should we not be having a conversation? You know, we do not want to be sending people to the doctors and the doctors are not seeing him. You can't tell us in one hand that this is a big problem and then in the other hand, you're not doing anything about it, because something needs to be done. It needs to be done now, because the numbers are what we know. Over 47,000 men a year are diagnosed, over 11,000 men will die. So that currently means we lose one man every 45 minutes. So, by the end of this day, it's 129 men, right?

These are numbers that were given to us; we didn't make these numbers up. It's currently one in 12 Asian men, one in eight white men, and one in four African Caribbean men. And the risk is even more frightening if it's in your family. But that is if there is a conversation.

**Errol C:** Yes, and I would add to that as well. It's not simply just about having this conversation. I think there's a very important element, which we recognize when we first started. We didn't have an awareness day for men; we have an awareness day for men and women. Yes, partly because they're the carers when things go wrong, and people have to be looked after. But there's another element, which sometimes we ignore. If your mother's had breast cancer, yes, it heightens your risk. So that conversation has to be had with men, even if they're not 40 or 45.

**Errol M:** Yes, and we need to get that into the community, because that's not something that they're aware of.

**Errol T:** The other thing is women are also the driving force behind the majority of the men who go forward and anyway I mean, you mentioned that yourself Errol

**Errol M:** I mean, we've spoken about them. We, I mean, for every 10 men that we talked to, we know that 10 of those men (I would say nine, but I'm going to be brutal and say 10 of those 10 men) that we talked to, it will be the women that are responsible for either getting them to go and get themselves checked. I mean, when I was offering 20% discount in my garage, more women took it than men, right? Husbands used to come and say to me, "Look, my wife's not giving me any sex, I'm in the spare room because of you and I'm not happy about this." I said, "Guys, it's a simple solution, just go and do the test. She cares about you more than your life insurance."

We know, and the guys have alluded to it, there's a big problem through fear and ignorance, the fear of knowing and ignorance to choose to do nothing about it. The bottom line is, this cancer doesn't really care about your colour, it doesn't care about your wealth, and it doesn't care about you. You leave it and ignore it; it will kill you.

**Errol T:** I think one of the things when you said "ignorance," it is not just the ignorance that they don't want to get something done. It's the weakness because they don't know. As I said, I knew about prostate cancer, but I didn't really know until it directly affects you in some way. So, until my brother got it, it really hit home. As I said, when Errol mentioned it, Errol C, about doing this thing, I said, "Yes, 100%?" because we'd sit there and chat with him while he was dying.

**Errol M:** Yes. And we can't let what happened to your brother Caswell go in vain because I'm talking to 14, 15, 16-year-old kids at the moment who don't even know what a prostate is, and that is frightening. Because in schools now, they're talking about periods. So, they've recognized that ladies need to have a better understanding. What about the boys? You know, if they do not know what a prostate is at 14, 15, 16, and we've got men younger that are dying young of this illness, at what point does the education really kick in?

**Marie:** You've all talked around this, as I'm recognizing that we are talking about a system, a system of things. So again, if you were to hear and sort of design this kind of ideal system in which some of the challenges that you're facing and getting the change that is needed to get that earlier testing, you know, prevent sort of people going further down the line where this illness and cancer ends up taking their lives, we know this is a problem for a lot of different health areas, not just prostate cancer, but I think there's something quite lethal about prostate cancer that makes it particularly important. So, what does that system need to look like to be effective?

**Errol M:** You take that one first, because I've got a beautiful answer to this question.

**Errol C:**  I think, let's, before we start talking about the system, we need to identify this term "health inequality" because nobody has actually defined what that is. What's the origin, and how is it still being maintained? If I was a person who knew nothing about prostate cancer, I want to be able to go somewhere and see something that will take me through the steps, what do I need to do as a man about testing, where I need to go? What I would do with a result, and if it was positive, what I needed to do? The negative side of it, okay, you eased on it, but you can't ease down on it because you got to still be aware, and what would happen if I was diagnosed, the treatments available, what I would have to go through because that's not clear. What's clear is about the physical side, perhaps, you know what options are available. It's too late when you've been diagnosed to try and actually for some people to digest, to get your head around all the necessary available treatments. What’s brachytherapy? What is the difference between that and radiotherapy? Because the pressures on you because you're having to deal with this thing that you can die.

So, the education comes first, key education, and then the system. The system needs to have an input from people who are able to best inform that system. That system is actually been developed by people who've never been affected by it. How is that going to change? There has to be changing policies. Yes, the policies will not change unless there's pressure being put on it. Let’s be clear, money can't be put before people's health, which in a lot of cases, it is.

**Marie:** When you go, and you work in this area, even as an area of research, and I have been privy to researchers putting economic cases forwards for, having some sort of change in some sort of way in which had services delivered in the NHS and, and unfortunately, it is in reality as well, the bottom line is cost.

**Errol M:** What, there is a there is a solution and I think that they are sugar-coating this situation to be blunt, really. I have to say that if they want to really get to the root of this problem, because there's some fantastic research work going on, first of all, they have to get the African Caribbean community involved in the research. If they want to get the right data, then they need to get the people that they're questioning, they need to get them involved.

**Marie:** What does that involvement actually look like?

**Errol M:** That involvement is sitting right here, there are three people right here, and there's a lot more that can go into the places which they class as hard to reach, which shouldn't be a term used anyway. There's three people here that are capable of going into these places and delivering the needs of what people need. The lack of trust is because no one's telling anyone yet, they're not telling anybody anything. By the time the conversation has had, as Errol C has said, we're turning up when it's too late, we're stage four. We have to have this issue way before it gets past the level 1,2,3 unfortunately. It is down to education, and we are capable because unfortunately, we have a qualification that we didn't want to go and get but we have it, to be able to go in and really have this man-to-man, toe-to-toe conversation.

You know, and look, sometimes, if a black person looks at a black person, you will feel that he's getting the truth from him, right? We have experienced this. This is not something that we made up. We're living with this issue because the three of us are living with this issue and the side effects, both physically and emotionally. So, when we're telling somebody, we're telling them from our heart, as well as our head. Why not use that equipment? I mean, for me as a mechanic, I was always told, if you want to undo and not use a spanner, do not try, and undo it with a hammer and chisel and do it with a spanner.

Look, we have the spanners here, so why not use them? It would solve a lot of the issues if we could just break those barriers down and get people to understand that listen, it's important that you go and do these tests. Because the people that are diagnosed with prostate cancer is one thing, but what about those who don't have a problem? What are their bodies producing that is defensive against this issue? So, it goes both ways, from a medical point of view, and from a researcher's point of view. They want to get the data, right? They don't want to speculate that we think there's an estimated number of people suffering this problem. They want to be positive about it, and if there's something that they can rectify through their research, who better than to come and ask us who are in the minefield anyway?

**Errol C:** That question of research, it sounds good, but you always have to ask the question, why is research necessary? You have research because you don't know. The question is, why don't you know? I'm looking at the brief, and it talks about research organizations working out how to build trust? Now, my question is, what work have you been doing? Because if you've been working, why haven't we seen you working? What's the nature of that work, and what's informing that work? You can make an awful lot of effort and get nowhere. So, what's needed is to stop looking at it from an academic point of view and look at it from a human point of view. You can walk into a community, and you can get a lot of information without having to do research. There's medical research, and there is social research. The medical research, you cannot bypass that. You can't shortcut that, but there's social research, which perhaps, in some ways, is more beneficial.

**Errol T:** I was going to say, that's the key. For me, the social is the key, because if you don't have the social interaction to get people to go and test, you are not going to have the research. So, that is the first thing. If you are looking at research all the time, you're not really going to be in a position to do research because you're not going to reach the people you want to get to come in. So, it's got to be a social interaction first, and then the research. So, we are doing it back to front.

**Errol M:** The understanding is a big issue because in our community, when you talk to people in our community, the first thing they talk about is erectile dysfunction. Now, let us go back further into this situation. When they told me that, I said, guys, if you're dead, you don't have any erectile function anyway. So, let's start at the beginning of this issue. The test that you need to have, you should make it an annual thing to go and do this test, you know, not use it as an excuse not to do it because at what point are you going to recognize that there's something that you have to address? You know, it is plain. They are telling us it is one in four. They are telling us early detection is key. Like Errol C is saying, we know the social side of it is not dealt with. You can do all the fantastic work that you're doing, but if no one turns up, it falls in vain. That is where the problem is. We have got to get a community that one isn't trusting because of lack of information, right, and not knowing the right things that they need to know. Two, to understand that it's important for them to be involved in what's going on, ask questions because, listen, we all organized groups that we talked to, and I have to tell you, and these guys will back me, the questions that they ask are questions they don't ask when they're sitting in front of their doctors.

**Errol C**: I think there is a reason for that. Doctors tend to be distant. If you have not built up a relationship with your GP and the only time you see the GP is when it's pretty bad, it's wrong. Then you're not going to have the confidence of actually speaking with your GP. You can speak to someone else who's suffering through the same ailments, but I think the knock because, don't forget, we have a network. I go to my GP and ask for a PSA test, and my GP turns me down. I do not keep that to myself. I told you, and I tell somebody else, and then this negativity just actually permeates through the community. When you go to the GP and the GP says, "Well, I would not worry about that for now because X, Y, Z is showing a degree of ignorance that should not be there at all.

**Errol M:** See, language is key. What Errol C is saying is language is key because the minute you say to somebody, don't worry about that that's his excuse to walk through the door.

**Marie**

Absolutely, it was such hard work to get that person to walk through the door and listen

**Errol M:** We could spend an hour talking to somebody and the doctor can send him out of that room in less than one minute. I mean, we just spent an hour talking to him, why?

**Errol C:** But the danger the danger is this, that that discouragement is embedded and never ever addressed again because I am not going back.

**Marie:** Exactly, that is my one chance, I am doing this once, and that's it.

**Errol C:**  So, I don't go back again and then what happens? Am I on a time bomb? Because when it explodes, it is not just me it’s a ripple effect.

I just I just bring my experience. I have a large family, extended family abroad. When I was diagnosed, I had to tell my wife because she was not with me when I went to get the result. It took me two days for it to sink into me first before I can actually tell her.

The thing about it is, she has been in the medical profession herself. Okay, so it wasn't from that point, but the other impact, and then you have to tell the rest of the family. You have to tell the children, you have to tell the brothers and sisters, and nieces and nephews, and of course, they were there on that journey with you. When you came out at the other end, you had to keep sending them the results of the tests. On how to encode, I will send an email, and I was sending it encoded. I was saying, 'You know, I went into bat, and I scored a duck.' They understood exactly what I was saying in the email. So, they're on that journey with you. They're asking, 'What is happening?' Because the impact is because of the relationship. You know, you have a relationship, and somebody is going to try and break that relationship. They are obviously very concerned about it. So, I would impress on people that it's not purely an academic approach that is needed. That social aspect of it is essential.

**Errol M:** I know that whatever Errol C is saying is true. No single man can deal with prostate issues on his own. There has to be a support network, you know, your wife becomes, or your partner becomes your carer. Not a job that she chooses to do but a job that ended up being because when you go through all different emotions. When you are diagnosed with this issue, you feel helpless, you feel lost. You don't feel like a man anymore. There's lots of things that you have to come to terms with and the women are powerful in dealing with this.

**Errol T:** I was going to say the reason why we had the conversation is because I said to him a similar thing, you should never, ever go into this on your own. You should never go into one of those consultation on your own. Errol, you knew about prostate cancer you knew how it worked and yet it still took you two days. A weaker person would not have said nothing.

**Errol M:** That's so true, one of the guys that we were in our sit and talk programmes with, for nearly three months, he didn't say anything to his partner. We kept saying, listen, it has to come from you. You have to tell her, and when he said it to her, she knew, she knew anyway. The sad thing is, is that for us men, as I say, we bottle it up, because we genuinely think that this issue is going to go away. We're going to wake up tomorrow and some by some magic it's not there. The reality is, it will be there, and it will be worse

**Errol C:** I'd like to raise something which you alluded to, and it's about the treatment. A lot of men, as soon as they hear prostate cancer, perhaps immediately think of death. It's not necessary, it's not death, and also your quality of life as well. Now, one of the drivers for me is how you're going to pursue a relationship when prostate cancer hits you as a man and as a father. And I want to convey to the chaps out there, go and start a conversation. If you start the conversation and happen to be one of those who have been diagnosed, it doesn't have to mean your life is destroyed. All of us are sexual creatures, and which man doesn't like to have sex, make love to his wife, and so forth. You put that in jeopardy when you go too late. Even if you have the prostate removed, at least you can have a nerve-sparing operation which gives you back your sexual function in a short while. Treatments are that good now, but if you wait till it's too late, they have no option. So, you find yourself in a whole world of pain. So, you're doing yourself and your wife a favour. You can't put a value on that. Your happiness cannot be counted in money. It is how you feel in the psychological aspect.

**Errol M:** What Errol is saying is right. What both these guys are saying is, your quality of life will definitely change. It's how much of that quality of life you want to sacrifice through the fear and ignorance, as Errol is saying. The long-term of this is, you're going to have to come to terms with the adjustment. You are not going to be Usain Bolt anymore. You are more likely to be Mo Farah. But you know what, as they're all ceases, there are many ways to make love. You don't have to feel that you're going to be Usain Bolt and do it in 9.9 seconds. You know, be Mo Farah.

In your heart and your head, you have to bring those two together to make that judgment, because the longer you leave it, the fewer choices you have. That is what is frightening because this does not wait for anybody. I mean, my situation was very rapid, and that's what's frightening, that this is a symptom that doesn't always show up in men. A lot of men who are diagnosed with this didn't even know they had the problem.

So that's why we've been sort of talking off here about the length of time that these checks should be done. I'm pushing for it to be a year. Errol C on my left is campaigning for six months, which makes sense. We just need to get something because at this moment, there isn't a national screening. We don't get a letter, like you ladies get. We don't get that all they recommend is, well, when you get to 50 or 45, well, in the African Caribbean community, or if it's a history and a family 45. The three of us know people younger that are diagnosed with this problem. So, the reality is, we can't wait for that.

You know, I mean, 36 years of age is a history in the family. When there's a history in the family, then you have to consider the implications that that's going to have on somebody in the family who is that young and having that problem.

**Marie:** So, what you've mentioned policy change, as well as the education bit. So just to kind of talk about that a little bit more now. Again, what are you really wanting to see, you've mentioned a letter? What does it look like?

**Errol C:** Let me just point out something that amazed me when I got into this. If you think about it, 2015 was the last substantive figures - everyone every 45 minutes. I asked the question, I said, "How many black men died?" and nobody could give me a figure. These are some of the stats. To me, it is a no-brainer. I am just saying this is to me, it's just a no-brainer. It does not take much thinking, a five-year-old thinking. I said, "What is on a death certificate? Oh, we don't put ethnicity on the death certificate." I said, "Really? So how are you monitoring the death of people? How? I mean, one in four black men diagnosed, and you do not know how many are dying every year accurately? It just needs a minor change on a death certificate, ethnicity. Then the research becomes easy because that data is there, and it can be compiled.

**Errol M:** But I think that's lack of data in the first place why that information isn't available

**Errol C:** No, it's not a lack of thinking about the minority that's greatly affected the most affected community.

**Errol M:** You know, so they're not, then there clearly isn't a data on it. Right? Because if it was important, there would be a data on it. So, what my issue is now is look, if there is not a data on it, what we want to do we want to create a mobile testing programme to produce that data as well. Because we will be given facts because for every one that is tested black, white or indifferent? We would have a data on it.

**Errol C:** The point is, have it on the death certificate. No matter what public record of how many people from ethnic groups are dying of prostate cancer. They have done it with COVID. The term is that everybody who is tested COVID is logged

**Errol T:** The silly thing is, it is only recently. It's not that long ago that they weren't putting prostate cancer on a death certificate. If you had prostate cancer, you could die from all sorts of stuff because it brings on other illnesses. So rather than say you died from prostate cancer, from heart failure due to prostate cancer, they don't put the fact that you had prostate cancer. Say you had heart failure, or you died from pneumonia. All that was brought on because you got prostate cancer, but they do not tell you that. So that is it. It needs to be more detail. The death certificates need to be more detailed if you want to do research because the research, as I said, doesn't make any sense. If you're just saying 510,000 people died from prostate cancer, what does it mean?

**Errol M:** To simplify what Errol is saying is, I mean, in my little garage, I was able to determine these are the number of men that came into my garage to tell me that they had this problem. Of the forty-eight guys, 28 of those guys were African Caribbean men, so that's data on its own. So as far as data goes, we feel it's down to us to produce this data. I know the guys feel the same way. We will have to produce this data in order to give people like yourself who are involved in the research a clearer picture as to what you're dealing with. If all that great work at the moment, if the situation is you're only testing one in every 10 African Caribbean men, then your answer is not going to be the same as if you were testing 10 out of every 10, and that's where the breakdown is.

If our people are not going to get themselves tested, then I think the solution, from what we feel, is to bring the test to them. Yes, you know, and we think that there's an answer to that question. We've not had one man, in the survey that we've done, that wouldn't do the tests. They wouldn't go and do the tests, as we know, but if you turn up at their doorstep, we know our community and the things that get them excited. They go to parties; they will come out and polish their cars. Their cars are the most important thing in their life with their jewellery. So, I say to these guys, listen, it's great that the car looks good, but if the engine is not working, it's not going anywhere. That is exactly the same as the prostate, as small as it is, it's the engine, and if that doesn't start, you can have on the best suit, the best shirt, the best trousers, the best shoes, if you're dead, you're not going anywhere. So, it is as brutal as that**.**

**Errol C:** The other thing which we need to do is okay, we can level of degree of criticism, organisation, the establishment, and so on, but we need to look at ourselves. There is the, I wouldn't call it a stigma, but the reluctance of men to be tested physically. They do not like the digital examination. Okay, that is your take, that's your position out of pride. I don't want any man touching me and so forth. Alright, in comparison, what women go through then it's small beer, it's nothing compared to what a woman goes through. Then that's a rather selfish attitude because you're not impacting just yourself. Others around you are actually going, so you don't want to be on your deathbed saying sorry to your family for being reluctant about getting tested. So, we've got to overcome that, and this is the reason why the research which has been done and the new practices which are of having the test and not done simply by PSA but to have scanning as well as the front end is great. We should be pushing that. We should be pushing for scanning to be mainstream that you go in, you can have your blood tests, but because with me, I was going every six months before I was even diagnosed because my uncle died of it. I wasn't having any annual, I'm having every six months, and that's what happened.

I went to see my consultant, and I walked in, and he said, "Mr. Campbell, I'm not even going to check you." I said, "I had a biopsy last year," and so forth, he said, "Nah," and it's still ringing in my head now because that's all I heard. I can't remember the rest of the conversation. He said they missed the cancer. So, I had a trans rectal biopsy, and they took bits of the prostate and checked it for cancer, and they missed it. So, instruction to me was when you see your consultant, because my consult was away and so professor took his list. I saw my consultant six months later, I said, "Well, Professor Raj said I've got to scan," he said, "Well, if he said you're going to have a scan, have the scan." Both sides, the prostate, not just one side, both sides the cancer was on both. I've had no symptoms whatsoever, I'm perfectly alright no symptoms at all. It's only because I was due diligence of having tests every six months. Of course, then I was given a window of opportunity because having a general biopsy under general anaesthetic, where they actually went in and did the biopsy that way, I had an aggressive form.

So, I had a window of opportunity before it broke out of the prostate and started doing real damage. So, if you're not involved in that, and I take what Errol said, and the thing is true, you can't be walking this journey on your own now."

**Marie:** So unfortunately, we've rapidly run out of time, and I feel like I could sit here for another couple of hours talking to you about this. It's been such a rich conversation, I really appreciate everything that you've had to say, and I couldn't agree more. I think it's incredibly inspiring the ways in which you're able to articulate so clearly what's really needed, and that you absolutely are already, but you know what needs to be done. You can see clearly how this can change. So, I just want to take the opportunity, I suppose, to ask you what is next for your work here? What are you really excited about, what your kind of mostly looking forward to in the coming months?

**Errol C:** Well, as far as President of Castle Thompson is concerned, I mean, I can definitely say that we have moved from the shadows to a place where research to be involved in research that is key and something that I was very keen on. Research done in Bristol some years ago and there is one Black person in the entire research group, and he is speaking to you now, only one. Okay, so you're not going to get much data out of that. Okay, not good enough. Yes. So that is what is happening. That's one of the things that we're really keen on and doing. We've got involved in that, and we are going to actually push that. That's one definite thing I can actually say. There are other things, but you're pressed on time.

**Errol T:** I've been on a research program for the last 15 years, and I have also been on the prostate research as well. So yes, research for me is key. It is key. They've got to put the information, the information is critical because if you haven't, you can do as much research as you want with your research, and it's a small portion. It's very difficult to get true answers and be able to deal with the issue properly. So, you've got to put results, as Errol has said before, on a death certificate. You've got to say whether that person had prostate cancer or not, you've got to say because otherwise, it doesn't make any sense.

**Errol C:** And the ethnicity.

**Errol M:** Exactly, and do you know what, we've probably been a little bit polite, but we have to emphasize the importance of this word 'research' and getting people involved. That's something that the Errol McKellar Foundation is doing. We're sitting and talking with people, we're getting them to understand, like Errol was saying about the information. We are the ones who have to bring that information. We have to make this change, and one of the things we want to do is we want to create a mobile project so that we collectively will go into the communities and get some data to help with the research. So, we're going to do our part. We just want the officials to do theirs.

**Marie:** Absolutely. Just to quickly say on that, from where I sit, I know that there are a lot of people who are really, really keen to change the ways in which research is thought about, and how it's even outlined and then who's involved in shaping that

**Errol M:** One message is we're here, ask us, we're here.

**Marie:** Absolutely. So yep, it feels like change is happening on both sides. It's just kind of making sure it meets in the middle and we can work properly together

**Errol C:** On the research, part of the problem is if I want to conduct research, I have to justify that research and of course, there's money involved. Why not simply undertake the research because it's necessary? This is necessary, we're going to do it, and then what will happen, the way the research is framed, it will be framed to suit the situation. You're not having a budget and academic looking through, going that word isn't right or the objective isn't right, and so, as we know, what we're trying to deal with

**Marie:** It's about staying true to what you're really doing here and why you're doing it everything like that, so I completely agree.

Thank you, again, so much. It has been a genuine pleasure to have you with me today. So that's all for this episode. Thank you for listening to this discussion about the G word and for joining us on this journey to highlight and debate the implications of genomics as it comes into the mainstream of healthcare and society. You can find out more about the Errol McKellar foundation at theerrolmckellarfoundation.com, and friends of Castle Thompson at foct.uk to discover more about the work they do.

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