**The G Word Transcript**

**Kate Grafton: Breast Cancer Awareness Month**

**Kate:** Hi, I'm Kate Grafton, Principal Lecturer in Physiotherapy at Leeds Beckett University, and a member of Genomics England's Participant Panel. Today's episode is a little different. In honour of Breast Cancer Awareness Month, we are sharing the discussion from earlier this year at the Genomics England Research Summit. My discussion was with Vivienne Parry, Head of Public Engagement at Genomics England. We explored precision treatments for the future management of cancer and the importance of making them more accessible, less toxic, and have greater longevity. We also discussed the importance of patients being part of the research process. Welcome to The G Word.

**Vivienne:** Hello, everyone. My name is Vivienne Parry, I'm Head of Public Engagement at Genomics England, and I get to do all the best stuff in Genomics England. So, that is being involved with our participants. I wanted to introduce you to someone that I think is extraordinarily special and bring us back to what patients want from the research that you're all involved with. So, can I introduce Kate Grafton to you.

**Kate:** Hello.

**Vivienne:** You're so welcome and it's so fab to have you here. Tell us a bit about you and your journey.

**Kate:** So, I'm Kate. I am 46 and I was diagnosed with Metastatic HER2 Breast Cancer at the age of 35. I'm a physiotherapist, I used to work in the NHS, I don't anymore. I work in academia, and I have been on chemotherapy for 11 years. I've had Gamma Knife radiotherapy on my brain. I've had surgery. I've had countless, countless surgeries. I've had numerous chemotherapies. I'm currently very well, I'm very happy on capecitabine and lapatinib, I'm one of the only patients left in the country, I think on lapatinib. I'm up in Leeds and now I'm able to work full time, I'm able to continue with my never-ending PhD, and I'm well and it's down to you. I'm here today because of everything that you do. And I may not be here forever, I didn't expect to get to 40, but I'm really hoping I can get to 50, and I should get to 50. But it's thanks to you guys.

**Vivienne:** We're going to bloody make sure you get to 50. There's no checking out early for you, Kate. Tell me, we're talking about research; so, what do you think that patients want, first of all from research? Apart from the obvious cures, but in your particular case, because frequently we're talking about cancer as a chronic condition.

**Kate:** That is what we want, we want to be able to live well with cancer. As someone who have lived for this long, it's not been easy. We talked about side effects, really, we ban them about: nausea, fatigue, neuropathy, lymphedema, but these are huge aspects, and you can't live a normal life with those side effects. What I want from you guys is kinder treatments, I want treatments that have longevity, but have less toxicity. I think that's what we would all like and we don't want to wait as long for the treatments. Precision medicine has been talked about from when I was diagnosed, and it only feels like now that that might be possible. I was very lucky, I had my genomes tested in 2007, after my mastectomy, and I got my results really quickly within six months. And I had a great conversation with my oncologist, with my geneticist. Not everybody has that experience and that's what we want. One of the questions I get asked all the time in our support group is, how have you accessed that? How do you get your genomes read? Because that's what every patient wants, they want the ability to say, these are the treatments that are going to work for me, forever. And that's hard, because getting access to those treatments is challenging and we've heard today about people that have had to crowdfund for treatments, and that breaks my heart. I have HER-2, I've had my genomes tested, I know what treatments are going to work for me. I can have that conversation with my oncologists, my awesome oncologists who will have that conversation with me. But don't think we don't talk about research in the support groups because we do, we look at your research, we analyse your research, we critique your research. We want to know, what does this mean for us? We all know that academic journals are not accessible to patients. I have an academic background, I can understand what you're saying and I spend a lot of my time trying to help the other women who don't come from a medical background understand that literature. So, my challenge to you guys is how can you make your patients understand your research? How can you get that out to them more effectively? Because we are interested, when we get offered the choice of treatments and our oncologists say, we've got this, we've got that, what do you want to do? That has to be an informed decision and that's really hard if you don't understand the research behind that decision. Oncologists help us with that, but we do talk about your research and we want to know more, we don't just want to be your sample. We want to work with you to look at, how can we make kinder treatments and how can we have longevity? I don't just want quantity of life, I want quality of life.

**Vivienne:** That's really important. It's really important, first of all, that researchers are able to talk to patients to find out what's important to them. Because as you say, life itself is not worth living, if the side effects are just so extreme, and the particular ones that most affect you, fatigue, you were saying, for example.

**Kate:** I will have to not be at work tomorrow for today. I've loved today, but the reality is that I've taken tomorrow off because I can't do, it's an activity in the night or the day and then the day off afterwards. And that's hard as a 46-year-old woman, I am not like my peers, I am now in renal failure, I’ve lost my fertility, and I have all these side effects that I have to cope with, as well as paying the mortgage and wanting to go on holiday, which we can't get life insurance for.

**Vivienne:** And you're from Leeds so you want to go out for the night.

**Kate:** Absolutely, it's a cracking nightlife in Leeds. But those kind of things that we just talk about in our papers, that's my reality. I live with that every day and my family has to live with that, my husband has to live with that. We don't do the normal things that every other couple, that you probably do with your partners, we can't always do that because I am knackered and I have to go to bed. Or I spend hours on the toilet because of the side effects of lapatinib. So, for me, living with cancer has been a challenge. But you have to read and you have to research and you have to understand how you can cope and live with those side effects. Because the alternative isn't really an option, is it?

**Vivienne:** The side effects are one thing, but also there's the next drug. Because that's the story of a chronic cancer, that you need to be one step ahead. Presumably you're looking to this crowd for that next drug too?

**Kate:** Absolutely, I'm on my second line. We'd like a third, a fourth and a fifth line please. Triple negative, when I was talking to the support group last night, I said, what would you like me to say? What do you want me to ask? I've got a captive audience of researchers.

**Vivienne:** Yeah, we’ve locked the doors.

**Kate:** What do you want me to ask? The big thing was triple negative, that is the real challenge for you guys. We don't have great treatments for that at the moment. To date, in our nationwide younger women's group of breast cancer patients under the age of 45, we've lost 26 women already this year and we're only in May. Every single one of those is your mother, is your sister, is your wife, is your daughter, with young children, with lives, with hopes. That needs to stop. We need to have this as a long-term condition that can be managed well.

**Vivienne:** How do you think that patients can be involved in the research process? We've talked a bit about talking to researchers about what's important. But there's also a bit about trying to ensure that you are involved in the research studies, and by asking to be involved. And, also, that you get to persuade people, consultants who perhaps don't see the value of genomics, that you persuade them that you ought to be included.

**Kate:** I mean, ideally, we'd love every single cancer patient to be able to have a blood test that tells them what their genetics are and what drugs is going to work for them. That would be the goal. I'm very lucky. My oncologists do talk about that. They offered me the opportunity to be part of the 100,000 Genomes Project. But we want patients to be able to go and say to their oncologist, what is out there. You have no idea how much time we spend online searching for drug trials and how hard it is to find that information. Sometimes your oncologists don't know what's out there, what's happening in another hospital, what's happening in London or Manchester. That's time consuming, and it's exhausting, when you're already exhausted from the treatments. So, we want to advocate patients to be able to go and have those conversations with you guys and say, what are the treatments available? What is the next line? And to be able to understand what has been said. I'm that patient that takes a research paper to my oncologist. I'm that patient. But you'll find there are far more of me out there now, because we have to advocate for ourselves, no one else is going to do it for us.

**Vivienne:** So, that goes back to what you were saying earlier about making papers understandable, and let's not go into open access here, which is a whole other question. And actually, I know that you want to publish in the best journals, but very frequently, they are not open access. I think it behoves researchers to make sure that, with patients, they are writing something in layman's language and there's nothing in your contract with Nature, you should be so lucky, that says, you can't do a layman summary somewhere. Where would you like those lodged and how would you like to see them?

**Kate:** I think you guys need to be creative. Yes, we all like the BMJ, we all like Nature and the highbrow stuff, but the people that really need to know what you're doing are your patients. And how you access those groups, you know, we have underground groups on Facebook and Instagram and Tiktok, and you need to be looking at the different social media platforms as to where your patient groups are. It's not necessarily with the big cancer groups, Macmillan, Cancer Research UK, Breast Cancer Now does not represent me. The groups that I'm involved in are things like MET UP UK, Younger Breast Cancer Network, Secondaries First, these are the groups that are my people, they are women who are dying from cancer, and we don't want to die from cancer, we want to live with cancer.

**Vivienne:** What information do you need from a study? So, let's think about a typical research study in genomics. What's the top line for you and how should it be explained?

**Kate:** It's definitely not the stuff you get in the papers, because we all get sent articles from certain papers. My parents are great at that. We want to know, really what does this mean for my type of cancer? You've done a study, you've recruited all these people, you've done your testing, what does that actually mean for me now? How long is it till I can get that drug? What are the side effects of that drug? How long is it going to work for me? Are there any other things that I need to know about that particular medication or that treatment? In simple terms. We've released a lay summary today of what language we'd like you to use for your participants and your patients.

**Vivienne:** Jillian will wave it.

**Kate:** We want you to use that language in your lay summaries in talking to patients about the studies that affect them, it needs to be in language that we can understand and that we can take forwards and use usefully. Because the highbrow journals, we can't use usefully because we can't understand them.

**Vivienne:** Actually, the BMJ are running a big piece this week about exactly that, about how some of the words like 'patient presents with' or 'send home' and all sorts of things that actually are very difficult for patients, and are either not understood or actually perpetuated a rather patriarchal system, that patients are ‘done to’ rather than equal partners. I want to take some questions from you, because a lot of you are researchers in here, and I want to know if there are things that you want to know about how to interact with patients in research, because this woman will tell you in unvarnished way. She's from Leeds. Anybody got a question?

**Prof Anthony Moorman:** Hi, there. My name is Anthony Moorman, I'm from Newcastle University. I do research into child's leukaemia, and we are currently faced with an issue. We are running a very large clinical trial, and we need to engage patients and parents. The sticking point we have is we don't how to get in contact, there is no official list. We are somewhat nervous about trying to find them on Facebook because it's an unregulated environment. We don't know who we're getting in contact with. So, we are trying to engage the patient groups that we know about and we do know some parents who are very active with some of the things that we are doing. But their worry is they don't represent everyone. So, how would you recommend, do you have any top tips on how we would actually go about it? Because it needs to be done on a national level, because childhood leukaemia is fortunately quite rare. And we potentially want to engage the older children themselves, but obviously there are issues with doing that, and also the parents. We need them to be, and we want them to be actively involved in what we're doing, not just in terms of the trial, but also the associated research.

**Vivienne:** That's a great question.

**Kate:** I think you need to look at who your patient representatives are, who are your patient groups, and get them to get the word out to the wider population. You won't be able to see the groups on Facebook, because they're all hidden. We like to hide under the radar and chat about you in private. They're the kind of groups that you want to access, and you'll find that there are large groups of patients that you know nothing about that have made their own support groups, that have made their own networks. You just don't know that they exist.

**Vivienne:** Of course, that's a big tip for all of them, that actually, once you engage with the patient group, you can find an enormous number of patients that you didn't know existed, but it's tapping into the right one and how do you find the right one?

**Kate:** Well, I would say it's the 'gobby' ones that engage with you, that come and talk to you about these things, that want to be interested and want to talk to you about this. Those patients that are challenging and are difficult and do ask those questions are often the ones that are most involved in the support groups and have the larger networks.

**Vivienne:** What about things like, could he go on TikTok?

**Kate:** Do you know TikTok? Do your kids know TikTok?

**Prof Anthony Moorman:** They probably do, but they would be embarrassed.

**Kate:** But that is where my students hang out. That is where the younger population hangout, is Instagram and TikTok, and Facebook's for old people, sorry. That’s where you need to be advertising.

**Vivienne:** It’s all right,I'm not going to ask who's got a Facebook account, it’s fine. Any other questions? There's one right at the back there and there's one over here.

**Public Policy Projects:** Hi, yes. I'm from Public Policy Projects, we're a think tank and I do a lot of work predominantly with rare disease and we have a patient group. Building up on the previous question, I was wondering if you have any advice or thought on the bridging of the gap? Because when I deal with patients and parents and am introduced, you have to put a lot of time in to build that trust and get them to share their experiences or whatever they feel comfortable with. But at the same time, in a sort of pre pandemic, post pandemic and during pandemic, the time restraints on clinicians, researchers, etc., are incredibly evident. How do we bridge that gap between devoting the time to build that trust but also recognising that you don't necessarily have hours to build that trust?

**Kate:** Well, you need to target the right people, don’t you, in the most effective way? And that's about looking at where are your patients hanging out. It may well be not doing your traditional routes of recruitment. It may be looking at the alternatives and tapping into those places that you never thought you would necessarily have to tap into. But, as a patient, I value that time and that energy spent talking to me about my disease and my problems, and I am much more willing to help you out if you spend that time and effort with me.

**Vivienne:** Kate Grafton, we've come to the end of this time. I just think you're fantastic.

**Kate:** Please don't use the word inspirational.

**Vivienne:** No, I'm not going to say inspirational, because I just think you're completely fab. That's you as a person, that's not you the patient, that's you as a person. What I wanted to do is put the last words in your mouth. So, what's the message that you want all these people to go away with today about patients and research?

**Kate:** I want you to think about quality of life, not just quantity. I want every patient to be able to live 10, 15, 20 years with incurable cancer, not just me.

**Vivienne:** Have you heard that? Very good. Ladies and gentleman, the fab Kate Grafton.

**Kate:** That's all for this episode. Thank you for listening to this conversation 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. If you have any views on these topics, or have a person in mind you would like to interview, do write to us at podcast@genomicsengland.co.uk. Remember to subscribe to The G Word on Apple podcasts, Spotify, or wherever you listen. And that if you've enjoyed listening to this, give us a five-star review, it really helps people find out the series. Can I also encourage you to make sure that you do check yourself, feel on the 1st. Until next time, I'm Kate Grafton, see you on the next G Word.