International Nurses Day Podcast

The G Word Transcript

**Naimah:** Hello, and welcome to the G Word. My name is Naimah Callachand, and I am the Head of Product Marketing here at Genomics England. On today's episode, we are celebrating International Nurses Day, and I'll be joined by Tiggy Johnstone-Burt, who is a McMillan Genomics Clinical Fellow and Clinical Nurse specialist; Sally Shillaker, a Health Visitor and Practice Development Lead in genomics, and also a Clinical Content Developer here at Genomics England; and Victoria Cuthill, who is a Nurse Consultant.

With a rapid advancement of genomics and healthcare in recent years, nurses have an unprecedented opportunity to leverage this knowledge to provide personalised, precise and effective care to patients. In this podcast, we are going to explore the ways in which genomics is transforming nursing practice. We will discuss how nurses are using genomic information to develop tailored care plans, identify patients’ risk of genetic diseases, and also provide education and counselling to patients and their families.

So, first of all, let us discuss the role of nurses and health visitors in patient care pathways. I would like to ask each of you to tell me a little bit about your role and how that fits into the patient care pathway. Tiggy, would you like to start?

**Tiggy:** Hello, my name is Tiggy and my background is in breast cancer as a Clinical Nurse Specialist. I also work for McMillan as a Genomics Clinical Fellow, but I have set up the mainstreaming pathway for our breast cancer patients. Just to define what that means quickly, it means delivering genetic testing to our breast cancer patients in-house, within our cancer team, so they get access to testing much more quickly and with us guiding them through the breast cancer nurses.

**Vicky:** Hi, my name's Vicky. I am a Nurse Consultant at St Mark’s Centre for Familial Intestinal Cancer. St Mark's is a national bowel hospital, and what my role involves is diagnosing people who are at an increased risk of bowel and related cancers. The most common of which is Lynch syndrome that many people will have heard of. So, we can carry out diagnostic and predictive genetic testing, and we also carry out clinical care for our patients and this is lifelong in nature. We really can care for the patient from the start to the end of their clinical pathway.

**Sally:** Hi, I am Sally and as a health V=visitor, we see children antenatally and then up to the commencement of school. Often, we are picking up for the first time with families who may be a little bit concerned about their child maybe missing developmental milestones, and we may be one of the first professionals to start wondering if there's perhaps a genomic cause for that child's delay. So, we really get involved with families from the start, and most of my work at Genomics England on the new Newborn Genome Programme and the Institute of Health Visiting is about how to support professionals and care for those families with that sort of diagnostic odyssey.

**Naimah:** Okay, so let's think about, first of all, why it is important for nurses to be involved in the whole patient pathway end to end, and what benefits that offers patients. Tiggy, would you like to answer this one?

**Tiggy:** Yes, definitely. I did some genomics education provided by Genomics England Health Education in England, actually, and the outcome of it was, that was really interesting, and I found it fascinating and wanted to really bring that back into our practice. To set the scene, typically a breast cancer patient, if you had a strong family history of breast cancer or fulfilled certain criteria like you were very young, they would be referred onwards to a regional genetics team and that referral currently stands at about six months’ waiting time on average. The results of these genetic tests really do impact on the cancer patient's pathway and their treatment options. For me, it made so much sense to bring that back into our team, the Clinical Nurse Specialists. We spend so much time with our patients, we talk to them, we help them navigate this really complex, stressful, emotional time. I thought, well, why not add this extra level? If this is a test that should be provided at diagnosis, we are the perfect people to be able to communicate the complexities of genetics and genomics and family history. We chat to our patients all the time, Nurses do that in our therapeutic relationship, so it makes so much sense for us to be the sort of main navigators and translators of that testing. So, the mainstream pathway has loads of, in management speak, deliverables and good outcomes for the patient. It means that we can have a chat with them, make sure they understand the testing after their diagnosis, and after things have settled down a bit, and send that blood test out and it is much, much quicker.

So, the return results for us are about four weeks, so four weeks versus six months, and it means we can get the results back in time to help have that chat with them about different systemic therapies that are available to them, or different surgical options. Then go into the kind of supportive area, why nurses should be involved in the pathway end to end, essentially, we translate complexity into clarity. And, I mean, this International Nurses Day I really want to inspire Nurses to help them recognise the skillset that we have in advanced communication, that nuanced communicating ability to know when to withhold information, not withhold but, you know, not deliver too much information. We know when to hold back a bit, we know when to give it to them. We see so many patients with such a broad understanding of science and we can really gauge immediately when they are feeling really emotional about things and when they need a little bit more, when they need a little bit less, and they can come back to us, and you have got that single point of contact for the patient going through this time. Instead of referring them to another stranger, another team and another site, we can carry them through this whole journey, and it just makes so much sense to me.

**Naimah:** And would you feel that patients feel more comfortable speaking to nurses?

**Tiggy:** Absolutely, you know, you build up that therapeutic relationship, it’s complex, it is personal, and sometimes that's why it is quite tiring, you know, doing what we are doing. And we do not realise it, you know, you are having these very emotive conversations, listening, supporting, guiding people through this journey. I know lots of people hate the word journey, pathway. I think a lot of people would feel going to a new appointment can end up falling into the trap of just nodding and ticking boxes; yes, I consent to that, yes, I consent to that, and yes, I consent to that. And as your Nurse that represents you as a patient going through your very kind of vulnerable moments, you can say, oh, I know you are having a really bad time with your husband, I know your partner's really struggling, I know your teenager's really finding this hard, but we can talk about this a bit more later, we can have a call tomorrow, do you want to do that?

We do not have that flexibility, I think, when you are referred to potentially having one appointment in regional genetics, which is a long time away. Now, biggest caveat here of today is I do not want to in any way take away from the absolute breadth and depth of knowledge of the clinical genetics teams. The Genetic Counsellors are so knowledgeable, and they know so much, and they are a hundred percent necessary and invaluable, and we will always use them, phone a friend, we will always refer onto them for those much more complicated conversations. The initial testing, the initial counselling and the initial support, Nurses are very well placed to provide that, and we are a multitude, we are many and we are one of the, you know, there are so many of us in the NHS, so use us, use that skill. It is there, you know, it is available, ready for the taking.

**Sally:** I was just going to chip in a little bit from the Health Visitors perspective and thinking about the child as central within a family. But so often for perhaps a child with a rare disease and their family who are on a lengthy diagnostical disease, there are multiple points of contact that we as Health Visitors and primarily Nurses will have with that family. Very much as Tiggy said, to sort of pick-up issues that are ongoing, but also to unearth issues that actually are going to be quite important for that child. So, you know, particularly around perhaps their particular needs or the support that the family may need in thinking about preschool and what is appropriate in terms of where a really good placement for that child will be, or in terms of the support that that family need financially because of the additional needs of the child. So, I just think there are many practical points that Nurses can have tremendous input into families that actually really improve that family's wellbeing and life outcomes.

**Naimah:** Now moving on to the benefits of embedding genomics into patient care pathways and the contribution of Nurses and Health Visitors. So, why should genomics form part of routine care? Sally, would you like to take this one?

**Sally:** Sure,I guess we should celebrate the huge technical or technological advances that now mean that genomic testing is far more available at scale with shorter timeframes and more affordable.So, I guess that is primarily why we are now in this genomics era, and that is hugely exciting. I would just like to quote from the International Council of Nurses, and they say, in terms of nursing, our future depends on every Nurse, every voice, to not only be on the front lines of care, but also on the front lines of change, and I think genomics brings huge change to patient care because of the technological advances. Also, in my world, it answers questions that children may have presented with some concerning presentation for some while, and genomic testing can offer the answers, and that has certainly been my experience for children and families. Also, I think our role is very much about ensuring that everybody has equitable access, so unless we know about genomics and know about our own kind of role and the potential that we have to explain that well to parents, in my situation, children, then we are not going to ensure equitable access and that is going to affect the lives of people who do not have that access, which is unfair.

**Naimah:** And how do you think the role of nurses and health visitors has changed over the years to include genomics?

**Sally:** I think, in my situation, it is very much evolving. I think Vicky and Tiggy are demonstrating huge changes in Clinical Nurse Specialist roles that, as a Health Visitor, we are yet to see really.So, I think fundamentally we are a little bit behind, probably in the sense of understanding what our role is, and partly that is about finding our role. I think the Newborn Genome Programme, the generation study where the potential for many children to be offered genomic sequencing at birth is going to suddenly enhance the appreciation of our role because, as a research study, they are looking to recruit many children for that. I think it is a bit about realising and being aspirational, and not worrying about the fact that this is highly advanced science. And yet the bottom line is it is going to improve the outcomes and the answers for children and families and hopefully mean that they have less time waiting for an answer. I mean, we should acknowledge that, for some, there is no answer yet, but actually that's the amazing thing about genomics that in time, with the research world and the research library, that hopefully answers are going to be forthcoming and ultimately treatments and that's really what it’s about. That actually not only do we find an answer to a child or an adult, but actually a treatment is offered to improve their life.

**Naimah:** And, Vicky, I was wondering if you could tell me a bit about how your role has expanded to include genomics?

**Vicky:** Yes, I have been in my current job now for 10 years, and I started as a Nurse Practitioner. When I first started in 2012, the genomics education programme was not in existence. There was not any formal training as such for nurses. So, over time training courses have been implemented and we have been able to go on them. We've got the academic background therefore to be able to say we can do these things, and that's given us that increased level of confidence to say, well, actually, as Tiggy was so beautifully saying earlier, we are the best people in that patient pathway. We are close to our patients, we are delivering the clinical care, and it just makes sense especially in the initial stages of that pathway to get that diagnosis in whatever area we might be working in. It is often the nursing team that are best placed to do the testing, and obviously call on support of regional genetic services when we need it. So, I have seen a huge shift even in the last 10 years, and I think all of us here today are really passionate about that change because I do think it does help empower nurses, it helps empower our patients about equity of access, as Sally was saying, but it is also about empowering nurses, midwives, health visitors as a profession, and I think that's a really important take home point.

**Naimah:** What do you think would be the best way to educate patients and their families? Sally, do you want to take this one?

**Sally:** That's a great question. I think, certainly in my situation, the opportunity to work with families and, as Tiggy said, not to bombard them with information, but really to try to think about what does it mean for that child and family, and to ask them, so often we are good at giving answers, aren't we? Or thinking about what we should tell people, but actually I think the fundamental thing l is what does that family need to know? Let's ask them what they need to know and then being really honest about, if you do not know the answer, going to find that out, and I think that probably will mean much greater integration with multidisciplinary teams, being much more open about contact and communication across the pan professional group that are supporting that child and family, which sounds so easy and yet often, you know, is the kind of really big area that we lack.

**Tiggy:** I just wanted to add to that, I think there are two pieces to this picture of expanding genomics in our healthcare system. Vicky is I think going to talk a bit about workforce education, so educating the workforce. Then the other side is, as Sally was saying, talking about how we get the patients and the family members up to speed. I was actually, it’s probably a really smarmy thing to say, listening to the last episode about science communication, and it is a really complex topic about how you get the public, the general public to know or care about issues that do not matter to them right now, and how do you inspire and engage people? Brian Cox said at the festival of Genomics, he talked about creating a narrative, an inspiring story to try and really capture people's imaginations, and I am sure he will really be upset if I misquote him, so I'll try my best, but he said, you know, even if the science isn't technically fully there, you have got that captivating narrative that will really help get people's imaginations going and get them interested.

I was just speaking on Friday to some really inspiring women who have all founded their own charities, they all have a personal history of a genetic variant in breast and ovarian cancer, and there were nine of them. The recurring theme that came up was in terms of the predictive testing; so that is, I have got a variant, I did not know about it. So, in breast and ovarian cancer, if you have got a change in one of these genes, you will be predisposed, so you will be a much higher risk than a member of the general population to developing a breast or variant, plus a few others, prostate, pancreas cancer, in your lifetime.

That is a really interesting area of healthcare because we are focused a little bit on the diagnostic bit, so you have got cancer, here you are, you have also got the gene, we will make these changes to your treatment. The predictive piece is probably a little bit more in tune with what Sally does in terms of we are anticipating future diseases. And all of them said that they felt so alone and so unsupported, and they were having to go through this very unique situation of having preventative surgery, having mastectomies, going through premature menopause, to have their ovaries removed, to reduce their risk of ovarian cancer. They are young, they have or have not had their families yet.How will I feel? How will I look? What about my sexuality? How do I come to terms with my identity?

Nobody talks breasts anyway in this country and our society, let alone scarred breasts or reconstructed breasts, so there is this massive space, and that's just breast cancer. In ovarian cancer there are so many other gaps we are really well placed to fill, and it is that kind of the guilt as well associated with people who are predisposed to things. One of the sisters, there were two sisters, one of them unfortunately had breast cancer and turns out she has a genetic ulceration in her PALB2 gene. Her sister said, my sister had to get breast cancer for me to know that I was at risk, and that makes me feel so guilty I will not have breast cancer because I have had this surgery, but my sister had to go through that for me.

So, I think it is all very emotive but really, really important. There are lots of things and there are lots of work to do, and I think those really powerful stories will help capture the general public and help people ask us and talk about it a bit more. Vicky?

**Vicky:** Yeah, I was just going to pick up points that both Sally and Tiggy made. The first thing, just when Sally was talking about going on the patient journey with the families, I think that is really interesting. Actually, what you are also describing is that inherent trust that obviously lots of healthcare professionals help with their patients, but if you are at that point and it happens, whether you have got a cancer or whether you are a Health Visitor working with a family, you are their point of contact. You are that family and that person's point of contact; they are going to put trust in you. So, it is really vital that we actually do have some knowledge of what we are talking about. Of course, you know, the patient has that trust if we are not sure, but we know where to go and ask.

And the other thing, just picking up on what Tiggy was saying about the predictive side of things, up until recently our centre at St. Mark's was considered fairly niche because there were a group of nurses and doctors who were both doing the genetic testing, but also carrying out the clinical care. So, for example, if you have a patient with familial adenomatous polyposis, for example, which is where people get lots and lots of polyps in their large bowel and need to have their whole large bowel removed as a preventative measure to prevent cancer, we will see the patient, we will discuss surgery with them, we will carry out the surgery, we will look after them after the surgery, we will carry out their endoscopic surveillance going forward, and I think that really is the future, you know, moving forward.

That we are in the middle of setting up a rare disease collaborative network for polyposis syndromes, we are so lucky to now have the NHS transformation project for Lynch syndrome. We do not want to be the only ones doing this. We want to replicate and support and help these sorts of examples to happen all around the country because of that equity of access, it is just so vital. If we are doing something great, we do not want to be the only ones doing it. We want every single person in the country with whatever inherited disease or risk of disease to have access to exactly the same level of care, the same level of genetic testing. Really that is why we are here today to promote that and say, you know, nurses, you are so well placed to be getting involved in in this.

**Naimah:** I think each of you have just described just how vital it is for nurses to be involved in every step of the patient journey. Sally, you mentioned about the multidisciplinary team. Nurses have been integrated well into the multidisciplinary team with regard to genomics?

**Sally:** Speaking as a Health Visitor, and bearing in mind I have mentioned, I think, that our role is definitely evolving in terms of our recognition of where we can contribute to that patient pathway, that child's journey. I think we are yet to really integrate, that isn't because the door is closed to integrate, but I think it is all about opening that door really to have dialogue within that multidisciplinary team, not just the kind of professionals that we are used to collaborating with and, you know, hopefully do well.It is about who else is important for that child, and often what information we have is of relevance to that multidisciplinary team, perhaps the clinical genetic team at the specialist unit, or whatever.

One of the things that we have done recently is to write some, they are called, good practice points for Health Visitors. Actually, the Genetic Counsellor who was the author and part of the team that worked on them was very clear that the sense is that we do need to open those doors wider, but I think it is just allowing that sort of catch-up process to happen now, you can't just say open the door and everyone's going to go in it.It is actually needing to be quite active in that. So, I think part of it is equipping the workforce to realise the value of greater collaboration and integration, but also somehow the mechanism that we make that happen. It will not just happen overnight, but it does actually have to be quite intentional. I suspect Vicky and Tiggy are great gurus really in that kind of respect so far, but probably for us there is some great work to do.

**Naimah:** So, now if we move on to talk about empowering nurses and health visitors and how they can get involved in genomics. Vicky, I was wondering if you could tell me, as the use of genomics becomes increasingly important in routine care, why is it important for nurses and health visitors to stay up to date with genomics and how can they do this?

**Vicky:** Well, I think both Sally and Tiggy have touched on this already, and I recently, it is one of the final things I did before I left as Macmillan Genomics Clinical Fellow, wrote a blog about demystifying genomics. I think that kind of sums it up really because if we as a Nursing and Health Visitor workforce are frightened of genomics as a topic, then how are we going to explain those concepts to our patients. If our patients are not equipped with that information and knowledge, then how are they making informed decisions about their care? They do not know all of the drug treatments, for example, which are on offer. Or if they have not had access to the right genetic testing, then they run the risk of not receiving the right care.

There are many examples actually where a genetic test may not find the answer, and then we have to make a clinical decision, and it is always not just about the person sitting in front of you. So many times we may not get the result that we want, but we know that something's going on in a family and, therefore, we offer advice, screening advice for family members.So, we've got to have that knowledge in order to equip our patients to make sure that all of them out there are receiving the right care, and I think, you know, it is as simple as that really.

**Naimah:** And what resources and education tools are available?

**Vicky:** Well now there are huge number of resources available.It is all very different to when I first came to this, but I think the first piece of advice I would give is for everybody to get onto the internet, obviously, and look at the genomics education programme. It has been set up for all of us, for all healthcare professionals. It has got some fantastic resources. If you are brand new to this, there is a great learning resource called Genomics 101. It takes you through very short courses, maybe 10 minutes, 15 minutes, where you can learn the basics. There is also Future Learn, which is the Open University's online learning, and there are MOOCs (massive open online courses) courses that you can do a lot of. These are free at certain times, or there is a small fee, well worth doing those. There are lots of taught courses that sometimes are funded through the genomics education programme. Watching videos on YouTube, I have found to be invaluable. If I do not quite understand a concept, I will quite often just Google it, go on YouTube, watch a video, things like that are brilliant.

Podcasts like we are doing today, I have learned loads from podcasts. Find out what is your local Genomic Medicine Steps Alliance. Get on the mailing list, make sure you are being kept up to date with study days and events that are happening. The NHS has a genomic medicine service and last October it launched its first Genomics UK strategy. Have a read of it, it is really interesting. There are other publications, like the Chief Medical Officers annual report from 2016 was on Generation Genome. That is a really interesting read. Things like the Topol Review that are about digital enabling in healthcare, but also have a strong component around genomics as well.

**Vicky:** There is so much to get involved with the third sector. Tiggy and I have obviously been doing some secondment work with the third sector who are also developing tonnes and tonnes of resources in this area. So, wherever you look there is resource available. You can do it in short bursts in your own time. If you are really interested, then please do look at some.

**Naimah:** Are there any resources for Health Visitors?

**Sally:** There are as I mentioned, the Institute of Health Visiting, the Genomics Education Programme have got some tailored resources for Health Visitors but for anybody interested as well, and you can access those very easily. And to the credit of Genomics Education Programme (GEP), there is a health visiting webpage, there's a midwifery webpage, there's a nursing webpage, you know they really are about engaging and educating our workforce. I would just also say I do not think genomics is an easy subject, and I think depending on your own background in terms of perhaps schooling or your interests, for some people it can be very, very daunting, and I have found that I have just needed to revisit the kind of 101 that Vicky mentioned really regularly, and do not be afraid of having to do that.

Also, that reflection is really helpful, and the reflection at practice point or perhaps a child in front of you and following that through and identifying what you know and what you do not know and perhaps what you need to know are also, I have found, really helpful. I think the other thing to say is if you are really interested, you know, there are many avenues, but ensure that you somehow get this on your PDR (performance development review). So, if this is something that's really bugging you and you want to know more then, at the moment, certainly in my sphere of nursing, it is sort of mandatory training. There are lots of arguments about whether that will happen in due course and the pros and cons about that, but certainly I think if it is something that you are interested in, you maybe see this as part of your career progression, maybe find somebody that you can talk to, maybe somebody that will buddy you or mentor you, will encourage you. There are courses that you can opt onto, so GEP do fund nurses and midwives to do some short courses. There are year-long courses, heaps out there.

**Naimah:** And with those people who are going through Health Visitor training now and Nurse training, is it now incorporated?

**Sally:** Yes, the NMC, so the Nursing and Midwifery Council, maybe Vicky wants to add a little bit more, have amended their standards in recent years and now there are components about genomic education being within that, which is really, really great. Definitely going to advance, I think, the knowledge of nursing students and ultimately the specialist community Public Health nurses as well.

**Vicky:** Yes, I think to varying degrees, it will come into pre-registration education. I think it is there in smaller amounts at the moment and it will increase. As you said, Sally, it is in the NMC standards now, and I know that projects are ongoing at the moment to work with universities and to improve the level of education that is provided in that area.

**Naimah:** I wanted to ask as well, do you feel like there are any barriers to nurses or health visitors being able to play their part in genomic medicine?

**Vicky:** Just to be a little bit controversial? I do not know what Sally and Tiggy think about this, but sometimes nurses can be our own worst enemies. I think we sometimes lack confidence that we can take part in certain discussions. I think genomics, as Sally was mentioning, it is seen as a complicated topic. It can be complicated, but definitely if any of us can do it and can get involved, then I would advise that anybody can. Some just may need a little bit more time than others, but genomics is a really good example of how we can empower ourselves. We are, as Tiggy has mentioned, at the forefront of that patient pathway. We have built up the trust with our patients. We want them to get access to quicker care if it means a change in, for example, their chemotherapy and medication. We want to make sure that diagnosis is right, and we want to do it quickly without taking them outside of that care pathway to do it. So, I think that this is a really good way of empowering us as a profession and helping us to get the professional respect that we really do deserve, and that potentially sometimes is lacking.

**Tiggy:** Just to add to that, I think Vivienne Parry was saying in the last podcast about science communications, how we do not necessarily need to be talking about base pairs with our patients. We do not need to be going into that level of scientific development. I have been involved with cascade education to my team, my nursing team, and initially so much of that work is trying to feel the confidence of my excellent, knowledgeable colleagues and help reassure them that it is okay. You know, a lot of them shut down and panic because they think genomics, crikey, stop. I do not know science; I do not like science. That is nonsense because you know so much of our world in healthcare is scientific and science. I think it is this perception sometimes of how nurses and Health Visitors see themselves and it is that lacking in confidence.

Whereas, as Vicky said, you know, there are so many excellent resources that will simplify this and as long as we can grasp the basic concept, a lot of cancer predisposition syndromes, I would say are autosomal dominant, most of them. Which means if you have one copy of the gene, each child will have a 50/50 chance of inheriting it.

I think Sally probably deals with recessive patterns of inheritance, which I appreciate would be a little bit more, well, much more complicated to explain to patients and colleagues. I was thinking, Sally, what you were saying earlier and reflecting on my own experience as a mother, and health visitors and nurses, both of us, we are safety nets for these patients. We are best placed in terms of picking up on things that will have been easily missed or slipped through the net because you are there at the patient point of care and any little sign, oh, look, my child's hip’s doing this, is that normal? – it’s the Health Visitor who's going to say, oh, hang on a sec, and pick that up and then escalate it and flag. We are the largest sector in healthcare workforce we see, it is us who are going to pick up on all those subtle nuances because the patient is going to see us the most. Sally, did you want to say something?

**Sally:** I was going to say, coming back to your question on barriers, I mean, I think we should acknowledge that time can be a barrier. Busy caseloads are a barrier and that is particularly true at the moment for many. I think the other thing is that maybe the value, as you have alluded to, Tiggy, of supporting colleagues at different points in their understanding. I really would love to see clinical supervision being a mechanism used much more widely, I think, in genomics. I think there is a huge amount of potential to do that and to support colleagues on their understanding. Somehow, having some sort of supervision framework, I think gives you an opportunity for colleagues to discuss cases, obviously in a confidential way, but also may be a way of educating, but also really focusing on the specifics of that particular case and maybe areas that could be better improved or outcomes could be reconsidered. So, I think, I was just going to say, time I think is a big issue and wouldn't it be wonderful to wave a wand and change that?

**Vicky:** I completely agree, Sally, and the level of genomics knowledge that you need very much depends on the area that you work in, and it is increasingly becoming needed in many, many different areas. But I think the first thing to think about if you are listening to this is where do you work and what do you need to know? What are your specific specialist areas? If you are on a ward, what are the patients that come in to see you? Are you on a surgical ward, for example, where you do happen to look after lots of cancer patients? What conditions are you seeing? Use that as your starting point. Then if you do have a specialist interest, make that case to your ward manager to say why you would like the education. You always have to give back as well. So, if you are going to do education, you then want to become the link Nurse for genomics on your ward so you can feed that back. You are giving a reason for your managers to provide that education and if you feel that your educational work is not being valued, there is a massive shortage of nurses and health visitors and allied health professionals at the moment, please do vote with your feet. There are plenty of workplaces out there that will value you and value your education.

**T**he other side of it is for those that are sitting there maybe and thinking, gosh, you know, I am so busy, we are all under such time pressure at the moment. Do I have time as a Clinical Nurse Specialist, for example, to be integrating this into my practice? I can only say from the other side of the coin where every week in, week out, I see patients that have been diagnosed with cancer that potentially did not need to be diagnosed with cancer. I have seen families bereaved because people died of something, which if we picked it up earlier, need never have happened in the first place. So, there are times, and this is one of them, where of course we are time pressured, but especially in the cancer world, and of course I am biased because that happens to be my area of specialty, is that we really can't afford not to do that work because it has such an impact on patients and families.

**Tiggy:** So, to go back to add to Vicky's point and focus on the cancer world, it does not seem very nice to think about this in economic terms, but a predictive test, a test where you know someone's got the cancer predisposition genetic change, is far cheaper to treat. Far cheaper to manage for the NHS than someone who has presented with a cancer, who has to then undergo lots and lots of therapy, lots of interventions, and if it takes that kind of business speak to try and persuade our leaders to try and persuade our managers to integrate this more and more, then that's what we kind of have to start thinking. We have to, you know, really change our mindset. We are always there for the patient so you can have a two-pronged attack. This slightly, you know, lacking in compassion, robotic approach of economically, this makes a lot more sense. Then also bringing it back and reminding people that these are people, and these are people's lives we are saving at the end of the day. I think when you bring it back to that, people cannot really say no. I am alluding to the potential barriers and difficulties nurses may face when they are trying to introduce new services and introduce new techniques into their current practice. I found it, as along with everyone else, there are lots of complicated things, hoops you have to jump through with governance. But it does seem to come back to time and money and sometimes that is quite a challenging conversation.

Nurses are not always trained to challenge their seniors, and those are difficult conversations to have, but I think using that kind of emotional emotive story, weaponising the emotive aspect of this, is a patient's life. Would you really still like to not proceed with saving lives? Because I think you would.

Then also what Sally was saying about the time, and Vicky was saying about the time in those snapshots of time that we have in busy clinical lives, from a little kind of tip from my area is using the MDT (multi-disciplinary team) as a teaching space, whether that's discussing patients’ cases and educating the consultants and other members of the multidisciplinary team in that setting. The more you talk about it, the more people know and understand about it. Then also we have introduced in my area a five-minute MDT break. So, we stop in the middle of five minutes, it is very strict, five minutes and somebody gives a presentation or an update on what they have learned or some new technique. We often use that as a sort of genomics update area. At least the guidelines, this is what you need to know. It is really effective because no one can say no to five minutes, especially when our MDTs sometimes go on for four hours. So, a long time, so everyone certainly welcomed a five-minute break. Vicky, did you want to come in?

**Vicky**: Yes, I was just going to say that just picking up on a couple of points that, of course, the regional genetic services are as good as the patients referred into it. So, if you are thinking about your position as a Nurse or Health Visitor in a pathway, do not be afraid. If you think, has anybody asked about family history or has anyone picked up on something, you may well be the first person that has thought of that. Of course, then you have that opportunity to refer on if you do not have a service set up, that is fine, but at least you can then link in with your regional genetics. So, I guess the message is never feel that you should not ask questions and never feel if you are given a piece of information and you do not know what to do with it, you are not on your own. There are areas that you can get advice from and you can link in with lots of different people about this.

The other thing that I was going to say is that over the 10 years that I have been enmeshed in genomics, if you like, it has not been an easy path. When I first started, I was questioned a lot as to my role, why as a Nurse was I doing this? I think the thing that has got me through is the absolute passion and belief that what I and the team were doing was the best thing for the patient to ensure that they got the genetic testing far earlier in the pathway. Also, for my area of practice, that we are looking after our families for the whole of their lives. So, we are there at the beginning and we are there in the middle and at the end. That now has come full circle and I am sort of validated in a way that I was not shouting out for nothing.

I think it has been a really important journey and I think to all nurses and health visitors and allied health professionals that may be listening, if you have a passion, you really believe in it, stick with it. Often you may be the lone voice to begin with, but that does not mean that you are wrong, it just means that people are not used to hearing the story told in the way you are telling it, and I think that is a really important thing to hold on to.

**Tiggy:** I have often found what a privilege, you do not often get an opportunity in your professional career to be a bit of a warrior, bit of an advocate for something that is right, and you are, you might be fighting a little bit, but this is right, and this isn't a nice to have, this is a need to have, and that is the bottom line.Patients’ lives will be saved by this, and in breast it is a simple blood test, and it is relatively cheap, and it will potentially save the lives of the patient and also their relatives. So, campaign with that in your heart, you know that you have got this amazing opportunity to be fighting for something that is really, really worthwhile, and what a privilege. I feel so lucky to have been existing as a Nurse in this era.

**Naimah:** I think that is all really great advice that you have both given there. So, I want to ask you, what are your aspirations or hopes for genomics in nursing and health visiting over the next kind of five years?

**Sally:** I would love for us to get to a point where nurses generally have a competence in their knowledge to then be confident in the practice that they can offer to children, family and patients, I think we are not there yet. So, I would love for us to get to that competence in our knowledge, but also be aspirational. I think, as Vicky and Tiggy have shared, that they have really built-up services that are ground-breaking actually, and let us be aspirational. Really believe in the work that we have to change lives and to harness the technology that is out there.I guess what I also really want to see is that not only are we better at testing and better at our understanding from those tests, but actually that the research that can only take place because of the results that we are getting is really changing treatment, is finding new treatments, is enhancing the research community's knowledge so that we really do start to see much greater success in our treatments.In my world, children and families surviving for longer and the outcomes being better through genomic knowledge, really.

**Naimah:** And Vicky, I wondered if you could give me your ten second summary of what your vision is for the future of nursing and genomics.

**Vicky:** Well, I would hope that in five years’ time, many more nurses are doing what I am doing, but that we are given the professional respect that we are doing this work and we can do this work. It is a sad fact that sometimes nurses are academically patronised. We are not seen as capable, we are capable. This is a beautiful example of advanced practice, and I think that we are perfectly placed to be taking this on, and I would really like to see a better recognition of that in the future.

**Naimah:** Tiggy, do you have anything to add?

**Tiggy:** Very succinctly, I would love to see an NHS service where genomic testing was part of the standard routine, standard of care, and everyone had access to it across the country.

**Naimah:** It has been a real pleasure to have you all on the podcast today, and it has been fantastic to discuss how we can empower nurses on the use of genomics in healthcare. Thank you so much to our panellists, Tiggy Johnstone-Burt, Sally Shillaker, and Vicky Cuthill. If you enjoyed this podcast and would like to hear more, you can subscribe to the G word on your favourite podcast app.

In the meantime, it is goodbye from me and thank you again to all our contributors.