The Cancer Professionals Podcast
November 2024 – Demystifying genomics - Building knowledge for effective cancer care

(Intro music)

00:00:09 Lydia

As cancer care professionals, understanding genomics is key to empowering patients in their treatment decisions. If we don't grasp it, how can they?

00:00:18 Tootie

I have to try and convince people actually be comfortable in your skin because you're already doing it, and sometimes it just takes a little bit more training to just be a bit more comfortable and really getting to the bottom of how do I facilitate my patients accessing it for their healthcare.

00:00:34 Paul

Hello. I'm Paul and I go by he/him.

00:00:37 Lydia

And I'm Lydia and I go by she/her. Welcome to the Cancer Professionals Podcast, a podcast from Macmillan. In this series, we chat to a wide range of guests, including health and social care professionals, to lift the lid on current issues faced by the cancer workforce.

This episode is in collaboration with UKONS, the UK Oncology Nursing Society. UKONS aims to promote excellence in the nursing management and care of all those directly and indirectly affected by cancer.

00:01:09 Paul

In this episode, we're joined by Mary Tanay, Macmillan nurse consultant in Genomics, and president-elect at the UK Oncology Nursing Society, and Tootie Bueser, Director of Nursing and Midwifery. Following our genomics episode in August, we delve even deeper into genomics in cancer care. We discuss genetic testing, its role in informing decisions and ways to incorporate genomics into our everyday conversations and practice.

Before we begin today's podcast, we wanted to acknowledge the genomics focused episode we released in August 2024. During that episode, we delved into the fascinating world of genomics and genomic testing. Kelly Kohut expertly guided us through the complexities of genomics, while Emma Jenkins courageously shared her personal journey after being diagnosed with Lynch syndrome. If you're new to genomics, we highly recommend giving that episode a listen.

Also in our August episode, we asked you, our listeners, to let us know which aspects of genomics you'd like to hear more about. So in response to your requests in this episode, we'll delve further into genomics pathways, introduce some new terminology, and discuss how you can integrate genomics into practice.

00:02:28 Paul

So hello, Mary and Tootie and I'm delighted to welcome you to the Cancer Professionals Podcast. Thank you so much for joining us today. Could we perhaps start by you introducing yourself?

00:02:40 Mary

Hello everyone I am Mary Tannay. I am a cancer nurse currently my role is as a Macmillan nurse consultant in Genomics at Berkshire Cancer Centre NHS Trust.

00:02:55 Tootie

Hi everybody, my name is Tootie Bueser. I'm the director of Nursing and Midwifery at the Southeast Genomic Medicine Service Alliance, and I'm based at Guys and St Thomas's and also at St George's Hospital. I'm actually a cardiac nurse by background, but my remit in my role is really to support the embedding of genomics in everyday practice for all nurses and midwives.

00:03:20 Paul

So Mary, we know genomics is complex and professionals are dealing with lots of different aspects of care and may be avoiding the subject of genomics until they have to deal with it. And I'm curious to know how your attitude to genomics has changed as you've built up your own knowledge?

00:03:38 Mary

I think Genomics has always been in the background of cancer practice and we know in recent years there have been a lot of advances in healthcare with regards to genomics and arguably cancer has been one that has seen a massive revolution or evolution of genomics within it. And what does this mean to me as a healthcare professional? I think the easy answer is to go back to the classroom whether that means I join sessions online about genomics, in person, or having my own reading on it. I think it is important for a cancer nurse like me to know what genomics is. How does this affect my practice, but also how I can support my patients and their families as they go through treatment. Because this is the future and if I say the future, I think it is also fair to say that genomics is here now.

And for a lot of healthcare professionals, genomics can be really overwhelming. And I think it's because it's a new language, it's unfamiliar term or terms. There are a lot of terms that we have to deal with again. But I think like anything else, it's about learning a new language and making it become more of a normal within our practice. And the

more we do that, the more that we can embrace it and recognise that it is actually part of our day-to-day practice and our day-to-day activities.

00:05:13 Paul

Thank you, Mary. And Tootie from your experience, what would you like to add?

00:05:20 Tootie

I think when we approach nurses or other health professionals about, you know what, what do you know about genomics? What does that mean to you? They kind of look at me with a bit of a sceptical look or like, oh, I don't know anything about it. But if you think about atypical cancer care a lot of that does involve genomics. Whether it's ordering an assay, the way you prescribe treatments sometimes it's based on the genomic information, even taking a simple family history, which all of us do, that is part of genomics. So I have to try and convince people actually be comfortable in your skin because you're already doing it. And sometimes it just takes a little bit more training, bit more education, as Mary said, to just be a bit more comfortable in really getting to the bottom of how do I apply genomics maximally? How do I facilitate my patients accessing it for their healthcare?

00:06:23 Lydia

I love that sort of championing people to have belief in their own skills. That's really great to hear. So as Paul mentioned a little bit earlier, one of our listeners got in touch and wanted to know a bit more about some key terms. So to start with, could you maybe explain some of the terms that we hear in genomics, particularly germline and somatic and how they differ in the context of cancer?

00:06:47 Tootie

So when we say germline testing in the context of cancer, I think we're really looking at testing for inherited cancers. So this is looking at pathogenic or disease causing variants in the cells that are in all of your cells. So these could be inherited from your parents. And so we're looking at here trying to detect an inherited predisposition to particular cancers. Now somatic testing is that when it's basically tumour testing. So tumours have their own sort of DNA and that we can detect those sort of pathogenic or harmful variants within those tumour cells and these aren't necessarily inherited cancers. But these are cancers that are driven by genetic factors. Some people will have both types of testing. Some people might just have one type of test, like for, for example, just tumour testing or somatic testing.

00:07:50 Lydia

And why is it important to distinguish between the germline variants when diagnosing and treating cancer?

00:07:58 Tootie

It's very important to determine whether a person has got a a germline variant, particularly pathogenic or a harmful variant, because obviously this has implications for themselves in terms of precision treatment, the types of treatments that that are necessary for a particular cancer. But also this has implications for their first degree relatives because these relatives could be at risk of inheriting that germline pathogenic variant.

00:08:28 Lydia

And we sometimes hear as well the term proband come up. I wonder if you're able to tell us a bit more about that, Mary?

00:08:36 Mary

So when when someone has been tested for a germ line pathogenic variant and that has been identified in that test, then that individual is called the proband, or in some cases, and you will hear that they are also referred to as the index patient. So basically this is the patient that was identified as having that gene and as a result of that all their first degree relatives will be tested as well, and that will be recommended to their family members as well.

00:09:14 Lydia

How does identifying the proband or index patient influence the genetic testing and counselling process for the rest of the family?

00:09:23 Tootie

So let's say a proband or the index case has a genetic test. They're found to have pathogenic variants, which confirms an inherited type of cancer. So their first degree relatives could be a 50% risk of this same cancer. So what would happen is, it would be recommended that that proband see a genetic counsellor and talk through the implications for the family members, implications for themselves first and then of course the family members because they would need to communicate this result with their family members. And this is the best way to try and prevent any sort of major or complications or even cancer occurring in that relative. So the discussions with the genetic counsellor could be around strategies of communication. How to explain the implications to them of this result, working through you know whether there's some hesitancy about sharing results because there's a lot of, you know, there's a lot of fear and a lot of emotions that patients go through at this time. And then of course, once that's communicated, the family members can then get a referral back to the genetic counsellor again to have their own conversation about how how they want to decide to proceed with the genetic test to see if they're also carrying that same pathogenic variant, and then the implications for that and how they would take that forward. So, I think key here when you're dealing with family members is is really having genetic counselling to help them make decisions about themselves having that test.

00:11:10 Mary

I think it is important to highlight here and I think going back to Paul's question earlier about like healthcare professionals thinking that I will deal with genomics later because it doesn't concern me at the moment but clearly with what Tootie has gone through there in terms of the process of testing identifying and referring, healthcare professionals will be at some point in the middle of all these conversations, whether or not they are seeing patients on an outpatient face to face basis or on telephones. Or maybe it is just a question from someone who's really worried in the ward or in while having their chemotherapy or SACT treatment. So if we're going to think about those steps, you will think, for example, for the index case or the patient who is going through the cancer diagnosis, but also having to start treatment there is a lot of implications emotionally and psychologically for this individual. And Emma mentioned in the last episode about feeling the sense of guilt for that individual that they are passing on a faulty gene to their families, that there is a lot we as healthcare professional can do to support our patients in that aspect.

And and Emma also mentioned in the last episode about having this, sometimes a life changing news as a result of of having a relative identified as having a gene that could potentially influence their and increase their risk of developing cancer. And again, that could be emotionally overburdening them while they are supporting their relative. They are also having to deal with something that is potentially unknown and potentially something that is going to impact upon their lives, not only in the short term, but also in the long term. So, there's a lot of areas there that I think healthcare professionals, clinical nurse specialists, oncologists and everyone who is supporting families and patients who were at that point, you can identify how they can support those individuals.

00:13:37 Lydia

I think as you say, well, it came across as one of the main themes really when talking to Emma is that there's so much emotion wrapped up in it. And so having good support is absolutely key. And I wonder if you're able to give us perhaps an overview of some of the types of tests that people might have with genetic testing.

00:13:55 Tootie

So you know, there's quite a few tests available to cancer patients when it comes to genomics. So it's not just, you know, just testing a tumour or testing for germline pathogenic variants. I mean, if you look at the national test directory. So I think that's key, to mention, the national test directory. Because it tells you for rare diseases and for cancer what can be tested, the criteria that one needs to meet to be able to avail of that test and the technology by which this test is going to be done.

Now I'm not familiar with all the tests, but there are quite a few common tests that are done in oncology. So a very basic one, let's say somebody is undergoing chemotherapy for some solid tumours, particularly breast cancer. So you would have a pharmacogenomic test to look for DYPD. Now this is important because this regulates an enzyme that helps in the metabolism of chemotherapeutic agents. So if you're a normal metaboliser, a moderate metaboliser low metaboliser, this will then either adjust or your clinical team will look elsewhere for other treatments cause this can cause very severe adverse effects for for that patient. So that's one so in terms of

pharmacogenomic testing and trying to get the the agent that's most effective and less harmful to you.

Then of course you've got your germ line testing for inherited cancers, so that would be a blood test or saliva test that can then detect a predisposition to cancer syndromes which Emma mentioned in the last episode, and Kelly talked through in terms of Lynch syndrome. BRCA is another example and tests for, like let's say, other inherited cancers. And then you'd have tests which is quite new in the NHS looking for circulating tumour DNA and which we shorten as ctDNA. Circulating tumour DNA is a test where where in particular tumours will shed some of their DNA in the bloodstream so this is a blood test that is a substitute for actual biopsy, which takes a bit longer and is a bit more invasive, so if they detect particular DNA of particular tumour types, then they can again either target the treatment to that and it has the potential to first of all help in diagnosis, monitor treatment and then look for recurrence. So there's there's a lot of potential for their use.

00:16:53 Mary

Just listening with what you've said there Tootie someone can be easily overwhelmed with a lot of information with a lot of terminology that you have mentioned there. And of course we love acronyms, don't we? But it's it's interesting you have mentioned all of that and and really explained each one really well because I think as healthcare professionals we need a lot of focus on learning about this to become more effective. There is a study by Vicky Cuthill, Claire Taylor, who's chief nurse of Macmillan that was published, I think, early 2024. It actually looked at the cancer nurses attitudes, knowledge and their learning needs about genomics and what actually showed there was that they actually need support in terms of identifying their learning needs because you don't know what you don't know really isn't it. But also the paper mentioned that only very few nurses have experience of ordering a genomic test, so that in itself is already a problem I would say or an issue, because without knowing how to do that, then how can we explain that to our patients? I think we come here in a in a period, or in an era where in it actually disturbed our skills and our knowledge a bit because previously I mean we have been dealing with SACT, a lot of tests, a lot of drugs, but straight away, you know when you say it's a EDTA, you know it's going to be a blood test, if it's a scan, you know where to refer your patients. But for this one you're presented with a lot of information wherein If you don't know the process itself, then it's difficult to explain that in layman's terms.

Emma mentioned that it is really important not to be too sciency about it. Avoid acronyms. Think about supporting someone with scary words when in fact we are actually threatened with these words at the moment because it's actually a bit overwhelming. So it's also and you mentioned here Tootie earlier about the National Genomic test directory. When I accessed that, there were about 3 pages back-to-back when I printed it of different tests in cancer alone, so you know, it's knowing where to find our information, where the resources are. And we have the genomic medicine service alliances who have nurses like Tootie or other healthcare professionals who are actually there, who can support us in understanding what is specific to our various tumour specialty groups, or indeed if you're in haematology as well. There is also another term which you will hear Genomics lab hub or genomics laboratory hub, which we always just freely say GLH. But these are the hubs where in we send the the samples

whether that's blood or tumour samples. So again, it's knowing the process who are involved in those processes whether they are based in the lab, whether they are our genetic counsellors, who we refer our patients to, and indeed in that research in that paper that I was referring to earlier, the nurses mentioned about communicating with the genetics team and how to go around with doing that and also they mentioned about the clarity of the roles of each individual healthcare professionals within that whole process. So again, it's understanding what we need, the learning that we need in our specialist areas, but also the skills that we need to be able to support our patients when explaining the tests and indeed the results and how to provide support to them.

00:20:51 Tootie

I think, Mary you you've got it on the ball about being able to you know that there's so much knowledge that we, we we kind of need to absorb and learn around genomics and if we're not confident in in that then of course that translates in how we communicate with the patients and that that that won't help people like Emma in the last episode to then obviously take that in, you know, cope with that information and then having to also communicate it further to her family. So I think it really is important that, you know, as health professionals, we all have the the knowledge we need because not everybody, I suppose, would consent for a genetic test or genomic test, so there are certain degrees of of which your competence is needed. But if it is obviously what you need to almost have a self reflection on on what your role is in within a genomic pathway of your patient looking at that and saying where do I fit in? And then what do I need to kind of make sure that I've done my best to get that patient on that genomic pathway then they're fully supported. In the same way that you give the holistic care maybe as a nurse and or or any professional providing oncological care. So I think that's that's really important and there's a plethora of resources available.

First off, we've got the genomics education programme, which has everything from one-minute videos to saying what is genomics to massive open online courses on consenting, how to consent in cancer and in rare diseases, and you've got masters level modules that are funded and then you can do a full fully funded masters course in Genomics. Also in the genomics education programme you can find at the clinic type resources called GeNotes and you know you can look up a condition or a topic, particularly if you're new to genomics, this is really helpful and it takes you step by step around what the condition is, what some of the risk factors are, what kind of tests will be recommended, and the criteria for that. And so it it really is a lot of hand holding so there's a lot of resources there. And of course, Macmillan I know they've got a very brilliant breast cancer toolkit in in terms of of genetic breast cancer. So I think that it's a comprehensive resource trying to get people enthused to getting them, making them aware and having this podcast I hope we're reaching some of you there to, to access these resources and of course, there are people in the GMSA so people like myself, who you can, you can approach.

00:23:42 Paul

If you're interested in any of the resources that Tootie has mentioned, see the episode description. Additionally, we offer a series of recorded webinars on various cancer genomics topics, along with links to additional external resources, all available on the

Macmillan Learning Hub, and you can also access the Genomics toolkit on Macmillan's website. Now back to the conversation.

00:24:05 Lydia

Coming from an oncology background myself, when you're working in systemic anti-cancer treatment, you know administering SACT, you hear about the genetic testing and you hear about patients who are anxious about waiting for results. And I suppose it was only when moving on to, like, a CNS role that I sort of fully appreciated that some of these tests get sent all over the world. Some of them are going to America and things like that. So I just wanted to to find out from you how professionals can alleviate some of those worries or support people as they're going through that testing, and specifically through those waiting times.

00:24:45 Mary

So there are two, two parts of that question, Lydia and the first one, I'll I'll answer the the bit about how how to begin really. I think that's your question there. So we have many SACT nurses who might feel that genomics is not part of their day-to-day because all the testing happens on an outpatient basis when patients are seen in clinics and then when they go to the SACT units, then the decision for treatment has already been done and it's almost just administering that that medication. But we know as SACT nurses, we must be able to understand what we're giving, what they are for and and why is that specifically given to a patient with a specific diagnosis and have a specific testing for it.

So, Tootie mentioned earlier about the many resources that are out there and I think my advice on where to begin, because I I was there at some point where although I know that genomics has been there in the background in, in our cancer practice and I have been aware as a clinical trials nurse during testing of of some drugs that are now available for patients. I didn't put a lot of focus into it. But I guess the easier way of doing it is to go back to the basics of our cancer training, understanding that cancer is an umbrella term for many diseases for many different conditions. Every tumour group is different. So I think what we need to do is to start from our specific tumour group, our specific area and start from from a handful of of various tests. Learn about those and what's the implication of those in terms of of the treatment for individual patients.

So going back to our SACT training for example. I think I can still remember about getting confused with mitotic inhibitors with vinca alkaloids platinum based containing drugs, so if we were able to understand those technical terms when we were still very young in our oncology practice. I am sure that if we do it slowly but surely think about understanding these terms, understanding the tests, the effect it has on the treatment decisions that that patients are given, then it will be much easier for us. And also appreciating that we can't know everything and that if we have discovered something, then it's also worth sharing that because genomics is not a secret. It's not something that we should hold very closely only to for us, but think about sharing it with our colleagues, maybe have those bite sized sessions within our unit so that we can all learn together about it.

The other one that is worth highlighting here is about when when patients are waiting for their tests. That could be a really worrying situation. Again, it's understanding the

process. How long do these tests take? Understanding who to contact if we would like to follow up and streamlining the processes as well so that we are able to mention to our patients how long this will take, reassure them if it's taking a long time, but also acknowledging that it is a really difficult situation, it could be anxiety provoking for them and support them then.

00:28:24 Tootie

I think it's probably worth mentioning that in in cancer, we know how critical time is. I think you know this is factored in into the work of the lab and how the genetic tests and genomic tests are performed. So compared to some rare diseases, I think the results for oncological genomic tests are actually quicker, but that doesn't mean that you know there's no waiting time. There will still be waiting times. So I think historically it it really has been a lot a waiting game with a lot of anxiety particularly for patients waiting for their germ line testing because they have to be, you know, they they get diagnosed with a particular cancer, let's say triple negative cancer and then they would be then referred to the genetics clinic to look at whether they are carriers for BRCA pathogenic variants. So that's a couple of months waiting for that appointment. And then they see the genetic counsellor and the genetic counsellor orders to test sends it off to the lab. Another couple of weeks for the results to come back. Then that comes back to the genetic counsellor. The genetic counsellor then informs the clinical team that the patient is, you know has this result. And then the clinical team makes a decision to to do any other sort of position treatment, whatever is appropriate for that result, and then that patient then gets referred back to the genetic counsellor so their families can then avail of the sort of any genetic counselling to look at their risk. So that was your traditional pathway.

Now a lot of services are now mainstreaming a lot of this is either led by nurses or consultants. So in mainstreaming, what happens is so some services have really innovated and adopted this mainstreaming model. So what happens is, instead of having to refer that initial visit to the genetics clinic, the testing for the germline variant is done within the specialist clinic, so your oncology services so then they they send off the result, they get the result back and they can then implement the treatment needed for that patient. There's no sort of in between person or a couple of months waiting. So the patient gets their results quicker, they're supported by the specialist team around this mainstreaming process, so they're usually in in close touch with their specialist nurse. And then they they get, they get that treatment sooner, but they still obviously get referred to their genetic counsellors or genetic counselling services for the risk for their family. But at least you can shorten considerably that that pathway for them. So I think that's really helpful. We've had a lot of mainstreaming in Lynch syndrome. So the services that Emma's father in the last episode and her now would be slightly different now might be a bit of a quicker experience with a lot more extra support these days depending on if, if they've if they've got, if they're in, they're in a mainstreaming service. And breast cancer. That's also possible. And also prostate cancer. So this is now expanding to a lot of the tumour groups.

00:32:01 Paul

And I was just going to ask because we talked a lot about the testing process, what what are the challenges in ensuring that these tests are accessible to all populations?

And especially like you've just mentioned, you know those that are maybe at higher risk of something like Lynch syndrome.

00:32:19 Tootie

I think the key here is is you, who is listening to this podcast because by knowing you you know the ins and outs of the genomic test directory for your particular area and being able to know where you know to to access that. I think then you would know whether a patient would be eligible or not. Or even have you know, have that in your mind to think Genomics actually can my patient have a genetic test or based on the family history that I just took, is there a kind of familial cancer going on here? So I think as a health professional, we should have that mindset because that increases access to the genetic tests because if there's nobody offering or there's it's, it's again as Mary said, it's not part of your repertoire of things that you offer to your patient. Then then who gets it? You know, the patient won't get that. So it has to be, I think, all of us looking after patients really have to have a that a bit of that genomics mindset and again, like Mary said, just a part of our normal is to think about it because that is the way that our patients will have access to that genetic tests and increased equity.

00:33:36 Mary

I guess it's almost saying that it should be genomics should be part of our assessment skills that you know, when we're assessing, usually we have that set of questions already in our minds. But if we are seeing a patient, it's almost like genomics kicks in like when you think about how do I manage this? I know exactly what to do I think genomics should have a a role in in our day-to-day like that, that it comes out really naturally easy and it's part of the conversation.

00:34:10 Paul

And Mary, could we talk a little bit about how genomics is being used in the diagnosis and treatment of other cancers? And maybe you could talk a little bit about the different pathways and the roles within that.

00:34:22 Tootie

So I think where whole genome sequencing and you know genomics is coming to the fore is in the diagnosis and management of sarcomas. You know this is a a cancer that's notoriously difficult to diagnose, but also a lot of delayed diagnosis within this patient group, because they've got a a lump or bump and and you know it's sometimes dismissed as something benign. But actually I guess what they need is probably obviously a referral to a sarcoma specialist centre if it is a suspected sarcoma based on some imaging, but once that is suspected and whole genome sequencing (WGS) is applied to that tumour and it's tested with WGS, it can then define you know it can confirm whether this is a sarcoma and therefore helps with the diagnosis, because you go on a particular pathway with sarcoma, you have different sort of you have particular chemotherapeutic regimes, radiotherapy regimes. You've got a a prolonged longer follow up period once you've had all your treatments. So it's it's all very different and I think then you get that tailored pathway for the patient. If you've determined that that it's a sarcoma. And of course it it's one of those rare cancers as well. So this also builds

up the knowledge around these types of cancers and contributes to research so that you can get more precision treatment in this in this condition. And I guess WGS is helpful in any sort of I guess if you do tumour testing because then some bumps and bumps, some tumours aren't actually cancerous and that saves a patient from all sorts of investigations, all sorts of treatments that, you know, they might put them to harm, so it has that that ability to enable quick and precise treatment, but equally if it's it's not cancer, then again that reassures the patient and they get the appropriate treatment for that as well.

00:36:44 Paul

Could I just ask Tootie if you could just explain the WGS just for our listeners who might not be familiar with that term?

00:36:52 Tootie

Yeah. So I guessI forgot to mention this in the in the testing. So before we had advanced technologies and then becoming a bit more sort of affordable, cheaper, we used to do a lot of panel testing to look at particular genes that may, let's say, involved in breast cancer involved in prostate cancer, etc so that was called just panel testing. So that may still happen in in, in particular sort of tumour groups and you can see which ones that those are in the genetic test directory. But in tumour testing, we do tend to do whole genome sequencing because and that looks at your whole genome and not just a few few genes. And that gives us a more comprehensive view of the possible variance that may be contributing to their condition, they still be genes of interest, but I think that that that gives a more comprehensive picture and obviously you can refer back to that whole genome sequence if there's something that needs reinterrogating or sort of other genes of interest come into mind, then there there's the possibility to interrogate that, that that sequence that's available there.

00:38:21 Paul

Mary, do you want to talk about some of the areas that you're involved with?

00:38:26 Mary

In gynae as well, there are a few areas where in genetic testing and genomic testing influence in terms of risk prediction, but also treatments precision treatments for these diagnosis. So for example in ovarian cancer when someone has a faulty BRCA 1 gene, then that suggests that they could have a 45% chance of developing ovarian cancer. And for those who are who have BRCA 2 then that increases their risk 20 out of 100 individuals with that gene faulty gene will develop ovarian cancer. So there are also tests that are available like B-raf testing and met mutations that if if these are detected that that could influence the treatment that are given up to our patients. There are also, like in endometrial cancer for example, as part of the Lynch pathway again there is a test where and it shows the MSI and MMR tests can also potentially influence the treatments down the line. So for example someone for previously treated endometrial cancer if they have a highly expressed MSI or MMR in their test then they may be eligible to receive pembrolizumab if their previous treatments are not as effective. So those are examples that clearly shows that this tests can actually drive the the treatments that we

are giving to patients and it is important to understand the again the decisions also made in terms of recommending certain drugs and not the others in these specific conditions.

00:40:31 Tootie
The thing it might be worth sort of elaborating a little bit further on the lung cancer and the application lung cancer and application of ctDNA because previously, you know, you'd have to have a biopsy, which is sometimes quite difficult, and patients have to wait a long time for the results of the biopsy to then initiate the treatment. But if you have a circulating tumour DNA test so just a blood test and this can be turned around in 14 days. So when they detect particularly in non-small cell lung cancer, if they detect particular pathogenic variants in the ALK fusion and tp53, then they can then prescribe a tablet called Brigatinib to sort of suppress the symptoms and make that cancer quite stable because they're usually by that time in stage 4 cancer. So I think that's really kind of important for the patients to get the results faster with with the tests and then be able to have the treatment which is quite simple treatment, but also helps prolong their quality of life and sustain them you know, despite a a very kind of serious cancer that that they have.

00:42:02 Lydia

And you've spoken about different areas of cancer care there, and I wonder if you've got any tips for people for healthcare or social care professionals who are wanting to find out more about a certain type of cancer and where they fit into the pathway. Do you have any tips on where people can go to find out that information?

00:42:26 Tootie

The first thing for me that comes to mind is the GeNotes within the genomics education programme, because you can, if you go into GeNotes, just type in a an area or specialty or let's say heart or lung or whatever, it does come up with all the topics that's needed and it it it's it's particularly focused on the genetic implications in a particular condition. So you that's an easy access one that that that can be that's readily available to everybody.

00:43:01 Mary

For me, I found the national genomic test directory really useful because it provides like a step-by-step approach of of what the test is, who's eligible and and information like that. I also find the NICE websites really useful, particularly if I'm asking things like why was this drug approved and why is the other one not approved? Why is this drug superior in this specific group of patients with a positive tests for something?
I would also like to share our experience of evaluating and improving one of our genomic services. So at the moment we are looking at our mainstreaming clinics for Lynch syndrome and one thing that I would like to highlight is the multi professional approach that I think we should adapt in implementing our genomic services. So at the moment I am working with our clinical nursing specialists, colorectal and gynae nurses, also a physician associate, our health support workers, surgeons and oncologists in developing this specific service. And what I can see from there is how each one has a different point of view like anything else, different perspective in, in developing and also

improving this service. And what we also found is that we don't have to start from scratch. Our clinical nurse specialists are already doing this, but because we want to improve our service, what we did was we reached out to those who are already implementing the service in their own areas and we really found the the help of our of the Central and South Genomics medicine service alliance, Tootie and her team in South East Genomic Medicine Service Alliance. So they were there to, to help us, things that maybe we are not seeing at the moment. We also contacted the nurses at St Mark's Hospitals, and they allowed us to shadow them and observe them in clinics.
So this way, Vicky Cuthill I would like to mention her name. She was very patient with us, going through the process what they are doing in their practice to to deliver the service. And for us, that was really very useful because we thought about what they're doing, what we can adapt in our practice or maybe what we can do, what things we can adapt and also change a bit so that it fits within our structures and processes. And I think those two areas, multi professional working and also learning from others and we really appreciate those who have shared their experiences and information with us. That actually helps in terms of developing a service that is efficient, that is sustainable and also one that meets the needs of our patients and their families.

00:46:07 Lydia

I really like that. I suppose it's like you have like resources are great and like e-learning courses are great. But having that opportunity to like work with experts who have so much experience in that field and then be able to ask questions I think is so important, isn't it?

00:46:21 Tootie

There's also, I think the the regional sort of MDTS or multidisciplinary teams that you have. They often have genomic champions and could be a good resource for for advice.

00:46:33 Mary

I think Macmillan's role in in all of this and what they have done so far is is really crucial in advancing genomics and also the motivation and encouraging the engagement of clinicians in genomics. For example, the role that I have at the moment is Macmillan funded and it's actually a unique role across the UK and I think the vision of of Macmillan in this role is is actually futuristic at the same time, very realistic on what we already have that is happening in, in our practice on a day-to-day basis.

00:47:10 Lydia

So just finally to wrap up the episode today, we're just gonna move on to our regular feature, which just three questions that we ask of all of our guests. So if I start with you Tootie. If you could go back in time to the start of your career, or perhaps when you first started in genomics, what piece of advice would you give yourself?

00:47:30 Tootie

I don't know, maybe I should have become an oncology nurse. It's such an exciting field. Seriously. Seriously, I think about involving my patients, patients in the public more in, in how we developed our sort of services and also thinking about developing our research because you know I've I've got a research sort of background as well, so you know, I I think we're better now at involving patient in the public and getting their voices heard and them co-creating sort of our resources you know looking at how we develop services so that they are it's more suitable to them but also being able to reach out to underserved populations. So I think, you know, going back, maybe we should that, you know, had that more incorporated with, you know, when I started out my career and thinking about that first.

00:48:35 Lydia
And for you, Mary?

00:48:36 Mary

Just looking back when I was a clinical trials nurse, when a lot of these activities were going on and pharmacogenomics was already part of the conversation, I wish that I actually brought that earlier to colleagues practice slowly learning these clinical trials you know the drugs might not come to fruition in the end, but it's the concepts, the principles, the early principles. We should have shared that more earlier then it would have been more of a normal conversation now if we would have.

00:49:11 Lydia

And Tootie, what change would you like to see to improve the lives of people living with cancer?

00:49:17 Tootie

I think it's really thinking about personalised and precision care. I think the more we're able to provide and it is not just the, you know, the medical side of things, I think it really is you know, using the tools that we can including genomics to provide that precision care and really you know implementing that and making that the norm, but also in the way that we support patients emotionally, psychologically and in in sort of their social context. I think more sort of personalisation around that I think, and then so hopefully the outcomes are better and patients are able to cope and live well with the diagnosis or recover from it.

00:50:05 Mary

I think like Tootie I am really excited on the potential of precision medicine. I'll say potential and promise of precision medicine and that it will take away cancer and and really treat effective more effective treatments, but also in terms of the side effects. I I would like to see that treatments will cause, I mean even if they have side effects, they will not significantly affect the quality of life of our patients and that they could live life at an optimum after treatment and then they can go back to work, they can go back to their to their normal activities before cancer diagnosis, so that will be my my dream. Which I hope genomics will be able to deliver.

00:50:57 Lydia

And then finally, what key point would you like listeners to take away from this episode?

00:51:03 Tootie

I think you know, Genomics isn't a a big scary beast. I think it's actually something that, you know, start in small steps to learn in terms of what is important within genomics, in your area, lots of resources, lots of people who can support you in that journey. So yeah, just think, genomics. And just take that one small step if for learning about it.

00:51:36 Mary

For me it will be using the phrase the power of now. Embrace genomics, start now, start learning about genomics. Take baby steps as well as Tootie mentioned there and also to acknowledge that it is OK to say I do not know and then act on it and and see what resources can help you and who can help you be part of the genomics network. Be a genomics champion even if you have the slightest interest in it. It's the right time to join the genomics network and Genomics Champions Group and share what you have learned. I think that is really key here. If we start sharing then we start to make you know makes us part of our day-to-day conversations and that will normalise genomics. As part of our practice.

00:52:28 Paul

Thank you both so much for the huge amounts of insight and knowledge which you've brought to the discussion today. We've learnt so much and we've loved having you join us on the podcast today. Thank you.

00:52:41 Mary

Thank you and thank you for inviting us.

00:52:43 Tootie

Thanks so much for having us here. Its such a pleasure.

(Outro music)

00:52:48 Lydia

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00:53:11 Paul

If you enjoyed this episode, follow us so you don't miss our next conversation where we delve into the transformative power of person-centered communication in cancer care. Recorded live at the Macmillan professionals conference at the ICC in Wales, we'll be joined by Richard Galloway, lived experience expert, Natalie Harrison, clinical specialist Macmillan dietitian, and Dr Caroline Coffey, consultant clinical psychologist.

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00:53:52 Lydia

I'm Lydia.

00:53:53 Paul

And I'm Paul. And you've been listening to the Cancer Professionals Podcast by Macmillan Cancer Support.