**Centre for Personalised Medicine podcast**

**Season 3 Episode 7**

***2024-25: the year in review***

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(Our podcast logo features a section of the artwork [‘A Lifetime of Measures’ by Aneesa, aged 12, from Oxford High School](https://cpm.ox.ac.uk/centre-for-personalised-medicine-art-competition-2022-23/), the stunning winning entry to our 2022-23 Youth Art Competition).

**SPEAKERS**

Rachel Horton, Anneke Lucassen, Susie Weller, Ali Kay, Sarah Briggs, Nishtha Bharti

**Rachel Horton**

Hi, I’m Rachel Horton, a Junior Research Fellow at the Centre for Personalised Medicine, or CPM. In this mini episode, we’re looking back at some of our highlights from the last year, and looking forward to what’s going to happen next at the CPM.

I’m joined by Anneke Lucassen, the CPM director. Anneke, can you start off by reminding us what the CPM is all about?

**Anneke Lucassen**

Yes, thanks Rachel. The CPM is the Centre for Personalised Medicine, which has now been in existence for 13th year, formed in 2013, and it's a communication, engagement and scholarship platform for research into a broad range of personalised medicine topics.

We're a partnership between St Anne's College at the University of Oxford and the Centre for Human Genetics, which is part of the Nuffield Department of Medicine, also at the University of Oxford.

In the last year, we devised a new strategy for the CPM, and our vision in that strategy is that effective personalised medicine should be available for all. Our mission is to be a trusted and collaborative partner supporting the development of equitable and effective personalised medicine, identifying appropriate questions, facilitating constructive debate and considering solutions across disciplines and audiences. And we do that through a wide range of approaches and activities.

**Rachel Horton**

Thank you, so let’s hear about some of the work of the CPM this year. In November, we held a wonderful event exploring the use of genomics in healthcare through music, and Susie Weller’s kindly joining us to tell us more…

**Susie Weller**

Thank you, Rachel. ‘Songs of Genomics’ was one of CPM’s many creative endeavours this year, and the event built on a previous collaboration between the CPM team, Kate Lyle from the Centre for Human Genetics at Oxford, and HIVE, which is a leading experimental vocal ensemble from Belfast, directed by John D’Arcy from Queen's University.

And previously, we'd worked with John to turn elements of our research with patients and families who'd experienced genomic testing into song, as a means of trying to communicate the complexity of patient journeys through genomics to a much wider audience.

So John produced this really interesting repertoire of songs based on our research papers, on our reports, and some anonymised extracts from our interviews, which HIVE performed at the Northern Ireland Science Festival. So building on that experience, we ran a second ‘Songs of Genomics’ in Oxford, and this time, the event comprised a song-writing workshop that brought together individuals whose lives have been affected by genetic testing.

So, participants including those involved in our long-term qualitative research, people accessing local genetic services, and families connected to the international charity Unique, which supports those affected by rare chromosome and gene disorders. So musicians from HIVE joined the group to help translate personal experiences into songs. And it was a really great day, so wonderful to see many of our research participants in person and also to learn about new ways of communicating complex ideas.

And after the workshop, we hosted a concert at Pegasus community theatre in Oxford, where HIVE shared the songs to a wider audience. And this was followed by a panel session involving those with expertise in genomics and music, those working in support organisations and those with lived experience, and you can see a short video showcasing highlights from the event on the CPM website.

**Rachel Horton**

Amazing, thanks Susie. And you were also involved in running our second research showcase, which was all about personalised prevention – I’d love to hear your thoughts about the day.

**Susie Weller**

The event aimed to explore how personalised preventative health strategies can fulfil their potential by addressing key challenges through discussion of ongoing research at Oxford and beyond. And one of the things we were keen to do was to facilitate interdisciplinary discussion, and also to support early career researchers to share their work alongside established scholars.

So the showcase started with a series of presentations from CPM Junior Fellows. So Sally Sansom introduced personalised prevention in the context of the CPM strategy, and we then heard about the work that you've been doing, Rachel, exploring representations of genetic testing in stock images. Sarah Briggs spoke about her work on public views on sustainable healthcare and how personalisation fits into this. And then Louisa Chenciner discussed approaches to communicating climate health risks to individuals. Ali Kay outlined her research on personalising *de novo* recurrence risk for couples whose child has a serious genetic condition. And then finally, I presented some of the work we've been doing on the place of additional findings and personalised prevention. I thought it was a great session that gave a real flavour of the breadth of research undertaken by CPM Fellows.

After lunch, we were really delighted to be joined by Dr Stuart Hogarth, Associate Professor in Sociology of Science and Technology at the University of Cambridge, who gave our keynote presentation. Stuart's talk focused on ‘predicting trouble, the rise, fall and re-emergence of genetic risk prediction’.

And then we had our annual PechaKucha session. So up-and-coming researchers at Oxford informed and entertained us with PechaKucha-style lightning talks, outlining their research in just 20 slides with only 20 seconds allowed per slide. And Nishtha Bharti won the prize for the best PechaKucha this year, which focused on race, ethnicity and ancestry in genomic medicine.

And the day closed with a panel session chaired by Anneke Lucassen, where Helena Carley, David Church, Harry Farmer and Charles Tallack spoke about the opportunities and challenges associated with implementing personalised prevention strategies in healthcare. It was a great day, and we're really looking forward to organising the next showcase.

**Rachel Horton**

Thank you, Susie. And just a couple of weeks after that, we held a day discussing newborn screening, reflecting on the challenges of balancing the benefits of extending screening for babies with rare conditions, with the involvement this requires from babies who do not stand to personally benefit – Anneke, what were your highlights from the day?

**Anneke Lucassen**

I thought this was a really interesting day where we brought together people with a wide range of perspectives. This is an area that's quite controversial in that there are some people who are very enthusiastic about expanding newborn screening so that babies can be tested for more conditions than are currently available in the UK. Yet others are concerned that we might start all sorts of new journeys for babies who have uncertain results, who might need to be followed up for quite a long time before the result is clear.

And what I thought was really interesting about the day was that we had a reasoned debate where people very much respected each other's views, and we found some common ground between these quite polarised views. So it made me think we need more of these sorts of dates, rather than relying on email or publications to try and thrash out the different perspectives.

**Rachel Horton**

Thanks so much Anneke, it was a great day and you can see the report from it on our website. In April, we held an event discussing the discovery of ReNU syndrome. This is a condition affecting development and learning which was first identified last year yet potentially impacts tens of thousands of families across the world.

Nicky Whiffin, who’s a former CPM JRF, very kindly joined us to talk about her research that led to this amazing discovery, and I think for me the highlight of the evening was a video that Sarah Wynn from Unique, the rare disease charity, shared, made by families living with ReNU syndrome, who were talking about what the diagnosis meant to them. And it was really moving, so many families had contributed to it and it really gave a sense of the scale and importance of the discovery. You can watch the video as part of Sarah’s talk on our website. And in Sarah’s talk it was also brilliant that she highlighted that it was Undiagnosed Children’s Day that week, and important to also remember the many people with a probable genetic condition for whom we’re still unable to make a genetic diagnosis.

Our next event was in May, when Ali Kay led a really creative and thought-provoking event called ‘Making it Personal’, a project using theatre to spark conversations around a couple’s experience of a *de novo* or new genetic diagnosis in their child, and their question: ‘could it happen again?’ Ali is kindly joining us to tell us more.

**Ali Kay**

Thank you so much for giving me an opportunity to talk about this project. It's definitely been an adventure, and what we wanted to achieve with this is really the true meaning of engagement, which is to get people to really connect emotionally and personally with the research that you're trying to communicate with them about.

When you're talking about genetic risk, it can feel really abstract to people, and ‘other’, and what we wanted to do, was to take our public on a journey of understanding as to what it *really* feels like to receive genetic risk information, and try and make decisions with that, work as a couple with that information. And there are sort of wider implications for all your other relationships, you know, for your own parents and friends, and how you then have to sort of redefine your normal, and your pathway forwards in deciding about whether you're going to have more children or not, and how you feel about that risk.

**Rachel Horton**

Thank you so much Ali. You can watch the ‘Making it Personal’ play via the CPM website, and I found it really moving and eye-opening, please do check it out.

In June, we held a really interesting afternoon aiming to start the conversation on the opportunities and challenges of rolling out new vaccines that aim to prevent cancer, and we’re going to hear from Sarah Briggs about that.

**Sarah Briggs**

Yeah, so this was a really fantastic afternoon, which brought together lots of different people. So we had clinicians, scientists, in terms of sort of oncologists and vaccine scientists, we had social scientists, patients and policy leaders and community representatives, and we all came together to talk about, really what it might mean to prevent cancer through vaccination.

And we had presentations covering the science of vaccination and sort of exploring where we are at the moment in terms of trials that are looking to prevent cancer in this way, and what the future might look like. And some really fantastic presentations from two patient representatives who really highlighted, you know, the potential for these new therapies to provide hope and options for patients who are often in very difficult circumstances. At the moment, these vaccines are being thought of in particularly in families who have high risk of cancer through genetic changes within the family. So these are people who already have a very high risk of cancer. But we also discussed the potential for these to be rolled out to a more general population, perhaps without that underlying high risk.

Another thing that came up a lot in the meeting was the importance of really developing these and talking about these, developing the way we talk about them, alongside patients and patient representatives, and the importance of building trust with patients as these new developments come through the sort of research and clinical pathway. And some of that was because of the challenges of the language around vaccines, particularly over recent years, but also the challenge of sort of implementing new approaches and new technologies with patients, and the need, really, to provide clarity and make sure people understand the purpose and the realities of what might be expected from a vaccine. So avoiding sort of overpromising on what might be possible.

But altogether, it was, yeah, a really fantastic day. Lots of voices in the room talking about lots of different aspects of some of the issues around developing preventive cancer vaccines and raising lots of issues for us all to be thinking about as these vaccines start to run into implementation and clinical trials.

**Rachel Horton**

Thank you, Sarah. And later that month, we had a fascinating afternoon thinking about how ethnicity is currently approached in genomic medicine, and how it might be reimagined for the future, and I’m really looking forward to hearing more about it from Nishtha Bharti.

**Nishtha Bharti**

Thanks, Rachel. So on 30th June, we brought together a panel of brilliant voices from across healthcare and policy to explore how various groups navigate the complex dynamics of ethnicity classifications in encounters within genomic medicine services. The panellists included Anneke Lucassen, Maxine Mackintosh, Zeshan Qureshi and Elizabeth Young, each bringing their unique perspectives to the table.

But here's what made this event really special for us. The panel reflected and responded to a set of co-created, forward-looking questions developed during a participatory workshop held earlier in the day with patient support groups and representatives. These participants discussed the limitations of current NHS ethnicity categories, which often fail to capture the sociocultural and historical aspects of patients’ identity. We organised a series of activities during the workshop to explore more nuanced, equitable approaches that integrate lived experience, social context, and biological ancestry. This event was our version of public switching, which aims to involve various interest holders early on so that they can help shape the direction of research and policy from the beginning.

**Rachel Horton**

Thanks Nishtha, such an interesting and imaginative way to explore a really pressing and challenging issue in personalised medicine.

These events and others kept us all pretty busy, and along with them we also held our two annual lectures, which are always such a highlight of the year. Anneke, please could you tell us more?

**Anneke Lucassen**

Our annual lecture in February was from Philip Ball, who talked about ‘how life works, dealing with biology's changing narrative’. This, I thought was a really thought-provoking and accessible lecture, talking about lots of complex ideas, and we had lots of feedback afterwards that this was one of our most accessible lectures to a wide-ranging audience. So Philip is a, I think he's a chemist by- and physicist- by background, and is a broadcaster and freelance writer. And he, in his lecture, challenged the very unhelpfully and perhaps simplistic ways in which we are often taught to think about genetic information, DNA, genes, and reflected on how we can access the benefits of medical care informed by genomic or genetic data without the risk of being blindsided by its limitations. For me this was a real highlight of the year.

And then we also had our annual Stanley Ho Medical Foundation lecture from Professor Peter Donnelly, who is one of the founding members of the CPM, and it was a real privilege to be at that lecture, because it was held in Hong Kong. It was my first trip to Hong Kong, which I thoroughly enjoyed. We were given a very warm welcome, and Peter talked about how polygenic risk scores might be utilised to help inform risk of common diseases.

**Rachel Horton**

Both those lectures are available on our website, and there’s loads on there from the past year, also including other events, like workshops on AI trustworthiness, and monogenic inflammatory bowel disease, so if you want to learn more about any of the events we’ve mentioned, please take a look because there will be videos and reports to explore.

And I also want to particularly highlight our ‘art and science connection’ page where you can see some of the amazing entries we received to this year’s art competition with a theme of ‘how personalised medicine affects our planet’. We’re running the competition again this year with a theme of ‘what does personalised medicine mean to you?’, so if you know any secondary school teachers or creative young people aged 11 to 13, please do let them know about it.

So that’s the round up from 2024-25. Anneke, what do we have to look forward to in the coming year?

**Anneke Lucassen**

Well, we're planning lots of activities, and some are more developed already than others. I'm really looking forward to a direct-to-consumer testing day that's going to look at lots of different aspects of various tests available direct to consumer and how this might affect pathways into healthcare, or change pathways into healthcare.

We also have an event coming up on how to achieve net zero in healthcare, that will be really interesting. We've got lots more work going on now on environmental impacts of personalising medicine, so that'll be a really good starter to explore that.

And we also have a confirmed annual lecturer for next year. We haven't got a date finalised yet, but I'm really looking forward to hearing from Professor Trish Greenhalgh at the University of Oxford about her wide-ranging work related to different ways of personalising medicine.

**Rachel Horton**

Thank you, it sounds like there’s loads to look forward to. Thank you so much for joining us to look back at 2024-25 – it’s been a great year for the CPM and we’re excited for the next one. Please follow us on social media or sign up to our mailing list to keep in touch and find out more.