



HOUSE OF LORDS

Science and Technology Committee

Corrected oral evidence: Innovation in the NHS: personalised medicine and AI

Tuesday 24 March 2026

11.45 am

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Members present: Lord Mair (The Chair); Lord Booth; Lord Duncan of Springbank; Baroness Jones of Whitchurch; Baroness Nicholson of Winterbourne; Lord Patel; Lord Ranger of Northwood; Lord Willis of Knaresborough; Lord Verjee; Lord Winston.

Evidence Session No. 6

Heard in Public

Questions 62 - 72

Witness

[I](#): Professor Anneke Lucassen.

USE OF THE TRANSCRIPT

1. This is an corrected transcript of evidence taken in public and webcast on www.parliamentlive.tv.

Examination of witness

Professor Anneke Lucassen.

Q62 The Chair: For the second session, we are very pleased to welcome Professor Anneke Lucassen, professor of genomic medicine and director of the Oxford University Centre for Personalised Medicine. Professor Lucassen is attending remotely.

The committee has heard from witnesses such as Sir Mark Caulfield and Dr Richard Scott of Genomics England about the excitement currently around genomics and AI to provide personalised medicine in the NHS. Could you tell us about your background in genomic medicine and where you feel that the field is right now? We are interested in areas where the gap between the promise and reality of genomic medicine is still large. What needs to be done in research and communication to address these issues?

Professor Anneke Lucassen: Thank you, and my apologies for not being there in person. I am a clinical academic working in genomic medicine at the University of Oxford and as a clinician in the NHS. The Centre for Personalised Medicine is a boundary-spanning space where researchers, clinicians, publics and patients test ideas against real-world realities. As Oxford University's academic champion for public and community engagement with research, my work sits at the interface of science, clinical practice, patient and public experience and the ethical, legal and social scientific aspects of personalised or personalising medicine.

I have been really interested listening to the evidence. The committee has heard much about genomic medicine and AI's diagnostic promise from previous witnesses. I want to start by drawing a distinction that is often missed or conflated, that of diagnosis versus prediction. To use a conveniently available analogy to draw that distinction, last week one of my household appliances broke. It was a complex, sealed unit. I found AI really useful in diagnosing what was wrong with the appliance. I described the symptoms, their sequence, the timing and what changed when I tested fixes. It gave me a very precise diagnosis of which component had failed. I could not have done that myself. The analogy here is that AI was looking at the genetic code of the appliance. However, I still needed to find a skilled technician to help me repair that appliance. I could not do that myself. That is diagnosis in genomic medicine—combining symptoms, tests, genomic and omic data to identify often rare disease causes. However, we still need clinicians to deliver the next steps.

Here is the pivot that is easy to miss. Had I asked AI, "Will this machine break and when will it break?", I would have got a vague and probabilistic answer at best. That is prediction. Using the genomic code in

healthy individuals to forecast which person will develop which disease and when, is much less good than using the genomic code in diagnosis.

I am not trying to say that there is no point in prediction, but the prediction here says something about a group or a population. We can predict which component of my machine is most likely to fail but not which individual machine will fail. We can improve our understanding of risk in populations, but we cannot perfectly predict which individual will develop a disease. Personalised or precision medicine—overlapping terms—works well in diagnosis but not so well in prediction. This distinction easily gets blurred by our language around genetics and DNA in all angles of society. We tend to talk about blueprints and instruction manuals, implying that genomes can predetermine health very clearly. In reality, genomic information is probabilistic, deeply context dependent and entwined with social and environmental factors. When we act as though the DNA blueprint can tell us exactly who will get ill and when, we set up unrealistic expectations for everyone and risk building policies on a scientific certainty that just does not exist.

Another conflation that you have heard about is between the use of genomics in rare disease and common diseases. I can go on and say a bit more about that but note for now that the NHS 10-year plan is rested on this prediction foundation, and screening with genetic scores for common diseases will have a much lower pick-up rate than diagnosing rare diseases in ill individuals.

Raising these concerns can sometimes be seen as a resistance to change or as being a bit of a naysayer, but it is important to note that scientific scepticism is not obstruction. It is the dual responsibility of the scientist to make new discoveries and to critically evaluate their real-world benefits when applied as tests or therapies. In publicly funded systems such as the NHS, where trade-offs are unavoidable, that really matters. Adopting technologies that work well in a diagnostic setting to predict and prevent, crowds out less glamorous, but proven, population-level measures that we already know do work.

Citing others, it is impossible to overrate the importance of context, yet we often overlook it when we come to DNA. In genomic medicine, that means recognising how much interpretation depends not just on the DNA sequence but on epigenetics, other omics, a person's age, their ancestry, their environment, their health status and social circumstances. Without that context, even the best science risks being misapplied or misunderstood.

The Chair: That was a most interesting introduction, thank you.

Q63 Lord Willis of Knaresborough: It certainly was. The ethical issues in genomic science and medicine are at the heart of the discussion today.

Our committee has heard about the potential for genomic medicine, but we have had less discussion about the potential ethical issues that it poses. You mentioned this in your introduction, but can you give us an

overview, with some examples, of the kind of practical ethical issues that are presented by the technology as it is used in clinical practice at the moment, and some of the ethical issues under debate? I am concerned from the last discussions we had about material that becomes available not only in the United Kingdom but throughout the world if we are going to make it effective.

Professor Anneke Lucassen: First, we need to be careful, when thinking about what ethical issues to consider, that we are not adopting a techno-optimistic stance around the technology, because that means we will miss some of the nuances.

However, to answer your questions more directly, lots of ethical issues arise in practice in the application of big data, including genomic medicine. For example, Ensuring consent is appropriate for these longitudinal long-standing endeavours. consent context is important; if we go into hospital and consent to have our appendix removed, for example, that is a different type of consent. We risk doing consent an injustice by trying to make it the same beast for something very complex, nuanced and ongoing that may involve others, like family members, alongside ourselves. Relatedly, confidentiality is a really important ethical issue. Since a genetic test of one person may reveal information about their close relatives, the concepts of confidentiality are often slightly different in genetics from what they might be in more routine individually based medicine.

You have already heard about trust. I would accompany that with trustworthiness. It is very easy to lose trust, so we need to think carefully about what happens when trust disappears. That can happen quickly, as we know: in things like vaccine debates, something can go from being very acceptable to groups to unacceptable quite quickly.

Rather than going on and making a long list, I will just also mention equity and diversity. We have heard a lot about how this technology might exacerbate inequities because it is more available to affluent members of society, but also it is trained more on people of northern European ancestry so our understanding of genomic information is enormously skewed, and that's not getting any better. That affects for example, risk scores. Looking at the genome to predict ill health works less well in people of ancestries that are not northern European. That is another important factor.

Lord Willis of Knaresborough: Who would decide ethical consideration? Who should be responsible for that?

Professor Anneke Lucassen: A team should be responsible.

Lord Willis of Knaresborough: Should it be set up by the Government? Should it be government policy or should it merely come through the situation that you work in?

Professor Anneke Lucassen: Recognising context as infrastructure, thinking about team science and lots of boundary spanning—all the people that you have heard from coming together and talking about how these ethical issues pertain to their work—would be a big step forward, and a recommendation from the Government to do so would be, from my perspective, really welcome.

Lord Willis of Knaresborough: When I was working for the Nursing and Midwifery Council, which I found incredibly difficult and challenging, it was amazing to see that a significant number of West Indian women were either dying with their babies or dying themselves. When we came to discuss that, we were told, “Everybody has to be treated the same way”. That is why I think about ethical procedures, and it is difficult for this committee to make a decision unless we are very clearly told by people like you what we should be doing.

Professor Anneke Lucassen: That is a really good example. That lack of equity is rife in healthcare in general, but in genomics, as well as in AI, there is the extra issue of us understanding the genetic code of certain ancestral groups less well, so they are already disinvested in the new technologies and will remain so, because those technologies do not apply to them since we have less understanding of the variation within them. There is a problem there that is not going away any time soon. Lots of people talk about improving diversity, but that has been very difficult to do. Despite the calls to do so for the last 10 to 15 years, there has been very little progress in improving diversity in genomics. Do not get me wrong; there has been some progress, but, because of the vast repertoire of genomes from people of northern European ancestry, there remains a skewing that needs urgent attention.

Q64 **Baroness Jones of Whitchurch:** Professor, I was very taken with your distinction between diagnosis and prediction. I am grappling with how we apply that to preventative care. I am assuming that, in your analysis, the plans to have a universal genome sequence for babies would be labelled diagnosis, whereas if we did a nationwide screening or measurement of genetics then that would fall into your prediction category. Surely there must be good opportunities here for the prevention of disease or treating it at an earlier stage. Where are the advantages and the disadvantages? What are the ethical questions about the genetic testing of every child, who obviously cannot give their consent so other people are giving their consent for them? Give us an idea of where you think it is going to be helpful in prevention.

Professor Anneke Lucassen: Prevention relies on prediction, and that is where my analogy could be useful. In the optimistic discourses around DNA—shiny double helixes and the clear-cut messages that we get from school days, Mendel’s peas and so on—it is tempting to think that if we know our genetic code then we will be able to diagnose earlier and therefore prevent. Actually, I argue that the number of times that that is possible is very limited, but it is not seen that way because of the very optimistic narratives, particularly around DNA.

I know that the Generation Study is researching this, but I argue that in a finite system such as the NHS we might be better off limiting our resources to diagnosing already ill children in neonatal care, for example, where the diagnostic rate through genomics can be as high as 80%. That might be a better focus of rather limited resources than screening every single child, of whom 99.9% will receive a normal result, while we do not know whether the percentage who get a screen-positive result will definitely go on to develop the disease in question. That is because our knowledge about such screening comes entirely from the diagnostic setting, so we are screening for diseases where we have no screen information. We know that these genes might be wrong in children who present with a particular disease, but it does not necessarily follow that if you look for those genes then all those children will go on to develop the disease. That is a conflation that we easily make through these optimistic narratives around DNA.

The ethical issue here is that—in our laudable endeavours to reduce the diagnostic odyssey, as Professor Sir Mark Caulfield highlighted, which have been years long in the past—we might set up a whole load of predictive odysseys where we follow up healthy children who screen positive but do not go on to develop the disease in question, but need to be followed up for a significant amount of time to make sure that they do not. Those predictive odysseys will take up a lot of finite resources.

Baroness Jones of Whitchurch: I am learning here, so I am listening carefully to what you are saying. I thought that if we did a genetic profile then you would be able to tell at an early stage if someone might get a specific disease—dementia, say, in later life—and maybe take some preventative action. You are saying that that would not apply very often. Am I understanding that right?

Professor Anneke Lucassen: Yes, I am saying that. The few examples we have where you could reliably predict that early are much less common than popular discourse might lead us to expect. If I were a parent about to give birth and I was invited to join the Generation Study, I might well think that being offered screening for 200-plus diseases was better than being screened for nine—that is what we currently have through the heel prick test—but I would want a bit more information around that, because a lot of those 200-plus diseases are so rare that they are unlikely to be picked up in the Generation Study since they affect fewer than one in 100,000 children. For a lot of them, we have no information on whether that particular genetic variant reliably predicts the disease in question.

We have very little evidence for that sort of situation. There is some from the US, paradoxically perhaps, where screening for a rare condition has taken place over the last 20 years or so. Genetic testing was thought to be a reliable predictor of a particular disease, but the data so far suggests that the positive predictive value of the screening test, rather than the diagnostic test, is in the order of 1% to 5%, meaning that if you test positive for that gene then there is still a 95% chance of not developing

the disease in question. However, a lot of those children are being followed up over years because they might still develop some symptoms.

It is so easy to be tempted to move from diagnosis using genomics to thinking, "Then it must also be useful to predict things". I go back to my analogy and say that on a population level it is really interesting to look at particular populations and see whether this population is more likely to develop this or that disease, but giving individuals personalised or precision medicine is much more difficult in the predictive setting than in the diagnostic setting.

Lord Patel: Which disease were you talking about when you said that 1% to 5% were picked up through screening?

Professor Anneke Lucassen: The positive predictive value?¹ I was talking about a rare disease called Krabbe disease, which is not on the Generation Study list—for that reason, I suspect—but is one of the very few diseases where we have some screening information. We have very little of that for other conditions.

Lord Patel: The important question is what you just commented on. The Government's ambition in the 10-year plan is to use genome sequencing as a way of promoting preventative medicine. You said that it is good at identifying population risks, which I accept, but not individual risk. Still, through the identification of a population risk, let us say of diabetes, you can then develop methodologies for developing preventative measures in an individual who is identified as higher-risk. Or am I talking rubbish?

Professor Anneke Lucassen: You are not talking rubbish at all. That is right, and I understand that aim, but there are a few points here. Common diseases have a genetic component to them, but they are not usually the majority component. On average, diabetes and those sorts of common diseases would have a genetic component of between 20% and 40%. When you are measuring the genetic risk factors, all you can talk about is that component; you cannot say anything about environmental or other components of that risk.

However, you can say that, in a population within that genetic predisposition, some people have manifold higher risk than other people, but that relative risk usually translates into very modest absolute risks. I might find through a polygenic risk score that my risk of, let us say, breast cancer has gone from a population risk of 15% to 17%. How useful that is for me as an individual is, I would say, debatable, because a 1% to 2% difference in absolute terms does not really allow me to take any preventative measures that are not already sensible precautions. Professor Mark Caulfield said, "Why wouldn't we take these preventative measures?" However, most of the preventative measures available for these conditions are common-sense measures: drink less alcohol, do not

¹ The witness has clarified that the positive predictive value (not the pick-up rate) was in the order of 1% to 5%.

smoke, do not be obese. We could apply that to the whole population; we do not need a risk score to identify that.

Lord Patel: So that component of the Government's 10-year health plan—using genomic sequences to develop a preventative medicine strategy—is false?

Professor Anneke Lucassen: Yes. It is based on a techno-optimistic narrative that does not play out in real life. Look at the risk scores for things like diabetes. Across the board: these scores will have a 10% to 20% pick-up rate, meaning that most of the disease will still occur in people who do not have a high risk score. So we still have to keep looking at those people and to keep advising the majority of the population about preventative measures that cannot be determined by their risk score.

The Chair: Lord Patel, did you want to ask about the leakage of data?

Q65 **Lord Patel:** I will come on to my main question. This inquiry focuses on the importance and value of genomic and health data—both combined, not just genomic data. There is a tension between our ambition to use this data for improving healthcare and the commercialisation of it, but we need the commercialisation because of their expertise, and that produces a tension in the trust that the public may have. The second part of the question is about the trust the public may have, particularly when there is the possibility of a data leak. Although it was not very personalised, there was a data leak from BioBank, as you well know. The third part of the question is related to the data that we collect through government funding—or NHS funding, whatever. If we engage with commercial institutions then they benefit from it, both financially and from using the data for other things such as drug discovery. That is another tension. What would be your advice as to how those different tensions could be managed, particularly the public trust issue?

Professor Anneke Lucassen: That is a really important question with no single easy answer. I would say that the so-called BioBank leak, although I do not think it was really a leak—

Lord Patel: It was code.

Professor Anneke Lucassen: It contained the possibility of triangulating with other data, such as social media data, to identify someone who was a participant in UK Biobank, and I would say that is different from data being released and pasted all over for example, a tabloid newspaper. I agree, we need to think about the context in which a leak might lead to trust being undermined.

While I was chair of the UK BioBank ethics advisory committee, we did some interesting work with UK BioBank participants that was more focused on the issue of consent, but that plays into your question. The narrative is often about whether or not we have consent: if we do then everything else follows, and if we do not then the thing is stuck.

However, Biobank participants said they were not really interested in what the consent form said—indeed, many of them could not remember it because they had filled it in many years previously—but they wanted to trust the organisation to handle their data responsibly. So it was more about a process that they felt they were consenting to than a yes or no version of consent.

Patients are often more nuanced in their views about what can and cannot happen with their data than we might think. Some of our focus group work has highlighted that people are happy to understand that, for the NHS to work well, it needs to be based on the best available evidence, and it therefore needs to engage with research in an ongoing learning way, and we need to inhabit that hybrid space between the clinic and research in a much more effective way. On the whole, patients and the public are on board with that, but I would add that we rarely get at the nuances of patient and public understanding because we tend to ask once, in a survey way, “Would you like your baby screened? Do you see any problems with that?”, and then we take their initial enthusiasm as the answer, but people have complex and nuanced evolution in their thinking about these long-term endeavours. We have seen in the 100,000 Genomes project that, after two, three or four years, people who gave their consent at the initial stages feel quite differently; they are not necessarily for or against it, but their views have evolved over time. I am highlighting that consent is a complex beast here, and it is tightly woven with trust and trustworthiness.

Lord Patel: I want to take you back to my other question about the relationship with commercial organisations because you are sharing data with them. What advice or lessons learned could be given to the Our Future Health organisation and the Health Data Research centre that has now been set up?

Professor Anneke Lucassen: As someone interested in ethics, I am never invited to be a commercial spin-out. The sorts of subjects that interest me are not commercially exploitable. However, as we improve the hybrid space between clinical practice and research, now with commercial entities, the Government need to be enthusiastic about that triangulation and about potential miscommunications and conflicts of interest. If you are a commercial company trying to make a profit, how might that influence how you talk about your technology to the NHS? How might we all be subject to those techno-optimistic narratives that risk destabilising this really important conversation?

The Chair: On the same subject, commercial partnerships, there is a concern that that there is a risk that datasets and assets generated by UK government funding may not ultimately benefit the UK but will pass to commercial organisations, notably in the US. Does that affect your point of view, or do you think it does not really make much difference whether it is the US or the UK?

Professor Anneke Lucassen: Those national boundaries are incredibly difficult to impose on data, in the same way that, during the Covid pandemic, it was really difficult to stop the disease spreading globally quite quickly because our set-ups are global. I will say with my clinical hat on that we have seen the effects of direct-to-consumer genetic testing giving very misleading results in certain situations. That is getting better, but it has imposed a significant burden on the NHS, which is left to pick up the pieces. There, the link between commercial exploitation and clinical data did not favour the NHS.

The Chair: Do you think it is unrealistic to suppose that the NHS and Genomics England should somehow restrict where the data gets released to, or is that unrealistic?

Professor Anneke Lucassen: I am sure it is possible, but this would not help us very much in addressing the urgent ancestral skews that we have in genomics. We really need global collections of genomes to understand better what variation matters in what population. If we restrict our developments just to the UK population, although it is much more diverse than it was just 20 or 30 years ago, it is still very skewed towards the white population. The UK BioBank population itself is, I think, 96% white. Just studying that population will never tell us more about the variations that exist in other populations.

Baroness Nicholson of Winterbourne: Professor, in your experience, is the UK definition of responsible data handling still within the context of the World Health Organization set of rules? Given that the USA has left the WHO, does that impact negatively or positively upon the use of our data?

Professor Anneke Lucassen: That is a really interesting question. I can see problems but I do not know whether the overall effect is positive or negative. I go back to data being a valuable commodity but, in order to interpret it, we need the context that goes along with it. It is not necessarily true that more is better. Knowing the context in which that data was collected is what will be really important in its usage.

Q66 **Lord Ranger of Northwood:** Professor Lucassen, it is becoming clear you are obviously thinking extremely deeply about this and considering it very carefully. Obviously there is the conversation about big data, but there is also a thread in our inquiry about the role of AI and providing better analysis of genomic data towards personalised medicine. That is where you focus in on the individual, and again we get to the conversation about ethical implications involving consent and where that can lead, and how that personalised data could then be used. What safeguards should be required or considered to put in place around data that is highly personalised—there is a certain value for personalised medicine—and how that would then be used in the training of AI?

Professor Anneke Lucassen: First, what do we mean by highly personalised data? When it comes to genomics, all of us are 99.9% identical in our genomic code. We all have around 4 million to 5 million

different variants in our code and around 100,000 rare variants. Importantly, we all have about 50 variants that have at one time in the literature been described as disease-causing, yet we are of an age to know that we are not going to develop that disease.

So we know that there is quite a lot of redundancy in the genetic code. I know that the narrative about DNA is that it is you yourself and it is highly personal, but I question what we mean by that sometimes, particularly because we share so much rather than differ so much. Sorry, I have slightly lost track of my answer.

Lord Ranger of Northwood: That is all right. Maybe I can add this point. You are quite right that it is personalised but there is still some breadth there. However, it is more about how that personalised view may potentially be used by others. The first place that I tend to go, as a non-medical person, is to the world of insurance and how this highly personalised information can then be used in that world, where range will be important rather than individual data. The more of that information you get, the more it can be utilised in modelling, cost and so on. There are concerns around that. How do we use that when we have such a powerful view that can be provided?

Professor Anneke Lucassen: Insurance is a really good example. There are long-standing concerns about how we might use our genetic codes to help the insurance industry to differentiate premiums. In the UK, we have had a long-standing code of practice since 1990—a moratorium at first—about not using genetic information to affect insurance premiums.

To go back to earlier points, there are very few cases where your genetic code will predict something clearly in an adult that they do not yet have signs or symptoms of. One classic example is Huntington's disease, but that is a rare condition. There are very few other cases like that where your genetic code will be able to predict, in a currently healthy adult, that at some point in the future you will be more likely to cash in your insurance. Actuarial underwriting will be very dependent on population-level information but less so on personalised information, because that personalised information will be diagnostic information rather than predictive information, and insurance companies are already allowed to access clinical diagnoses. The predictive element is the only thing that the insurance industry might want to get hold of, but it will be very rare that it can get hold of strong predictions for individuals. The data might tell us about populations but not individuals.

Lord Ranger of Northwood: I understand what you are saying, and it is a wonderful way for a medical professional to present it, but I still have questions about the population data. Even now, when we are quizzed by our GP about the amount of alcohol we have, say, or how much we smoke in order to make an assessment, there is still some personalised data that is overlaid with the population data to give an answer, and I would say that a commercial model might take that and make an assessment from it.

Professor Anneke Lucassen: Absolutely. Their genomic data is just another form of data. What is probably more worrying is whether my data about my weight, my alcohol consumption or my social circumstances is released, rather than my genomic data. I would see genomic information as an important part of the information that needs to be kept private and that we need to have appropriate controls on. We often think of it as different because we have these very positive narratives around genomics but really, in a way, it is a bit like saying, "What's your haemoglobin count?" but in a slightly more detailed way.

Q67 **Lord Willis of Knaresborough:** I am quite pleased that this is happening when you get into your 80s and you have every disease there is. Another significant area of interest is around the possible uses of clinical prediction AI models to help physicians with decision-making. That is the next big issue. What safeguards do you think need to be in place before AI tools make or inform clinical decisions based on patients' genomic data?

Professor Anneke Lucassen: AI tools are already used. Again, we need to draw a distinction between describing a set of symptoms and data that was already collected on someone who is looking for a diagnosis. There, I think AI is really useful. When it comes to taking a healthy person and asking AI to predict what chances they have of developing a particular disease, that is much less using genomics, and it is much less likely to lead to a useful, personalised medicine. It will be a useful research tool to look at populations, but for individuals it will always remain limited. We are talking about diseases that have many other risk factors attached to them. For example, people's postcode in early life can sometimes be as predictive as a genetic risk score in terms of developing particular diseases, yet we do not worry so much about the use of AI in looking at postcodes as we do in looking at genomic codes.

Lord Willis of Knaresborough: Is it not the situation that when babies are born, with the use of AI, we ought to be able to use considerably more initiatives in order to present a code that will last them for a great period of time? We do not do that.

Professor Anneke Lucassen: Could you just reframe that? What sort of code do you mean?

Lord Willis of Knaresborough: Whatever code is necessary to be able to look at how they may or may not need activity and stuff later on in their lives.

Professor Anneke Lucassen: The ability of our genetic code to predict something, with or without AI, is much more limited than we might think. We are living in a society that has enormous techno-optimism but also sees genetics as very clear-cut, when actually it is hugely context dependent. We need to have a really low threshold for investigating the genomes of children who have signs and symptoms of disease much earlier than we have been used to when genetic testing was offered at the end of a three or four-year odyssey. We need to get straight in there

and use genetics to help to decipher their symptoms. But the genomic code of a healthy baby without any signs or symptoms will be much more limited in predicting what is going to happen to them in future than many people think. I go back to my domestic appliance analogy: we can say that these domestic appliances fail 5% of the time, but we cannot say when it is going to happen or which appliance it is going to happen to. Exactly the same is true for healthy babies.

Q68 Lord Duncan of Springbank: I want to touch upon the concept of consent, public engagement and the role of Government. I am struck by the way that consent currently works in the area of our internet usage, GDPR and so on, where consent is quite often a box we tick and think no more about it. You said earlier that consent is an evolving reality where the beginning of the journey, the staging posts along the way and the end are actually quite different. As this progresses how do you anticipate a Government inspiring public confidence within the consent framework? What would they need to be able to do to allow an individual or a parent to have the confidence that their consent was being respected and tested? I am also quite conscious of the difference between privacy and ownership—the notion that you can maintain privacy but not necessarily own certain types of data—and trying to put all that together with purpose into a government approach. There is a lot in there, but that is the question.

Professor Anneke Lucassen: Your point about consent is so important. When we tick a box signing up to Google, or whatever it is that we tick lots of times a day, that is not really consent. It is permission at best, but I argue that it is not consent. Informedness, understanding and voluntariness are all missing from those tick-box approaches. We need to see consent as one of the ethical issues that are really important in ventures like this, but not to treat consent in the way that we might have done in the past. Has this patient consented? Yes/no. Have they signed a form? Yes/no. That is not as important as taking patients and the public with us on a journey.

We talk a lot about good science communication. That is really important, but different from longitudinal public patient engagement on issues like this, because people change their mind or their views evolve and become much more nuanced than that initial yes/no tick box. We had some interesting research in the 100,000 Genomes project that showed that people did not remember which boxes they had ticked. When they thought that they had remembered, they remembered it wrongly. The important thing was that they did not mind because they trusted the process and wanted to engage with it, yet they could not remember what boxes they ticked.

We need to move from a “consent as a tick box” approach to something much more nuanced that is integrated with other ethical issues and is not a standalone yes/no toggle of, “I have got consent so therefore ethics is ticked—on we go”.

Lord Duncan of Springbank: In my head, the concern is the tension

between the medical profession, which might like it to be a tick-box exercise, retaining the permissions throughout the entire journey, versus the ongoing information required by the individual to understand each stage of the journey and then be retested on their consent at each of the necessary stages. I can see there being a strong tension between medical ambition and individual permission.

Professor Anneke Lucassen: A lot of medical professionals who want that signature on a form may be acting from a defensive position in thinking that a signature will cover them. That may exist a lot of the time, but if we have an ongoing relationship with patients—which is less common with more and more cuts in NHS services—we feel less reliant on those forms and signatures. I would argue very strongly that we should not be moving towards a model where we ask for consent to reconsent and keep sending forms and asking for more tick boxes. That is not the model that I am proposing.

I am proposing that we have much more of an ongoing dialogue with participants, patients, publics, whatever the venture is, to say, “This is where we are now, this is where the governance of this particular venture is, please let us know your thoughts about it”. Some patients will want to know a lot. Some will want to know very little. We need to be able to adapt those things and not see it so much as a medico-legal venture but as a part of an ongoing relationship.

Q69 **Lord Patel:** I have a challenging question. The summary of what we heard suggests that you do not think that there is any part that genomics can play in either preventative health care or a predictive aspect of a disease in an individual. In terms of personalised medicine, what aspect of genomics can play a part?

Professor Anneke Lucassen: I am not against genomics at all. I am a professor of genomic medicine. Genomics plays an important part in early diagnosis, when someone has got signs and symptoms, and in the prevention of advanced disease—prevention as part of developing diagnoses. It has much less of a part to play than we might think in predictions in healthy individuals, because predictions in healthy individuals work well at the population level and not at the individual level. It is the conflation between diagnosis and prediction that lands us in that difficulty.

Q70 **Baroness Nicholson of Winterbourne:** Given that it is impossible for any big database to be inaccessible from outside by somebody, would it not be more sensible to have small databases of individuals who agree that although best efforts will be made, certainty of inaccessibility will not be guaranteed?

Professor Anneke Lucassen: Yes, there is a really strong argument for that in some situations. I agree that more is not always better. We strive for these massive databases and want more and more data to feed better and better algorithms. That is not necessarily the right way to go. It will be sometimes, but at other times having small databases with a very rich context around them will be more useful. That is important for

Government to consider. Sometimes less is more with good context applied.

- Q71 **Lord Winston:** Thank you very much for a golden session. It is much appreciated. You were sitting in on the previous session and people from the catapults were suggesting that we should take more risk, not less. Would you like to comment on that?

Professor Anneke Lucassen: I cannot comment on their particular areas of risk. We need to take more risks but think carefully about the foundations of that risk-taking venture. I agree that having a one-year process to get ethics review of your particular research study is not helping research. We need to get better at those situations. However, being risky on a foundation that makes a wrong assumption about the power of AI and genomics in a particular situation will not be helpful either. We need a much better look at the foundations of where we want to take those risk endeavours, but they are necessary. For innovation, we need to be risky but ensure that developments in healthcare are based on the best available evidence and not just, "Well, let's see what happens. This is a risky venture, so we'll see what comes out of it". At the risk of sounding like a techno-sceptic, organisations and institutions such as NICE and the UK National Screening Committee exist for a reason. We need to use them to make sure that the risk is appropriately contextualised, rather than see them as blocking progress.

- Q72 **Lord Verjee:** Thank you very much, Professor, for a really interesting session. We have covered a lot, but our inquiry will ultimately result in a report that makes conclusions and recommendations to the Government about how more effectively to deploy personalised medicine in AI in the NHS. What would be your top priorities and recommendations for the Government to ensure that these technologies can benefit the most patients in an ethical and responsible way?

Professor Anneke Lucassen: I repeat that we need to be careful not to conflate various bits of evidence. We need rigour before adoption and not so much techno-optimism. Personalised medicine works well for individual-level diagnoses but less well for prediction of common diseases, particularly in healthy adults.

My other recommendation would be to think much more about context as infrastructure. Rather than technology as infrastructure, we need context. We need an approach to engagement of publics, patients and communities that goes beyond good science communication and is more slow-cooking rather than fast food—slow-cooked public engagement. Diversity needs more attention in that context setting, and consent is not the one-off tick box that we so often are tempted to think about it as.

My last recommendation is boundary-spanning capacity. Government could do well with getting heads together from lots of different areas. Team science is much talked about but difficult to enact, recognising the hybrid space that necessarily exists between clinical practice, research and commercial ventures. How do we make those interactions work more

effectively, moving beyond the technology to implementation and thinking about what the obstacles to that are and trying to remove them rather than obstruct progress.

The Chair: Professor Lucassen, you have been incredibly interesting. Thank you very much. We really enjoyed your domestic appliance analogy.

Professor Anneke Lucassen: Which I still have not got fixed.

The Chair: We are all speculating on what domestic appliance it might have been. We have learned a lot from you about the ethical issues and the issues of trust. Thank you very much indeed for coming to talk to the committee. We very much appreciate that.