HOUSE OF COMMONS

# Health and Social Care Committee

## Oral evidence: Pre-appointment hearing for the role of Chair of NICE, HC 175

Tuesday 10 March 2020

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Watch the meeting

Members present: Jeremy Hunt (Chair); Paul Bristow; Amy Callaghan; Rosie Cooper; Dr James Davies; Luke Evans; James Murray; Taiwo Owatemi; Dean Russell; and Laura Trott.

Questions 1 - 39

### Witness

I: Sharmila Nebhrajani OBE.

# Examination of witness

Witness: Sharmila Nebhrajani.

**Chair:** Welcome to this afternoon's session and a particularly warm welcome to Ms Nebhrajani. Thank you for coming along. I hope it does not look too intimidating having a whole panel of people here. We just want to have an open discussion. We are very aware that you won't know absolutely everything about NICE. We are a new Committee and we have lots of questions we would like to ask you, if we may. Before we start, Paul has some interests to declare.

**Paul Bristow:** I would just like to declare that my wife owns a communications consultancy that has clients that regularly deal with NICE.

Q1 **Chair:** Thank you. To kick things off, would it be possible for you to tell us a little bit about yourself and your background, and particularly the things in your background that are relevant to this potential new appointment?

***Sharmila Nebhrajani:*** Yes, of course. In my dim and distant background, I studied medical sciences at Oxford University, and medicine and science has been a very rich theme through all of my professional life.

I have built the mainstream of my career across the private sector at the BBC and in commercial activities in financial services. Alongside that, I have done a lot in the health sphere. I have served on the south coast, where I live, in the NHS as director of financial services and contracting. I was chief executive of the Association of Medical Research Charities, which represents almost every charity you will have heard of in the UK investing public money in medical research, and most recently I was a member of the management board of the Medical Research Council.

So I have a science and research interest; I have an NHS interest, although I am not an NHS career professional; and I have a background in the private sector, the public sector and charities. I am hoping that bringing the threads of those things together will enable me, if appointed, to be an effective chair of NICE.

Q2 **Chair:** Thank you. What did you learn as chair of the Human Tissue Authority?

***Sharmila Nebhrajani:*** It was a very interesting role, not least because at that time the Welsh legislation for deemed consent had just passed for organ donation; that is coming in in England shortly. For me, as chair of that arm's length body, I realised I had a broad set of roles: to provide leadership to the organisation, which was essentially a regulator, regulating storage of research and materials, and regulating live organ donation. It can sound like quite a scientific process, but the thing that I learned through that experience was that such an organisation, which has

come out of a controversy with the challenges in Alder Hey and the retention of tissue without consent, had at its heart patients and the public's interest, and the public's feelings about tissue.

One can approach these sorts of organisations purely as an intellectual activity, but when you are dealing with health you are dealing with people's lives; you are dealing with patients who have real visceral connections to the issues that you are dealing with. That was a big learning for me at the HTA.

Q3 **Chair:** There are going to be a lot of patients and patient groups who will feel very aggrieved that NICE has not recommended a particular medicine that may often be proved to cure their condition as being value for money. If you look at the history of Governments in this country of all political persuasions, who have often got things wrong in dealing with patients and their families, how will you approach that incredibly difficult issue of being seen to be the person who is playing God when it comes to medicines that people are desperate to access?

***Sharmila Nebhrajani:*** I think it is very challenging. The first thing I would say about that is one has to remember in all these sorts of cases, and NICE in particular, that we are dealing with real human issues that affect patients, families and loved ones. Approaching those situations with a degree of humanity and sympathy is very important.

The other side of that is trying to represent the role of NICE in balancing the interests of the broadest possible set of patients against finite budgets within the NHS. It is never easy to make those sorts of cases in the teeth of controversy. When you are called upon to explain a decision or maybe defend a decision, people are not listening to the framework. They are listening to the answer for a particular case. Therefore, an organisation such as NICE—and we did it also at the Human Tissue Authority—has to explain the principles by which it comes to its decisions early, repeatedly, and in a very open and transparent way so that people understand how decisions are made.

That is a quarter of the battle. Having to defend a decision that people find difficult or that patients do not agree with is a very emotional thing. I think being true to the transparency principles and the open principles that NICE works with but still displaying a human heart is very important.

Q4 **Chair:** How accessible do you think you would make yourself as chair to those patient groups?

***Sharmila Nebhrajani:*** Very accessible, partly because you never win a battle by hiding, but also because it is the right thing to do; it is the humane thing to do. It is hard. I have done it in the Human Tissue Authority. On my board, I had patients whose loved ones had been affected by the Alder Hey scandal who felt the decisions that we were taking not only on an intellectual perspective but at a personal perspective. Heavens, that is the job we do. You cannot do it without

being human, being accessible and being prepared to take some of the emotional heat of those decisions through the role that you take. I do not know if that is a clear answer.

**Chair:** Thank you. Dean had a question on social care.

Q5 **Dean Russell:** You have an incredible CV and an incredible background. However, there is a gap around social care, or an in-depth knowledge of social care. Is there a risk that that makes you under-qualified for this particular role? I would be interested in your take on that.

***Sharmila Nebhrajani:*** Yes, of course. I said in my questionnaire that that is an area in which I am aware I have not had a huge amount of expertise. In my time as director of finance and contracting in the NHS south coast, many of the decisions we were working with there were abutting at the interface of health and social care: for example, decisions we had to take about very basic services such as toenail clipping services to prevent falls, and trading that off against mental health services in Lewes prison; and trading that off again against cardiology services in the hospital. Those sorts of decisions that we had to take as a management team very much abutted against some of the elements of social care.

At that point it was the transition of public health budgets going to local authorities, so I have a bit of an understanding of some of the issues facing directors of adult social care, but I am not an expert. One of the key things I have to do if I am appointed to this role is to get to grips with it, understand it and speak to people who are experts in that arena. I know it is on my priority list.

Q6 **Dean Russell:** Do you have a sense of what specific things you would do in the first three to six months to make sure that you get on top of that understanding? Obviously, it is a very important part of the role.

***Sharmila Nebhrajani:*** Indeed. The first thing is talking widely and meeting widely, for example, with the groupings of directors of adult social care and children's social care, and the Local Government Association; sitting in on NICE committees where they are debating around the guidance for social care; and working and spending time with patient groups and the public to understand how they experience health and social care, because we have this slightly arbitrary line between them, but in the end they are a continuum. Those are my first forays into it.

The second thing for me, coming at it with a scientific background, is that I am aware of the sources of evidence in thinking about medical interventions. I feel I need to read very widely around where the research is for social care interventions. I would be interested, if appointed, to make a roadshow around some of the providers of social care, both in the private and in the public sector, to understand how it feels to them. How do they use these guidelines? Can they use these

guidelines? What is the feedback of what has worked and what has not, to try to make sure that we are tackling some of the issues in that remit?

Q7 **Dean Russell:** Do you have a sense of what that "first 100 days" plan would be in terms of how you would make sure of that? You are going to be taking on a very full-on role. You are going to have lots of time pressures. How will you make sure that you create time and plan that in so that you can get on top of that part of the brief?

***Sharmila Nebhrajani:*** I will make time for it because it is the area I have already identified as an area of a gap for me, as you rightly identified. It will be one of the first things I will be sitting down with a team to work out. Let them direct me in the first instance to where they think I can learn quickest, but I have, as I think I said in my earlier remarks, the places to which I would like to go to see how it is working, how the guidelines are working and how it is working in practice.

Q8 **Chair:** I have a question about independence, because fundamental to NICE's success and its global recognition is the fact that it operates independently from Ministers, but at the same time, as I know from my own time at the Department of Health, you have to work with that Department. Are there any examples in your previous incarnations where you have had difficult moments where you have had to demonstrate independence from Ministers? How do you see yourself preserving that independence for NICE?

***Sharmila Nebhrajani:*** In my time at the Human Tissue Authority, we often had to have conversations with the Department and with the Minister, who was Jane Ellison at that time, about things that were not working well and there being an early warning system for problems that were going to happen in the system.

For example, one of the things that the Human Tissue Authority does is to inspect mortuary facilities, and it becomes an early warning indicator of when there is going to be a problem with mortuary capacity. It is a classic kind of Cinderella service in the health service. I had to go back to Department of Health colleagues with the issue we had uncovered—the fact that there were beginning to be pinch points around the country in mortuary capacity. It is slightly outside the HTA's remit. It is not part of our remit to do that, but we took that message back to Ministers and to Department colleagues to make them aware that something needed to change in that arena, both as to what we would do in the immediate term if there was a scarcity of mortuary capacity, but also what we could do in terms of advancing the case for capital and infrastructure that would enable hospitals to upgrade their mortuary facilities. That is an example.

I am acutely aware of the need to have an effective working relationship with the Department and an effective communication channel to Ministers, but to retain that independence. That is, after all, what an arm's length body is designed to do.

A second example might be in the field of live organ donation, when we were working with the Department of Health on the conditions required for an effective opt-out policy—a deemed consent policy—for live organ donation. We were working with colleagues to share what had happened in Wales and what the learnings might be from that for England. At that time there was quite a lot of ministerial interest and desire to see a deemed consent Bill happen in England, as will happen, but we were very clear as an organisation, and I was very clear in my conversations with the Minister and the Department of Health, that deemed consent was part of the problem. If you did not also have intensive care beds, if you did not have a proper public information campaign, you were not going to see what one wanted to see out of that, which was an increase in availability of organs. Those are two examples of that.

**Chair:** Thank you. Paul had some questions about the recruitment process.

Q9 **Paul Bristow:** How rigorous did you find the recruitment process?

***Sharmila Nebhrajani:*** Very rigorous. Would you like me to tell you about it?

**Paul Bristow:** Yes.

***Sharmila Nebhrajani:*** I had to prepare my CV and recruitment documentation. Then I had to prepare a presentation. I had quite a searching interview panel comprising Professor Chris Whitty, Sir John Bell and Stephen Powis. It was a very detailed conversation and I was glad of it, because in those sorts of conversations it is a dialogue. You learn quite a lot about the organisation you are putting yourself forward for.

Q10 **Paul Bristow:** What was the most difficult question you were asked?

***Sharmila Nebhrajani:*** Other than this one, the most difficult question I was asked was probably around the role of NICE in helping the NHS to transform. That is interesting, because NICE has a clear remit and a clear set of principles that it works to, but it works within the wider NHS system.

My response to that question was that if we see, as we do in the long-term plans, key objectives to improve innovation and the adoption of innovation in the health service, NICE is very well placed to do that, to work with colleagues in NHSE and NHSI to improve innovation. From my experience on the south coast, there is quite a big gap between what happens in the NHSE universe and what happens down on the ground when you are running a commissioning unit or, in those days, a PCT or a hospital. I was aware that there was some knitting to do between that ambition and delivering innovation at the coalface.

Q11 **Paul Bristow:** Do you think that is the same with NICE—that there is a difference between what they say publicly and what guidance they publish and the reality on the ground?

***Sharmila Nebhrajani:*** I do not think there is a gap in philosophy, but I do think there is a gap in making the guidance as useful as it can be. One thing I would like to achieve in my time as chair of NICE is to see that the guidelines process and the guidance formulation are made more useful to practitioners, be they doctors, nurses or those in the social care sector. That requires a different way of formulating guidance and it needs to be available at point of care, integrated in the clinical decision tools.

I was a NED, and still am a NED until I stand down, at the BMJ. That has a little MedTech business, and we have done a lot of work, in its product called Best Practice, about taking guidance and being able to layer it and refine it in a way that at the point of use, the doctor has guidance that he can use for the patient in front of him. There is that linkage still to make.

Q12 **Dr Luke Evans:** I am a GP by trade, so I am really interested. You have already moved into the section that I am most interested in. What are your thoughts on the CKS, how they come through and the impacts that they have?

***Sharmila Nebhrajani:*** The CKS?

**Dr Luke Evans:** The clinical summaries that NICE produces. For the benefit of the panel, NICE produces guidelines—there are about 330 out there—for practising doctors and nurses that we can follow. It is interesting that you mention how you join those dots up, because what NICE says in the guidelines is what I will prescribe and follow because that is the safest way to practise. What are your thoughts about where the shape of that educational clinical governance aspect goes?

***Sharmila Nebhrajani:*** There are two or three themes to that question. The first is about ensuring that the right topics are in the guidelines. The second is about how that data is updated and made absolutely current so that practitioners know they are dealing with things that are informed by the latest, most important evidence. The third is making sure that the information is useful at the point of consultation or at the point of intervention.

Q13 **Dr Luke Evans:** You are exactly right, and that is exactly where I was coming from: keeping it up to date, making sure it is relevant and accessible, and then making sure it is robust and you uphold that. You will be the chair, so you will be in charge of running that. Can you talk me through how you perceive that working? It may be that you use previous roles that you have had where you have done this. This is system-based stuff that has real tangible feelings down at the ground. Can you explain your thoughts on how you might achieve that from the top up but for someone like me, who interprets them?

***Sharmila Nebhrajani:*** I am not yet in NICE, so I will give you my view from the outside. There is a huge amount of guidance out there and there continues to be a plethora of data and evidence that could impact that guidance.

The first thing that NICE needs to do is to be clear about which elements of guidance need updating by priority. That is a non-trivial task when you think about the volume of evidence that is being produced around the world in these interventions. Using technology and AI, for example, may be good ways of trying to distil out the evidence that is most pertinent to the guidance that is being produced and get that virtuous circle of continuous updating.

The second thing is trying to get to a "write once, read many" principle. I did that during my time as chief operating officer at bbc.co.uk. Essentially, what you are trying to do is create a layered set of information that can be segmented so that it can be used for a variety of different products. Taking a trivial example to make the point, you may have guidance on how to take blood pressure. That might appear in many different guidelines that clinicians are using. You have got to write it once and be able to piece it together for a particular product that a clinician or healthcare professional is using in this setting. Using atomised content—that is the horrible jargon—and being able to atomise the content, and being able to re-establish a useful guideline for clinicians, which does not have too much extraneous detail for people to have to wade through when they are trying to make an intervention, is the second part of that.

The third part is making it usable with the clinical decision tools that a doctor or professional is using at that time. At BMJ Best Practice—you probably use it or have seen it—they have layers of different clear advice, with differential diagnoses and tests that can be done. Below that is the encyclopaedia of the NICE guideline. I think we could go further up that chain to make sure that the guidance that we are developing is genuinely useful at the point of care.

Q14 **Dr Luke Evans:** I agree with a lot of what you are saying and would like to translate this a little further. I appreciate you are not going to be writing the guidelines yourself, but there is an element of knowing your approach to risk when it comes to this.

Let me give a practical example. There is a drug called Entresto, which is great for heart failure. It was pushed through very quickly because the trial data was so fantastic. The difficulty we had was that two years later I had never even heard of it, as a GP, until I went to an update, and all the cardiologists were still getting information about it. That was two years lost on patients, when NICE had come through and clearly said that this was on the guidelines and we should be using it.

I have a question about how, first, you practically connect that up, and, secondly, the attitude to risk from the chair, because you are setting the tone. There is a balance to be set. We need to make sure we are safe and clinically robust, but at the same time on something like this, and indeed given the current coronavirus, et cetera, you might start saying, well, as trial data changes, at what level do we put that into guidance? That is something that the individual clinicians will give you guidance on, but it is still a strategic decision based on what you think, maybe, as the chair,

given the state of the committee. Have you given that any thought and could you talk me through that approach?

***Sharmila Nebhrajani:*** There is definitely risk in uncertainty, but there is also risk in doing nothing. One has to take a balanced approach to that sort of risk.

My answer in that particular sort of case would be that NICE is not responsible for testing that a drug is safe; that is MHRA's job. In NICE's case, to decide whether something is clinically effective—as well as, one assumes, in your case, cost-effective—we accept that we may be dealing with therapies where there is great uncertainty. The world does not behave like a randomised control trial. Being able to keep up to date with the evidence, and finding a clever way of making sure that the people who are using that data understand what we do not know as much as what we do know, will be part of the handling or part of the metadata that goes around those guidelines.

In some of the things that I have observed NICE doing in terms of managed access schemes, where the data is a bit uncertain and where they are trying to use real-life data about what is happening with patients in co-morbidities, for example, which you do not ever get from an RCT, it could be making sure that the data is available to clinicians so that we can make one judgment about risk but they are making the balanced judgment about risk for the patient in front of you.

Q15 **Dr Luke Evans:** That leads me neatly back to where I go all the way back out again. A lot of it is balancing QALYs—quality-adjusted life years—and how that fits in. What is your approach, as the chair? Do you see them as a valid way of judging medication use or is there a better measure that you might use?

***Sharmila Nebhrajani:*** As an outsider, I do not yet know what other methods would be used. Quite a lot of statistical research has gone on to look at QALYs and alternatives. My sense of it is that we do need a common language and a common vocabulary that underpins the decisions that NICE takes. It may be over time that there is some other mechanism, but we would have to think quite hard about the upsides and downsides of changing that mechanism. I am sure QALYs are not perfect, but being able to think about the cost-effectiveness in terms of the adjusted life year benefit gained against the existing treatment seems to me to be a very intellectually robust way of thinking and it is easily understood.

Q16 **Dr Luke Evans:** What do you see as your role in selling that to the public? I often feel the public do not understand the difficulties NICE faces. Do you see that as your role as chair, or are you saying, "No, it is a professional decision; get on with it", or do you see it as selling it to the public, or somewhere happily in the middle?

***Sharmila Nebhrajani:*** I do not know about the word "sell", but we absolutely have to explain our position to the public, otherwise we do not

have legitimacy. After all, the public are the patients and the public are the taxpayers. The sorts of conversations that I believe NICE ought to have, and I would have as chair, would be very much trying to explain the principles, explain the purpose, find a way to explain what a QALY is, so that we have some public legitimacy for the decisions that are being taken.

Q17 **Chair:** We have moved on to discussions about NICE itself and lots of people have questions they want to come in on. I want to follow up very briefly on Luke's question. At the moment, the threshold for QALYs is between £20,000 and £30,000. I do not want to ask you about any individual drugs, particularly as you have not yet taken up the role, but, broadly, is your sense that we are getting it right in the proportion of drugs that we are approving as being value for money and the proportion that we are rejecting?

***Sharmila Nebhrajani:*** It is a very tricky balance. Clearly, the QALYs at £20,000 to £30,000 are set with a reference point to the money that is available in the NHS budget. My instinct is that if the balance is right now, the pressures coming down the line in personalised medicine and drugs for small patient groupings are going to put significant and even greater pressure on QALY thresholds. That is going to be very tough. There already exist some modifiers to the QALY, for example, for end of life at 50k, on the HST pathway at 100k.

Over my tenure, if I am appointed, there is going to have to be some more conversation about that, because precision medicine is a huge boon to patients and it will give us the solutions for diseases where the disease burden is extraordinary, but their patient sizes will be small and therefore the cost could be high. We have to find a way—a sweet spot, if you like—of finding the right answer for the taxpayer or the patients, but also finding a way to fairly recompense the life sciences industry for the research that they put in and to incentivise them to invest for the future.

**Chair:** Thank you. Amy has a question.

Q18 **Amy Callaghan:** Do you believe that NICE needs to adapt the way it is traditionally operated to deal with funding and other pressures?

***Sharmila Nebhrajani:*** There is going to be significant pressure, and there are two sides to that question in my mind. The first side is the funding pressures that are going to be in the health service, which we have talked a bit about already, in terms of new technologies, new drugs and health inflation. We have a growing population; we have a growing ageing population; we have an ageing population with multi-morbidities; and we have people living longer lives with more drugs taken per person. There is going to be a lot of pressure in the system, and therefore the decisions that NICE takes about cost-effectiveness are going to come under greater pressure and greater scrutiny. That is one side of the costs pressure.

The other side of it, of course, is that NICE has a desire and ambition to continue to speed up its guideline provisions, to speed up its technology assessment, to do more and more with less and less. There will also be funding challenges within NICE the organisation as we seek to do more with the resources that we have. The answer there is that NICE will have to think very smartly about the use of technology to try to speed up the technology assessment process, the guideline formulation process, and some of the things we talked about with Dr Evans such as updating evidence and data. Those are the two sides.

Q19 **Amy Callaghan:** I know that another issue is incredibly emotive in my constituency. Vertex Pharmaceuticals argued that NICE's processes are outdated and not suitable for the appraisal of new therapies, specifically in relation to Orcambi and the availability of that. Do you believe that to be the case? I know you are coming into this role and it is not your job at present, but what are your thoughts on that?

***Sharmila Nebhrajani:*** I do not believe it is the case. NICE has to do a very difficult job of balancing some of the things that we have been talking about. Drugs such as Vertex are high-price drugs. It is very difficult to find a balance. NICE has an internationally renowned reputation, deservedly, for taking these difficult decisions with evidence using the experts.

Going back to my earlier remarks, we are going to see more of this sort of cost pressure because the drugs are getting more expensive.

Q20 **Amy Callaghan:** Do you think NICE could have handled the Orcambi situation better?

***Sharmila Nebhrajani:*** From the outside I do not observe that to be the case, but I do not know enough from the inside about how it was handled or how it could have been handled.

Going back to my remarks at the start of the meeting, there is the intellectual approach, the analytics, the evidence, all the rigour that goes into the decision, but these are also human decisions. Institutions like this that work in the health service also have to show a sympathetic and human side.

Q21 **Laura Trott:** Do you believe that NICE has made mistakes in the past?

***Sharmila Nebhrajani:*** That is a difficult question because I observe it only from the outside. If I were to think of things that needed to improve, my instinct is that the guideline process is incredibly rigorous and the evidence base is not quick. There is more to do to speed that up, bearing in mind the conversations that we had with Dr Evans about making sure that the guidance that is produced is really useful at the point of clinical consultation.

The other challenge in the future is one of horizon scanning and being able to see exactly what is coming down the road, not one year or two

years out but five years out. The best way that NICE can do that is by forming strong international linkages with co-thinkers to help to do that.

Q22 **Laura Trott:** Your priorities going in would be to speed up the processes and international linkages.

***Sharmila Nebhrajani:*** No. I was answering your question about areas for improvement. My priorities are probably fourfold.

The first is definitely to speed up and smooth the process of guideline formulation so that it can be future-proof. That has an evidence and a content angle, and it also has a technology angle in being able to make sure that guidance is atomised and is able to be managed in a sophisticated way so that it can be supportive to people making decisions and using them at the coalface.

The second priority for me will be to think about how NICE responds to developments in MedTech. Many of the interventions right now are predicated on a molecule or a medical device. It seems to be, certainly in the work I have done recently in global health, that many of the interventions are going to come in the future from an app. How does guidance change for an app? How do we assess the efficacy of an app? The companies that are developing them may not be pharmaceutical companies. They could be tech companies. They are not used to regulation in that way. There is a whole series of interventions, of new developments, that the NICE of the next generation will have to think about. I was reflecting on my way here on the train how many times my apps update on my Apple phone and the speed with which we need to think about how those interventions change will be a huge thing.

The third and final priority will be around supporting NHS transformation and properly being wired into the vanguards, and the adoption of innovations supporting NHSE and NHSI in that process.

Q23 **Laura Trott:** What do you think have been the barriers to NICE being able to do these things to date? You have mentioned funding before in terms of the speeding-up of processes. Is there anything else you think is standing in the way of NICE being able to do these things?

***Sharmila Nebhrajani:*** The difficulty is always that all organisations are busy, and NICE is no exception. Being able to identify what to stop doing to create some headspace to do new things will be quite a challenge. I do not yet know how I will do that because I am not yet there, but one of the first things as I work with the senior team will be to identify some headroom to take on some of those challenges. Some of the things I have talked about in terms of speeding up the assessment processes and the guideline processes will require technology, and that requires investment. It also requires a change programme, because people will need to work in different ways. Being able to keep the show on the road while trying to develop and do new things will be one way in which I will have to drive the organisation forward.

Q24 **Laura Trott:** Is there anything from your past experience that makes you think you will be able to lead that change effectively?

***Sharmila Nebhrajani:*** Yes. In my current role at Wilton Park, which is an Executive agency of the Foreign Office, I have introduced a change programme that has a technology aim to smooth the production of the policy work that we do, but it also has a cultural change programme so that, in a way, staff are totally embedded in the change process and are engines and owners of it. That is the only way to make that sort of change. The challenge has been, and the challenge will be the same in NICE, that if you are requiring people to do the day job as well as change, that is a non-trivial task.

**Chair:** Both Jameses, Taiwo and Paul want to come in on this section. I will start with James Davies.

Q25 **Dr James Davies:** Can I ask about the cancer drugs fund that was introduced in 2011? I know it initially came under quite a lot of criticism. It was re-hashed in 2016. Do you think it is effective in its current form?

***Sharmila Nebhrajani:*** Many patients have had access to expensive therapies because of the cancer drugs fund, and that has to be an advantage, a good thing. I have an anxiety that cancer, although a really significant and terrible disease, is one of many significant and terrible diseases. In my head, I have a feeling for the priority also of equity among the wider patient group to ensure that all patients can have access to the most innovative treatments at a cost-effective price. I do not have a criticism of the cancer drugs fund per se, but I do have in my mind that there are many other diseases that might warrant such intervention. I know the Government has a plan for an innovative medicines fund. It will be interesting to see, when the proposals come out, how that will work and what sort of drugs could be within its locus.

Q26 **Dr James Davies:** Clearly, the cancer drugs fund and everything that NICE does has such an impact not just in England but in other parts of the UK, and in fact worldwide. You talked before about international links. Do you think there is more of a role for the international community to influence NICE's work in terms of the enviable but responsible duty it has?

***Sharmila Nebhrajani:*** Yes. My reading and my observation from the outside and from the work that I have done in and around the health sector is that NICE is a kitemark of quality. That is worth quite a lot. It is worth quite a lot to pharmaceutical companies to have that imprimatur, and it is worth a lot in the health system.

The international thing has three dimensions. The first is horizon scanning. I know it is already working on an international partnership with Canada and Australia. In the new architecture of Europe, it is very important.

The other side of the international dimension is that many of the fastest research interventions are not coming from the usual suspects. They are coming from China, south-east Asia and, increasingly, India. There is a pivot to think of the international environment in the broadest sense.

The final point of your question was about whether NICE should learn from other organisations.

Q27 **Dr James Davies:** It was about whether they have an input into its work, really, rather than just a Department in the UK Government. Admittedly, the Department is paying for the work, but it has such a large influence across the world.

***Sharmila Nebhrajani:*** Health is a global game, so it would be nuts not to do that. As I understand it from the outside, NICE is already thinking about those interventions. Many of the most surprising and most interesting and challenging international linkages may not come from the usual suspects. Some work I have been doing in Wilton Park, for example, in global health, is looking at AI and technology in Africa, and colleagues around the Committee table may be aware of this. There are some incredible leapfrogging interventions happening in Africa. I saw one in Senegal where there is an AI mediator diabetes app, which will test your blood sugar level. You put in your insulin dosage, and in Ramadan it will tell you when you can eat and how much you can eat. That is gold dust. It is not in our sphere; it is not in the European sphere; but learning from those sorts of examples in the broader sense can only be good for the health system here and overseas.

Q28 **James Murray:** Thank you for your answers so far. There has been a question that has been touched on by other Members that I want to probe a little more on about how you think NICE is perceived by the general public.

***Sharmila Nebhrajani:*** I think that NICE is probably not well known by the general public. I answered that a little in my questionnaire. It is a very interesting question. It seems to me that NICE probably comes to public attention through the media in times of crisis—at the time of the Vertex case, for example, or other cases. That is never a good time to engage the public with what you do and why you do it. It is never a good time to explain the principles. It seems to me that there is an opportunity for NICE, and I am sure they are doing this already, to work hard to explain to the public why it does its work and how it does its work, and therefore gain public legitimacy for that work. There may be things that could be done, for example, in the citizens' assembly model that explain how NICE makes these trade-offs and why it makes those trade-offs.

In my earlier life I did some work on the citizens' meetings on mitochondrial donation. It sounds like a very esoteric bit of science, but when we took that out to the public they were incredibly engaged in the issue, they wanted to understand more about what mitochondrial donation was, and what were the risks of a three-parent baby so

described in the media. I found it a most engaging experience because you realise that the public has a strong intellectual interest in what you are doing for your day job. There is a real opportunity to take some of what NICE is trying to do to the public, partly because these are decisions on their behalf, and we should.

Q29 **James Murray:** That is a really important point. As a follow-up question and pushing it a bit further, citizens' assemblies are one way of involving the public. Putting that in a broader context, how should NICE involve patients and patient representatives? I guess you could broadly divide it—feel free to disagree with me; you may categorise it differently—into two different ways of engaging with patients. One is more in an emergency case when an issue flares up and you need to engage very rapidly. The other is more routine, calmly, when there is not a crisis present. How would you see the way of engaging with patients in those two different scenarios or, indeed, others if you think you would categorise them differently?

***Sharmila Nebhrajani:*** The answer is you have to do both. Where you are trying to defend a decision—the first of your categories—you are almost always in reactive mode. A situation is coming up where you are trying to defend a decision and you have to do that with all due openness, with transparency and with some humanity.

The other side of your question is what you do in the rhythm of the normal operation to involve patients and the public. When I was chief executive of the Association of Medical Research Charities, almost every charity in the UK, leaving aside the Wellcome Trust, gets its money because somebody puts a fiver in a tin outside Tesco. This is the public voting for medical research.

We thought hard about how to engage the public in the research agenda about research priorities and share what comes out of the money that they have donated. Citizens' juries or citizens' assemblies are one way of doing that. A proper online campaign, a social media campaign, is another way of doing that.

The final answer is involving patients and the public in the work that we do. I know that NICE has patient panels; it has patient representatives on some of its advisory work. My anxiety about that is that it is talking to people who are already in the system, albeit that they represent a patient interest. The bigger opportunity is people who are outside the system, not necessarily wearing their patient hat, but it would be useful for them to know about what NICE does and the trade-offs that it makes.

Q30 **James Murray:** I have one final question about the perception of NICE generally. You are an independent, arm's length, not ministerially run part of the general public sector. If a crisis did flare up and you had to deal with crisis management, how do you see your relationship with the Secretary of State playing out?

***Sharmila Nebhrajani:*** The first thing I have learned from my time at the Human Tissue Authority is that in the relationship with the Department, the Secretary of State and Ministers there should be no surprises. To try to make sure that everybody in the system is kept abreast of issues as they emerge so that people are not blindsided by an issue is very important. It depends on the issue, of course, but the answer to how you remain independent is by sticking to the principles by which NICE makes its decisions and defends its decisions, and being clear about the open and transparent nature of those and the criteria that are being adhered to, and being able to defend those in the locus of decisions that NICE has taken without stepping into the issues in the tray of the Department or the political process.

**Chair:** Taiwo has a question and Paul is going to ask about your priorities.

Q31 **Taiwo Owatemi:** Given the fact that drugs produced nowadays are rather expensive, how do you ensure that patients can access medicine at a socially affordable price?

***Sharmila Nebhrajani:*** That is the critical role of NICE in its technology assessment. There are two or three different factors in there. The first is that NICE will assess the clinical effectiveness of a drug and its cost-effectiveness against the QALY threshold. That is the beginning of a commercial negotiation that will take place between the manufacturer of the drug, NICE and NHS England. The new commercial framework—I think the consultation has just closed—sets out a very clear way in which that process can work.

The second thing to say is that the NHS is the biggest buyer of drugs in Europe. That is incredibly strong buying power in the negotiation with drugs companies. That will help to get some sort of commercial parity in the negotiations for price.

Thirdly, the UK is a reference market and NICE is a kitemark of quality, so the drugs companies will rightly see that having approval in a reference market with NICE's imprimatur is very valuable for their wider business.

I can see at the heart of your question that there is a tension between the profits-optimising objectives of the company and the value-for-money objective for NICE on behalf of the taxpayer. That is undoubtedly the case. My answer to that, in addition to the things I have said about buying power and the imprimatur, is that profit is a function of price and of volume. Being able to guarantee that where NICE recommends a treatment per the NHS Constitution, it will be adopted is a very helpful way of finding the sweet spot between a company's objectives for profit optimisation and the objectives of NICE, on behalf of the health service, for cost-effective drug pricing.

Q32 **Taiwo Owatemi:** Do you believe that, currently, the NHS and the

Government are involved in negotiating the price of drugs with pharmaceutical companies? Do you believe it would be more effective for NICE to directly negotiate that, and, if so, how do you imagine that to be done?

***Sharmila Nebhrajani:*** It is better that there is a separation between those things. NICE can take those decisions with robustness and rigour precisely because it is thinking about cost-effectiveness and clinical effectiveness and does not get into the territory that NHS England does, rightly, of negotiating drug prices.

The world is a grey place. It is not as binary as I have described it, and I think that NICE would recognise that it has a role to support the life sciences industry in bringing its best drugs to the NHS for adoption. Some things exist in the Office for Market Access and in the scientific panels that it has to try to smooth the process, to begin the dialogue early with life sciences companies so that the relationship that is built does not have to be adversarial; it can be a commercial negotiation without being adversarial. NICE has a very important role to play in smoothing access, because that is how you get drugs quicker to patients, but I do not think NICE should be involved in the commercial negotiations as NHS England is.

**Chair:** Finally, Paul.

Q33 **Paul Bristow:** I have a very simple question. Why do you want this job?

***Sharmila Nebhrajani:*** Well, I suppose, for three reasons. I am intensely interested in the subject matter, which is very engaging. For me, that is a very interesting and exciting opportunity.

The second thing is that it is a role that really matters. There are times in your life when you can do things that are really interesting and there are times in your life when you can do things that are really important. It seems to me that NICE is in the high-interest, high-importance box, so that in itself is hugely engaging and it would be an honour to serve.

The third thing is that I genuinely believe that my private sector credentials, my work in the NHS—although not being steeped in the NHS, being somewhat of an outsider—having been a NED and having been a chair mean that I can pull those threads together and be a successful leader of this organisation at a time when the challenges that we have talked about in terms of price, competition, the growth of medicines and the role of technology will require a broad set of variegated factors to be successful.

Q34 **Paul Bristow:** They often say that having someone from outside gives that wider perspective about what needs to be done. Do you think you can offer that?

***Sharmila Nebhrajani:*** I do think I can offer that. I can offer that in three dimensions: partly because I have worked within the NHS but I am

not steeped in it. That is helpful because I understand the vocabulary of the NHS. All sectors have their own vocabulary, so I can understand the vocabulary of that world.

Having worked in the commercial world for many years and in some of my NED work still in that arena, I understand from the life sciences perspective the profit optimisation issues and how to find a sweet spot in that.

The third thing is that organisations have their own cultures; different organisations have different cultures. Having come from the private sector, and having worked in NGOs in the charity space and latterly as a civil servant, I hope I will be able to bring together some cultural diversity as I take on the role.

Q35 **Paul Bristow:** Do you think NICE needs a change in culture?

***Sharmila Nebhrajani:*** NICE has had the most extraordinary stability. To have two chairs in its history and one chief executive is stability that one dreams of in other environments. I do not necessarily think that NICE needs a cultural change because of some problem in its past, but I do recognise that when a new leadership comes up, a new chair and a new chief executive almost simultaneously, there is going to be quite a feeling of grieving in the organisation. This is a huge change. It is going to require the senior leadership team and the chair to be sensitive to how to make this organisation respond to the challenges ahead with ambition and with confidence at a time when its founders, if you like, are leaving.

**Paul Bristow:** That was very well answered; thank you.

**Chair:** Thank you. Rosie, you have not asked anything yet. Do you want to say anything?

Q36 **Rosie Cooper:** Perhaps I could ask how you would make NICE more public-friendly. We have talked around it a lot and we have talked about reaching out to the public. How are you going to engage them and get their interest other than in a crisis? Why would anybody on the street think it matters?

***Sharmila Nebhrajani:*** It is a tricky question because we all think it matters, but it is very difficult to find the axis that makes it interesting to the public. Having said that that is the case, what I observe is that, going back to my mitochondrial donation example, the public are very interested in issues of health and science.

My observation from my other job is that they are interested in the intellectual thing. What is it that this thing does? What are you doing there? They are interested because it matters to them and their loved ones. We are definitely pushing at an open door as far as the public are concerned. The trick will be to find the question that is engaging them that matters. From my observation, you cannot do public engagement as a veneer. You have to have a meaningful question to go out to people

with, otherwise you are just promoting yourselves, and God knows there is enough of that in the world.

My answer to your question is that I do not quite know what the question will be, but if we can find a clear question that is important and interesting and engaging to the public, that would be a very good way to begin to explain and begin to involve them in the work that we do.

Finally, I would say that those sorts of engagements are dialogues. We need to listen. We may hear some stuff that we do not like and we will learn from that dialogue, so it is not just a one-way street.

Q37 **Rosie Cooper:** I have been hugely impressed by what I have heard so far. I just think you need to go where the public are—I hear that you get that—but it is about the mechanism and making that a friendly place to be. I think it is quite a difficult task.

***Sharmila Nebhrajani:*** Yes, it is. I do not underestimate it; it is tricky.

Q38 **Dean Russell:** Your background has been great. Looking three years ahead, when you are sitting in that seat and we say, "What have you achieved?", what would you want that answer to be in three years' time?

***Sharmila Nebhrajani:*** The first thing I would say is what I said to a point I made to Paul. This is an organisation that is going to go through unprecedented change in its internal incarnation. A new chair and a new chief executive is non-trivial for any organisation, but particularly with the history NICE has had. I hope in three years' time, if you are looking at me, I will be displaying to you an organisation that has weathered that change and has ambitiously, confidently and energetically pursued its new strategy and its new business plan—some of the things we have talked about today around technology, content management and guidelines.

If I am asked back, the second thing that I hope I will be able to demonstrate is that NICE has taken that role in facilitating innovation and adoption. It is the biggest challenge in the NHS, or one of the biggest challenges in the NHS. I certainly felt it when I was on the south coast. It is so hard to do the day job that it is very hard to carve out the time for the new thing. Sometimes the new things do not even permeate to you. If we have managed to accelerate the guideline process but also change it so that it is genuinely helpful to clinicians and in social care, informed by the latest research, then that will have been a huge win.

The third thing is the point I was making to Ms Trott about technology and AI, and beginning to see how technology is changing the way NICE works and the way in which it interfaces with the wider NHS.

**Dean Russell:** Thank you.

**Chair:** Are there any other final questions?

Q39 **Paul Bristow:** I have one final one. If someone came forward with a potential cure or vaccine for COVID-19, do you stand ready to rip up NICE's existing processes in terms of time to speed things through as quickly as possible?

***Sharmila Nebhrajani:*** That would be an example of the fastest of all managed access schemes. If you can save lives and speed it up, that is what you need to do.

**Chair:** Excellent. Thank you. You have given very helpful, very good and very informative answers, so we are very grateful for your time. If we do go on to recommend you for the role, we wish you every success in it.

***Sharmila Nebhrajani:*** Thank you so much. Thank you very much for your time.