HOUSE OF LORDS

Select Committee on Science and Technology

Corrected oral evidence: Life Sciences and the Industrial Strategy

Tuesday 21 November 2017

11.05 am

Watch the meeting

Members present: Lord Patel (The Chairman); Lord Borwick; Lord Fox; Lord Griffiths of Fforestfach; Lord Hunt of Chesterton; Lord Kakkar; Lord Mair; Lord Maxton; Baroness Neville-Jones; Lord Oxburgh; Lord Renfrew of Kaimsthorn; Lord Vallance of Tummel.

Evidence Session No. 18 Heard in Public Questions 153 – 159

Witnesses

Sir John Chisholm, Executive Chair, Genomics England; Professor Dame Ottoline Leyser, Fellow, Royal Society.

USE OF THE TRANSCRIPT

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Examination of witnesses

Sir John Chisholm and Professor Dame Ottoline Leyser.

Q153 **The Chairman:** Good morning, Sir John and Dame Ottoline—I hope I pronounced that name correctly.

Professor Dame Ottoline Leyser: It was pretty good.

The Chairman: It was pretty good. You will tell me the correct version, anyway.

Professor Dame Ottoline Leyser: It is Ottoline.

The Chairman: Thank you both for coming this morning to help us with our inquiry. Despite what you may have heard in the last session, our inquiry is mainly focused on the life sciences industrial strategy and Sir John Bell's report, and how that now might be taken forward. We want to explore with you the challenges and opportunities related to it—but mainly the challenges—and how we could contribute through this inquiry to addressing and mitigating some of those challenges.

Particularly in your case, it is about the data aspects of Genomics England and the data it will generate. One of the key issues in Sir John Bell's report is of course the wealth of information we can get from our health service and how that can be used more productively in driving some of the industrial strategy.

For the record, if you do not mind, could you introduce yourselves? I know who you are, but please introduce yourselves. If you want to make an opening statement, please do so. Dame Ottoline, I know your expertise is in a different branch of life sciences, but I would invite you to make a comment about industrial strategy that focuses mainly on the biomedical aspect of life sciences. Please feel free to comment on this particular strategy, the fact your particular area is not part of it and how that could be developed.

Sir John Chisholm: I am Sir John Chisholm, and I am executive chairman of Genomics England. I start by admitting that I am a long-term advocate of industrial strategy. It goes back to the late 1980s, when I found myself elected as the president of the then engineering trade association. We decided that our theme for that year would be the need for an industrial strategy. Indeed, I spoke to your previous witness on that subject at that time. It has always been my view that the Government are a huge player in the economy and they should be thoughtful about how to use that to increase the wealth and well-being of their people. That is something they can have a very beneficial effect on, as you can see in other nations.

What I will talk about today is a prime example of that. Nearly five years ago, the Government made what was then a very surprising commitment to do something extremely ambitious, which was to collect 100,000 genomes at a time when most of the collections were only a few hundred—this was two orders of magnitude further—and to link them

with routine health data coming out of the health system. This was incredibly ambitious. When I was asked to chair the venture that was put in charge of it, I spent the first couple of months or so going around the world and talking to all the major centres. I was told nearly everywhere that this was ludicrously ambitious, could certainly not be done for the money and was probably a step too far at that time, given the state of the technology.

The truth is that, as a consequence of that government commitment and the credibility of it, the world changed. If you look at the graph the NIH in the United States published on sequencing costs, you find it went down very fast and then levelled out at about $10,000. Almost immediately after we came out—a year or so afterwards—it dropped to $1,000. What I am saying is that sometimes a really thoughtful industrial strategy has a major effect.

The Chairman: We will come to how this data can be used effectively.

Professor Dame Ottoline Leyser: I am here representing the Royal Society. I chair the Royal Society's science policy advisory group. Our interest in this strategy has been substantially in the context of data. I also recently chaired a project that was a collaboration between the Royal Society and the British Academy on data governance and data use. It is largely in that sphere that I am here.

As has been pointed out by a number of colleagues before, I would also like to point out that, while we are excited about the industrial strategy and very much welcome this component of it, the dubbing of it as a life science strategy is a little bit of a misnomer. It is terrific as a kind of health science strategy. Even there, it is a little bit limited, since health involves an awful lot of things beyond biomedical-type interventions. From the point of view of the Royal Society's role as the national academy of science, we would like to point out that this is an important component of life science but it does not include plant science and environmental science, which have very heavy life science components and contribute to human health and well-being.

Q154 **The Chairman:** Thank you very much indeed. To kick off, and you have already partly answered this, what was your overall impression of Professor Bell's report, *Life Sciences: Industrial Strategy*? Obviously, from what you have said, you welcome it. If I could expand on that, is it deliverable?

Sir John Chisholm: I believe that as written it certainly is deliverable. It has very clear propositions within it that I believe would be very helpful.

Professor Dame Ottoline Leyser: To me, there is a major missing strand, which is a clear and fully integrated public engagement and public dialogue strategy. None of this will be deliverable unless we bring the relevant stakeholders along firmly with us. It would be a tragedy to lose the extraordinary advantages that can be gained from the kinds of datasets in the healthcare system because of a lack of public acceptance, which is a real danger.

The Chairman: That will be one of the challenges. Are there any other challenges?

Professor Dame Ottoline Leyser: Skills, yes.

Sir John Chisholm: Yes. There are an enormous number of components to make this work. Certainly, skills is one. Infrastructure is another. These are all part of putting together a coherent strategy.

The Chairman: We will come to the implementation of it in a minute.

Q155 **Lord Kakkar:** I would like to turn to that specific question: who should be responsible for implementing the life sciences industrial strategy? To whom should they be accountable? We heard from our previous witness, Lord Heseltine, that it should be the Department of Health. Does the department has sufficient credibility to be the custodian of and lead such an important strategy, bearing in mind the other tensions and responsibilities it has? If it is not credible to do that at the moment, how could it develop that type of credibility?

Sir John Chisholm: There is a structure in place. The Department for Business, Energy and Industrial Strategy has a lead role and has funding to address that. As your previous witness said, health strategy is hugely in the hands of the Department of Health, because it is by far the major player. Linking the two, you have the Office for Life Sciences. There is a structure there that shares responsibility between the two. I cannot think of a better way of doing it, given that you have two major departments that have to co-operate on its execution.

Professor Dame Ottoline Leyser: "Deliver" is a difficult, very broad word. A lot of the strategies that are going to come out under the umbrella of the industrial strategy will require the engagement of a large number of different stakeholders, who will have to talk to each other properly to make them work. At some level, vesting responsibility for an overall strategy in a single body is going to be problematic. In the end it may not result in the outcomes we want. We need to find ways to integrate across the system, so that the level of communication across it is adequate to allow the delivery of the strategy. I am not sure it is going to be straightforward enough to say, "These people should be responsible".

Lord Kakkar: How does one achieve that integration across such a complex system? Who should then take the lead or be responsible for that? Who should be held accountable for it, if it is a question of co-ordinating across multiple elements?

Professor Dame Ottoline Leyser: At the point, I will focus back on my data hat, which is a large part of the reason why I am sitting here. In its report with the British Academy, the Royal Society has recommended that there should be an overarching body that looks across the whole data landscape and can perform some of this integrating piece in a way that is sufficiently transparent, open and inclusive so as bring the various stakeholders, including the public and patient groups, along with it.

That is not to say that that body is responsible for governance across the system, but it is to say that it has looked at the governance in the different sectors, which will be specific to those different sectors, to ensure that good practice is being shared and that appropriate governance arrangements are in place across the system. Those kinds of integrative views are going to be important in allowing some of these complex strategies to move forward.

Sir John Chisholm: I would certainly agree that integrative bodies are important. Your next witness session will include Dame Sally Davies, and you will see that in her *Generation Genome* report she suggested the creation of a national genomics board, which is one of the integrative bodies that can help pull together what is inherently a complex environment. I would absolutely endorse the suggestion that the big data questions should be among that.

Lord Kakkar: On the specific question of big data, Sir John, from your experience from the genomics enterprise, specifically with regard to the governance structures that attend it and the capacity to hold to account a system that is delivering a national strategy, does that provide a potential model for the life sciences strategy?

Sir John Chisholm: In many ways, the models need to be appropriate to the particular task you are trying to do. You will have doubtless read John Bell's evidence to the other Science and Technology Committee. He made a big point about the fact that the creation of Genomics England was appropriate to carry forward the strategy in genomics in the Department of Health, because it was a body with a very specific goal that could bring together the various strands and make it happen. That was entirely useful in giving Genomics England its remit. Extremely high on that remit was patient and public acceptance of what we were about. If you like, we were given a whole pile of things to co-ordinate and make a programme out of.

Lord Kakkar: That has created credibility for a model of delivery and implementation, where the Department of Health has had supervision and a specific entity within it has taken forward that responsibility. More generally, how will that influence the perception that the Department of Health has the capacity to lead in this co-ordinating role to achieve the implementation of the life sciences strategy? Secondly, how much of an impediment might be the fact that the bulk of the department's responsibility is the delivery of the NHS? From your experience of the work in genomics, does the department have the capacity to take on something as substantial as this?

Sir John Chisholm: I think it does. You are quite right: the Department of Health has an enormous range of responsibilities. Inevitably, there are short-term pressures. At the same time, it has to deliver the long term. Most organisations faced with that kind of dilemma create special bodies to make sure they cover those things and that one requirement does not drown out the attention that must be given to another. You are not creating new organisational science to say that is a good thing to do; it is a good thing to do. The overall body can then look at the success of its

various units and apply resources or whatever to encourage them to be successful in the role they have been given.

The Chairman: Sir John, you started off by concentrating on Genomics England. It now has a huge database. You have 100,000 genomes from the population, and you have phenotypic or other information about the patients. This is one data resource that is completely distinct from the rest of the information or data we have about the rest of the health service. The assumption is that this particular database of 100,000 genomes and the information about those individuals could be used for all kinds of things in developing industrial strategy or taking that bit of science forward to innovation. Am I correct in assuming that?

Sir John Chisholm: You can think of the 100,000 programme as a pilot for what you can do broadly across health. You have to think about it in that context. It is not something that will be done, put on the shelf and left alone; it is proving the thesis that genomic data allied to routine clinical care can produce really worthwhile diagnostics for patients, at the same time as delivering a resource that can further discovery, which will end up in better diagnostics, therapies and other treatments for patients. This is about proving that thesis and we are well on the way to so doing. That then becomes something you can carry out as a platform—which is a word you will hear me use quite often—into the health system more broadly.

Q156 **Lord Fox:** Staying with data, clearly data is a central part of what the Bell report seeks to unlock. If we were starting with a greenfield site, in a sense, it would almost be easier than where we are now. I would like you to comment on the technological challenge of the wider dataset—not your dataset, but the wider NHS dataset. Does the NHS have anything close to the hardware, software, governance and skills needed to deliver at least some of this potential?

My second point is really around the release of that data. Professor Leyser, you have already alluded to that in how people are giving away data all the time, but this data is seen as being particularly sensitive and particularly close to them. The notion of informed consent, which your report went into in some depth, is a potentially specious notion. Beyond simply engaging people, how do we actually get down to that?

My third and final point is about the commercial exploitation of this. How do we share it?

Sir John Chisholm: There are three questions there.

Lord Fox: It is: the technological and skills context; unlocking data from a personal point of view; and then how you exploit it and share the spoils of that exploitation.

Sir John Chisholm: Let me start with the technological thing. Let us not beat ourselves up. I go all over the world and the same problem of how to manage data resources in hospitals and the health system exists everywhere.

Lord Fox: We are as bad as other people.

Sir John Chisholm: We are no worse than you find elsewhere. That comes from the fact that health worldwide is a cottage industry.

Lord Fox: That is set in the context of people telling us, sitting in these seats, that we have a unique resource. If we have a unique resource, we have a unique challenge in unlocking it.

Sir John Chisholm: In Genomics England, we have certainly done a very important thing: we have created a resource and made whole genome sequencing useful.

Lord Fox: I am thinking about the wider dataset beyond that.

Sir John Chisholm: It would be hard to say we are unique in collecting data, because that is done in most health systems in the world. Bringing it together in a useable way so we get from it first the maximum patient benefit and then the broader benefit is a challenge still to be achieved, frankly. If you ask me whether we have the skills to do it, I believe we are as well-placed as anyone in the world. I am not saying that is easy or will happen immediately, but huge strides have been made. We are in a much better place now than we were 10 years ago. With the projects going on, such as mine and others, in five years' time you will see another big step forward.

The second question dealt with the issue of consents and how best to go about that. As you know, that is an area Dame Fiona Caldicott has given a tremendous amount of attention to. I will talk from our own perspective in Genomics England. From the start in our project we took the decision that our patients had to be fully aware of what they were getting involved in. Therefore, we set up a really elaborate consent process.

Lord Fox: Does some of it come down to the fact they know the exploitation of it is going to be for a greater good rather than for an individual company?

Sir John Chisholm: We explained that very clearly to them in the process. In the early days of the process, it took an hour and a half or so of explanation. That was us learning how to reach a point where we were satisfied the patients and their family understood what this was about. We were very clear from the start that not only was the personal benefit to them not guaranteed, but we would make the data available for other researchers to access, including industrial people.

Lord Fox: I am also keen to hear what Professor Leyser has to say.

Professor Dame Ottoline Leyser: There is a general point from a number of your questions, which is that the Genomics England situation is a very specific case. It is a very unusual situation, where you have a very well-structured dataset that is uniform and easy to control.

Lord Fox: That is what I meant by a greenfield site.

Professor Dame Ottoline Leyser: It is way over here on the scale of the data landscape. That is excellent and terrific work has been done, but we have to deal with the entire data landscape, which goes from that

situation to something way messier over here, which is people's Fitbit data, air quality data and all kinds of information coming from a whole variety of different places, which, ideally, one might want to link back to this beautiful dataset at Genomics England. We need to find a way that looks at the full complexity of that landscape and allows people to navigate it in a way that creates the benefits we are talking about for society and for the economy.

From that point of view, the Royal Society's proposal is that we need an overarching set of high-level principles about how to do that, filtered through an overarching body that looks across the piece and engages deeply with all the relevant stakeholders to allow those conversations to happen about how best to realise the benefits and mitigate the risks in an open and transparent way. It is a scary prospect, but we have to do it because the traditional concepts that have been used in this space—privacy, confidentiality, ownership and consent—are very difficult to pin down when the landscape has become that complicated. It is not that people are resistant to all kinds of their data being used for benefit. We know that what people mostly care about is the purpose for which the data is being used, who benefits, what the risks are and whether those risks and benefits are equitably shared.

Those are the core things people care about, and we should focus on finding ways to site those things in an appropriate space so we can move forward. If we withdraw to look at only individual parts of the space separately, we risk losing the opportunity of the wider linkages and generating data-governance train wrecks in a different part of the system, which would have ripple effects in even a very well-regulated part of the system.

It is really important to do this piece of work on having zoomed out, high-level principles and bringing people with us. Otherwise, none of this is going to work effectively. We have already seen the problems that arise when you try to do it in a more constrained way that does not engage people appropriately.

The Chairman: You mentioned this report and the overarching body that could be set up. The pity was that, in the report, you did not actually describe what this body could be. You suggested setting up such a body, but you did not say what the body should be and what it should do. Tomorrow will be the last day of the Committee stage of the legislation related to data protection, and we hope the time has not passed—it might have—for what the Government might accept in setting up such a body.

I take the point you made on the question that Lord Fox raised about the data from the whole of the NHS that could be used for this life sciences strategy. There has to be some mechanism to be able to use this data. I am not so sure that hitherto the legislation has identified how that will be done. If I could get you on the record, how can it be done?

Professor Dame Ottoline Leyser: The reason we are proposing this stewardship body is precisely because different parts of the system are working differently well with their own local governance arrangements, and there is no need to perturb those. We have the ICO; we have a lot of

pieces in place. But there are also gaps. We need a better understanding of exactly where those gaps are and how they can be filled. We need integration; we need to bring the different parts of the system together and think about them in a more integrated way. That is point one.

Point two is that this is a very fast moving area. The whole point of having a visible, clear and integrative body is precisely that it can react to new things that were not even thought about yesterday. The idea that one can make a list of the exact things it will do does not match the needs of the system. If there was a list of exactly what needed to be done it would be relatively straightforward to do it. There is not: there is an anxiety that the current system is not sufficiently well integrated, good practice is not being shared and any minute now there could be some public confidence disaster, which would have a major impact on our ability to harness the extraordinary benefits that are possible. That is why we have gone for these high-level principles that people can really get behind and a very visible, participatory body that will allow them to be articulated specifically in particular cases, as and when they arise.

Lord Fox: Is the primary objective of this body to harvest the data or protect the rights of the patients?

Professor Dame Ottoline Leyser: The body goes much wider than the health sector.

Lord Fox: It has to have a primary mission.

Professor Dame Ottoline Leyser: Its primary objective is that data should be used to promote human flourishing.

Q157 **Baroness Neville-Jones:** I have a comment on what you just said. An integrative body sounds like a very good idea. My problem is that, without a specific mandate, it seems to me that it will get drowned by the authority of the Information Commissioner, who may well have a rather different view from the border. Her job—it is a woman at the moment—will be just to implement the legislation.

In connection with the draft legislation going through—our Chairman has just mentioned it—are you entirely content with all its provisions as regards where it touches on research? I mean in your area, health, but obviously "research" covers more general research in academic bodies and, indeed, the voluntary sector. They are not necessarily classed as public-interest organisations. I would be interested to know whether you feel the legislation as drafted serves the interests of research.

Could I also ask you, and Sir John in particular, what the timescale is for the exploitation of the data that Genomics England holds? It is obviously extremely valuable, and it would be very interesting to know where and when you see it turning from activities that you are directly responsible for into something that is commercially viable and potentially a wealth creator.

Sir John Chisholm: That is something I can certainly help you with. At one level, it is already happening. Companies are already starting. Some

companies have already been started as a consequence of the programme, and they are earning revenues and creating jobs. At one level, that is starting. As you would expect—the same thing has happened in other industries—it starts with things like the tools and capabilities that enable the programme to happen. We are seeing investment happening in that space right now.

You will see the first therapy consumed by a patient much later, simply because the timescales are much longer. We already have considerable interest from the commercial space. Right now, as we sit here, there is a meeting of what we call the discovery forum. That has some 50 companies, which have come to talk about how they can participate and gain value from the dataset we are creating.

There is activity. We have to be patient to a degree while we develop an understanding of how to use a dataset of this richness and how to turn it into products that will be really helpful to patients. We will have to be patient. That will take a little while. Part of what we are about is trying to construct the machinery and the connections that will make that happen. I am going to use this word "platform" again. We are in the business of creating a platform from which those things will emerge.

Baroness Neville-Jones: You used the word "investment". Where is the money coming from? Is there private-sector money in there or are we still on public funding?

Sir John Chisholm: There is public funding in it. That was the nature of the 100,000 Genomes Project.

Baroness Neville-Jones: Yes, sure. You have lots of interested companies. Are they putting some money in?

Sir John Chisholm: Companies are spending their own money to participate. Indeed, at this stage they are providing some money to us as a fee for coming in and gaining access. There is private money going into the project at the moment. We firmly believe that we will see a flowering of that as the value of the data emerges.

Baroness Neville-Jones: Are we talking about decades? What are we talking about? In your mind's eye, when do you think something will emerge that people recognise as a real change and that makes us capable of doing something for patients that we have not been able to before?

Sir John Chisholm: If you were to invite me back in, say, four years, I think I would tell you a very good story.

Professor Dame Ottoline Leyser: The GDPR is a very important piece of legislation. It has been greatly improved on the way in its ability to support basic research as well as protecting individual rights. Of course, it is limited in its scope and it is never going to address the whole landscape because its focus is still on personal data. A lot of the interesting applications are going to be from linking things that are potentially covered by the GDPR with things that are not. There are also

lots of interesting grey areas about data aggregation. It is a complicated business.

This is where the relationship between the body that the Royal Society and the British Academy have proposed and the ICO comes into play. The ICO has a very clear regulatory role and it is doing a fantastic job, but there will be grey areas. There will be new things. The technology is going to move much more quickly than legislation can ever keep up with. We need flexible ways to understand what the new things are and how they fit into existing regulation. Where the existing legislation is not appropriate, we need to support the safe deployment of these new applications.

It is difficult. At some level what I am talking about is fundamentally wishy-washy; a better way to say that is that it is flexible. This is something where we just have to grasp the nettle. There is no way, in a space this fast moving, that we can nail down with clear lists what is going to happen, precisely because the idea is to have in place a system that deals with the new and unexpected in a way that people trust, rather than a way that provides a shock to the system with ripple effects that destroy a really exciting area for our public services.

Baroness Neville-Jones: You precisely outline the problem; I agree with you about its definition. I asked you not about the GDPR but about the UK data-protection legislation going through the House of Lords at the moment. Does it take intelligent advantage of the derogations available inside the GDPR for national legislation in this area? The legislation that is in that Bill, the Government's draft, is far from being wishy-washy; it is extremely precise. Are you happy that it provides the required scope and, indeed, enables the issue you have just pointed out to be dealt with? I am almost asking this question: is it an advantage or is it an obstacle?

Professor Dame Ottoline Leyser: It is neither, because the issue that I am trying to highlight is precisely about things that have not been anticipated.

Baroness Neville-Jones: The legislation therefore needs to provide a situation in which it can be dealt with. Will it do that?

Professor Dame Ottoline Leyser: I do not know.

The Chairman: You might not be able to answer the question, but it is an important one, particularly as it will apply to all the data usage in the health service. Will the legislation allow for that, or will it create so many barriers that people will just give up? If you cannot answer the question just now, I suggest that you might look at what has been happening in the debate over the last few days. In two weeks' time we will have an opportunity to articulate a different view. If this is going to be a barrier, it could be very important. If it cannot be done at that stage, the time is gone.

Baroness Neville-Jones: Yes. There is an issue there.

Lord Hunt of Chesterton: There is a country that experimented with

data quite early on using almost the whole population, which was Iceland. I wondered what lessons we have learned from that or any other country.

Sir John Chisholm: I can certainly answer on the Icelandic programme in genomics, which was very early. The lesson from that absolutely makes Ottoline's point: you really have to have a national conversation.

Lord Hunt of Chesterton: It led to a positive result in Iceland, as I understand it.

Sir John Chisholm: In the end, yes, but it went through a very rocky patch to get there. It set out without doing that, and it had to stop and think again.

The Chairman: Both of you referred to that. Who should initiate this dialogue?

Sir John Chisholm: I can only give our own experience, I am afraid, because I can only speak from our own experience. From the start we were tasked with seeking to carry public confidence. Therefore, we set up an ability to do that and we have conducted a conversation with the people. We have sought to gain the best understanding we could of where the public are going to stand, what the concerns are and what we can do about the way we do our business to address those concerns. At the same time, we were trying to educate. That is what we have tried to do. In my view, this is what needs to be done on a wider scale than specifically genomics.

The Chairman: Could I take you back to the answer you gave to Baroness Neville-Jones? If you were invited back in four years' time, you would have the answer to her question. Yesterday we heard in the Chamber that there were 660,000 start-ups created last year or something in the UK. My analogy for that is that making a splash does not mean you can navigate the ocean. I know you are one person who is well-versed in growing a start-up into a unicorn. Sir John Bell's report suggests that we are going to grow four unicorns in five years' time, a unicorn being a company worth at least £1 billion, for those who do not understand.

Lord Fox: They are also mythical creatures.

The Chairman: Are we really going to manage that?

Sir John Chisholm: The question is how we are going to achieve that. The only way we can is by creating the infrastructure to do that and creating a resource that is very helpful for that. The nation can provide the environment that makes that kind of growth more likely to happen. The really vigorous industrial ecosystems around the world tend to have a place about them. A lot of companies are doing similar things at the same time. It is not about focusing on one company as a national champion, but about creating a whole infrastructure of companies, all of which gain strength from each other.

In the genomics space, we are at the very early stages of understanding how this technology works. That is a good position to be in, because we

are regarded across the world as the world leaders in population genomics. Therefore, we are setting standards for how this is done. In setting those standards, there are companies involved with us—more than 30 companies are part of our platform in one way or another—in making this happen. They are all doing little niches, which are part of this total system.

This can and should build into a very important ecosystem, which will attract investment. In the discovery forum that I mentioned, which is going on right now in another building with 50 companies, among those are investment companies that are there because they are interested in what is happening and where the investable opportunities will arise. It is that kind of ecosystem you need to encourage, which will yield the benefits you are looking for.

Lord Fox: The question the Chairman asked about who engages in this question was clearly answered from the genomics point of view. For the wider dirty set of data, as you described it, I am assuming it is not the stewardship body, so who instigates this process of engagement that unlocks or at least starts the process of unlocking this data?

Professor Dame Ottoline Leyser: As we have heard, there are spaces in the system that are working very well. The body can identify spaces where they are not working well. The job is then to get together the right groups of people within those spaces to put in place the necessary governance. It will depend on the particular sector.

Lord Fox: It is a whole bunch of people, then. There is not a specific line or a drive that will say, "Here's what we're going to do. There's going to be one in every hospital. They will co-ordinate this and there'll be a bunch of boxes to tick". It is not going to be like that.

Professor Dame Ottoline Leyser: In the healthcare context, it is possible that it will be an option to have something that is fairly standardised across the system. That would be one of the options. But, as I say, you could look much more widely and try to link with people's Fitbit data, Tesco Clubcard data and all the rest of it.

Lord Fox: Let us crawl before we can walk.

Professor Dame Ottoline Leyser: Yes, absolutely.

Q158 **Lord Mair:** I was going to ask about privacy and data, but that has been very well-covered in the various questions you have been answering. I want to ask about the other Royal Society report on machine learning and what you could say about that in the context of the industrial strategy for life sciences.

Professor Dame Ottoline Leyser: It goes back a little bit to this question about how fast things can happen. The opportunities in machine learning are really extraordinary. There are examples popping up now where we could deploy it in the healthcare system really very quickly and it would be a good thing. There is an example of cytology slide screening, where machine-learning algorithms can recognise precancerous states more accurately than humans.

There is huge potential in this area. One thing that has been highlighted by yet a different report, Wendy Hall's report on this topic, is the need to have available safe spaces with datasets that companies can use to train their algorithms to test out different ideas. That is really quite a concrete example where access to data is very important in driving forward the very high potential, from a public benefit point of view. At the moment, it is not really clear how that will happen. There are different ways it could happen. It is possible the ICO will be able to deal with it, but it is another situation where an independent body, separate from the regulator, may be able to find creative solutions that will be different in each case and allow this to move forward in a way that accelerates the rate of change rather than slows it.

Lord Borwick: First, I should declare a very, very small interest: I and my family represent six of your 100,000 genomes. A genetic tendency to join the House of Lords is something that has not been raised.

Sir John Chisholm: Thank you for your contribution.

Q159 **Lord Borwick:** I wanted to ask about the NHS data later in this process. It seems to us that data is held in the NHS in many different forms, in separate systems that do not talk to each other. How can this technical challenge be overcome? We have tried to do centralised NHS data and failed on several occasions in the past, have we not?

Sir John Chisholm: The idea that you uniformly apply the same system across the whole 200-odd hospitals is unlikely to succeed. On the other hand, the internet certainly manages to collect data from all sorts of strange beasts and it does so very successfully. It is not a matter of trying to change all those individual systems, but about creating a network that can harvest the data under controlled conditions, for obvious reasons, and provide it to the people who can make use of it, such as the clinicians who want to use it for serving their patients, and hopefully the researchers who want to find the insights that will create the therapies of the future.

Lord Borwick: Is this already being done? Is that latter part being done?

Sir John Chisholm: We are certainly doing it in the genomics space. That is very precisely what we are doing. We have 80 or so hospitals currently providing data through such mechanisms. Is it perfect? No, it is not. Will it be better in a couple of years' time? Yes, it will. We are making progress all the time.

The Department of Health has a programme to do the same across the whole of the data space in health. That has a timescale of another five years or so to get to the same point. We are not up against something that cannot be done. Is it very difficult? Yes. Do we have to navigate incredibly important points of data privacy and things like that? Absolutely, we do, but there is a programme to get there.

The Chairman: Of course, it is true that the dataset you have, Sir John, was designed from the beginning and information is collected in a structured way. That can be used as a resource for all kinds of things you

already mentioned about disease profiling, diagnostics, et cetera. Who owns the IP?

Sir John Chisholm: The Secretary of State ultimately owns the IP.

The Chairman: Companies are interested in using this dataset for a specific purpose, presumably. Let us say it is developing a diagnostic test. If they succeed in doing so, who then owns that IP?

Sir John Chisholm: They bring IP to us, because companies do not come to the data without having a very good idea of what they want. They have molecules and suchlike and they want to find out whether they are of importance in a particular disease. They own their background IP and foreground IP.

The Chairman: If they are bought out for millions of dollars by an American company, what happens?

Sir John Chisholm: That is the market. At this moment, we do not have any means of preventing somebody voluntarily refinanced by another company taking that IP back.

The Chairman: We have the information that generated the diagnostic test that led to millions of dollars' worth of company, but we got zero out of it.

Sir John Chisholm: Hopefully we will not get zero out of it, because we will have employment and economic activity here in the UK.

Lord Vallance of Tummel: Coming back to data for a moment, I can understand that having common platforms and common applications is unlikely to be achieved right across the NHS. What about common mandated formats for collecting data? Would common formats be advantageous?

Sir John Chisholm: Indeed, yes, we have that.

Lord Vallance of Tummel: Do you have it right across? You have it in your area.

Sir John Chisholm: Just saying a format is one thing; how it is implemented is another thing, along with getting to the discipline of that implementation. We talk about this as if it is a UK problem. I have to tell you that it is a worldwide problem. Everyone has the same issue. If you had this discussion in most other countries, they would think we are ahead because we are actually doing this in the UK and it is working.

Lord Vallance of Tummel: Are there any downsides to having a centrally mandated single format?

Sir John Chisholm: You have to keep abreast of technology and of understanding elsewhere. You certainly have to keep abreast of security threats. It is a serious obligation, if you are a standard-setter, to take account of those things.

Professor Dame Ottoline Leyser: Yes, these are the kinds of discussions that go on all the time in the research community. On the one hand, uniformity is very helpful. On the other, something new could

happen next week with the kind of data you will be collecting or trying to link to the genomic information, for example, or with the platforms and the tools you will have available to you. The idea that you can somehow lock in some standardised anything and that it will be wonderfully helpful forever is just not true. Again, the flexibility and the tools to convert things from one form to another are always going to be important. Even in the genomics area, there were multiple file formats for quite a long time.

Sir John Chisholm: There still are.

Professor Dame Ottoline Leyser: People just wrote simple algorithms to convert them from one to the other. Those kinds of things are always going to be there, particularly when you start trying to link in data that has been scraped off the web and has no standardised format at all.

As a life science thing, you could think about evolution and the way evolution works. It has done a pretty good job of making some very interesting organisms, which function pretty well. That has always been based on what there was before, not on some greenfield principle of designing from scratch. We do not need to be too scared about the idea that the system that evolves may not be the optimally designed solution for this moment. It can none the less be functional and deliver the outcomes we want and be sufficiently flexible to deliver the outcomes we do not even know we want yet. Worrying too much about those details slows thing down. Worrying about them not at all also slows things down, and you need to be somewhere in the middle.

Lord Oxburgh: Is it totally unrealistic to think of a royalty arrangement for the use of NHS data by companies that may become extremely successful?

Sir John Chisholm: We have exactly that idea.

Lord Oxburgh: That is a partial answer to the question that was asked before.

Sir John Chisholm: We had a bit of an arm wrestle with the universities on this subject, but that is what our idea is.

The Chairman: Thank you both very much for coming today to help with our inquiry. It has been most useful.