HOUSE OF LORDS

Select Committee on Science and Technology

Corrected oral evidence: Ageing: science, technology and healthy living

Tuesday 25 February 2020

11.35 am

Watch the meeting

Members present: Lord Patel (The Chair); Lord Borwick; Lord Browne of Ladyton; Baroness Hilton of Eggardon; Lord Mair; Baroness Manningham-Buller; Baroness Penn; Viscount Ridley; Baroness Sheehan; Baroness Walmsley; Lord Winston; Baroness Young of Old Scone.

Evidence Session No. 16 Heard in Public Questions 139 - 146

Witnesses

Charles Lowe, CEO, Digital Health and Care Alliance; Professor Julian Peto, Professor of Epidemiology, London School of Hygiene and Tropical Medicine; Dr Paola Zaninotto, Associate Professor in Medical Statistics, UCL; Dr Jeni Tennison, CEO, Open Data Institute.

USE OF THE TRANSCRIPT

Examination of witnesses

Charles Lowe, Professor Julian Peto, Dr Paola Zaninotto and Dr Jeni Tennison.

Q139 **The Chair:** Good morning. Thank you for coming this morning to help us with this inquiry. I note that some of you have been listening to part of the first session. Before we start, would you introduce yourselves and declare any interests? If you want to make an opening comment, please feel free to do so?

Dr Paola Zaninotto: I am associate professor in medical statistics at UCL and co-investigator of the English Longitudinal Study of Ageing.

Professor Julian Peto: I am from the London School of Hygiene and Tropical Medicine. I was head of epidemiology at the Institute of Cancer Research for 27 years. I am here to represent British epidemiology and clinical trialists.

Dr Jeni Tennison: I am CEO at the Open Data Institute, which is a not-for-profit organisation that focuses on building an open and trustworthy data ecosystem. We work across sectors but have some specific projects in relation to health with the Wellcome Trust, Health Foundation and Health Data Research UK.

Charles Lowe: I am past president of the Royal Society of Medicine's digital health section. My principal reason for being here is I am chief executive of Digital Health and Care Alliance, which is an organisation of about 850 SME members sponsored by the AHSN Network. I am here to represent SMEs and the challenge they have in working within the health service exchanging data.

The Chairman: We know what SME means, but what is AHSN?

Charles Lowe: The Academic Health Science Networks (of which there are 15 in England, themselves forming a single Network).

Q140 **Viscount Ridley:** The Chair kindly said I could ask the first question because I might have to leave before the end of the session, for which I apologise. Please give examples from your work of how healthcare data is used in analysis, including explaining the following: the sources of the data and how you gain access to it; who uses the results of the analysis and for what purpose—for example is it used for planning healthcare services or for diagnosing illnesses, or providing tailored advice to patients, or for medical research or for some other purpose?

Dr Paola Zaninotto: We collect data for the English Longitudinal Study of Ageing directly from the participants. We collect a wealth of information, including subjective and objective measures of health. The data is linked to Hospital Episode Statistics, to the mortality and cancer registry. The linkage is provided by NHS Digital. The data is anonymised so that we do not know who the participants are who have contributed their information. The data is used for medical research to monitor the timing of frailty, disease onset and causes of death over time, to explore social inequalities in disease risk and access to social care, and to

establish the consequences of ill-health from economic, social and well-being perspectives. The data is not only used by us but is freely available to researchers and policy analysts who are able to download the dataset for their research purposes.

Viscount Ridley: Professor Peto, can I press you on the written evidence you supplied in which you were very critical of the way in which bureaucracy gets in the way of medical research? You said the relationship is no longer based on the assumption that medical researchers are trustworthy and that "Our burgeoning army of data custodians was created to solve a problem that did not exist". Can you expand on that point?

Professor Julian Peto: This is a key point. The one thing your Committee could do which would have a transformational effect would be to revise the law on medical research. In my 50 years of experience in this field, I have held hundreds of thousands of named patient records and I am not aware of one example—not only in my work but in that of my colleagues—where there has been a serious breach of medical confidentiality as a result of us holding that identified data. I am not suggesting we should hold names any more—that time is long past, unfortunately—but we could at least have NHS numbers.

There is enormous bureaucracy and restrictions involved in accessing these data. It covers everything. We are even supposed to destroy the data after five years. We have to produce data destruction certificates, which is a huge amount of work because they have to be removed from every backup disk, which is almost impossible. There is a whole army of people in my institution and elsewhere in the IT department who are responsible for producing data destruction certificates to prove that we have destroyed these extremely valuable data that we have spent three years getting permission to get. It is an enormous obstacle to absolutely everything we do.

I spoke to Sir Rory Collins at the weekend, the CEO of UK Biobank and head of the Nuffield Department of Population Health in Oxford. I asked, "Would you agree that we could get more than twice as much work done if we had ready access to NHS data?" and he said, "A factor of two is an underestimate". It is also an extraordinary burden within NHS Digital and the other organisations that hold these data. The only reason for this is the legislation in relation to privacy. The only way of curing it is by changing the law. There are very minor changes that could be made. One striking example is that we have the Hospital Episode Statistics, or HES, which is centralised, but we do not have GP data.

GP data are centralised at EMIS and TPP, which are the two organisations that have computerised virtually all GP records, but the contract is between them and the GPs. The GP is recognised as the data controller; the data controller is the person who holds the data and is therefore responsible for it. You have to get the permission of every GP practice in England to access their data. GPs are very busy and you are doing well if 20% answer the letter, and I do not blame them. You can change that

agreement centrally whereby those data records are accessible in exactly the same way as the HES data.

Lord Winston: Would such a legal change include the use of tissues?

Professor Julian Peto: It should do, yes. The idea that under the Human Tissue Act histological material is being destroyed because it is illegal to retain it for research is an absolute outrage. The valuable results in epidemiology and clinical trials, particularly in the elderly, come from very long follow-up. You have to retain these records for ever. It is very nice to be able to go back and retrieve tissue samples.

We have done a study, for example, looking at how much asbestos people are breathing in, which is an important question. We have lung samples taken when people had a collapsed lung; it is a harmless condition that is easily treated but the surgical samples are kept. We obtained informed consent via GPs to ring the patients up. It was quite a job getting access to them, but we did it eventually. We rang them up and said, "Can we analyse your lung tissue?" and they said, "Yes, sure". We showed a hundredfold reduction in the amount of asbestos in people's lungs from people born in the 1940s to those born now. That is a minor example. The genetic opportunities from tissues are absolutely enormous.

Viscount Ridley: We heard in the last session that people are very happy to share their data on the whole. Is that partly because they know there are bureaucratic safeguards in place, however tiresome?

Professor Julian Peto: No, not at all. It is the opposite. When I go into the pub and tell people what I do, they are astonished to find we do not have access to their records. A previous witness referred to an irreducible minority who object on privacy grounds in any circumstances. Should they be allowed to halve the output of British medical research, which is the effect of the legislation which is purely driven by them?

Lord Browne of Ladyton: I go to the pub to talk about football. In the penultimate paragraph of your very interesting short submission to us, you are quite specific that an amendment to the National Health Service Act 2006 would serve this purpose. Is there any other resource we could go to, to dig more deeply into that, to test whether there would be some unintended consequences of that reform, which is sometimes what happens when you try to do something through legislation?

Professor Julian Peto: The Patient Information Advisory Group, now renamed the Confidentiality Advisory Group, or CAG, was set up by the Health and Social Care Act 2001 with power to set aside the legal obligation of medical confidentiality for the purposes of research. The problem is that it can tell NHS Digital that it will not be prosecuted under the law for giving us data, but it does not direct it to give us the data. NHS Digital is still the data custodian or, in the case of GP data, the individual practices are the data custodians. If they give us their data they will not be prosecuted, but they have the responsibility to decide whether it is ethical and the study is worthwhile.

So, we go through the process of an expert research ethics committee to approve a study. We go through the process of getting funding for the study. We then go to CAG to get approval for the study, but NHS Digital then reviews the whole process in even more detail. It takes years and thousands of emails exchanged simply to get the data which we should obviously have, and the process is of absolutely no value. I am suggesting that that responsibility should be devolved to CAG, which would have to be expanded.

The Chair: We have explored that area although it is not directly related to our inquiry.

Lord Browne of Ladyton: I am supportive and have been persuaded by your evidence to us that there is something here. It would be helpful to know if more work is being done about the mechanism to reform this that we could read and consider. I understand the problem. Is there anything more than this available from people you have been working with?

Professor Julian Peto: I think that is all there is to it. NHS Digital should be directed to give us the data rather than being permitted to, so that it has no legal responsibility. At present there is no obligation on NHS Digital to give us the data.

The Chair: If you have information that would be useful, please feel free to send it to us. That is the request from Lord Browne.

Q141 **Lord Kakkar:** I want to turn to how effectively data is shared in terms of what is collected in the NHS outside the NHS. We have touched on it in relation to medical research but beyond that, bearing in mind that the health economy is plural in its nature, that individuals are managed in a number of different environments and that there are determinants beyond pure questions of health that will impact on clinical course and health outcome over a lifetime, how effectively are data being shared?

Charles Lowe: Our SME members have great difficulty accessing any data from the NHS. We work with the GP Systems of Choice and secondary care electronic health records. Currently, a significant amount of money needs to change hands as well as the ethical considerations before an integration is possible. The NHS's new contracts specify that that exchange has to be done at a significantly lower cost than is currently charged. That will require the creation of an application programme interface, or API, that is published and commonly available. Certainly, in the case of the GP systems of choice at present, those APIs are not yet available. It is quite challenging.

From the other side, the SMEs do a lot of collection of data from individuals. They are healthcare data and fitness-type data. The current view of many clinicians is that much of that information is not reliable and doctors do not have time to analyse it. Artificial intelligence, which you were talking about earlier, offers a huge opportunity. We have to overcome the issue that just because information is collected in somebody's home it is not reliable.

I will give one example of why that is important. Like many people, I have white coat syndrome. The moment I am put into a hospital or GP's surgery and my blood pressured is measured it goes up significantly. However, if I measure it at home it is significantly lower. There have been one or two cases where people have been measured as having normal blood pressure in a GP's surgery and it turned out they had very low blood pressure and subsequently fainted simply because of white coat syndrome. There is a lot of merit to be had in measuring things in people's own homes if we can get across the acceptance of responsibility for analysing that data.

Lord Kakkar: In terms of NHS data being shared outside NHS institutions, do you think there is sufficient engagement with patients in a way that they have confidence that that relationship should be pursued? On the other hand, if SMEs and others are collecting important data and generating large datasets, how do they ensure those datasets and individuals whose data has contributed to those are content for it to be shared back into a broader collection of data nationally?

Charles Lowe: When they receive the data, it has to be on the condition that it is properly looked after, properly stewarded and properly ethically managed. There is not an issue with returning that data or adding to it, so-called writing to health records as well as reading health records. There is a requirement that when the data is written to the health records it is of a very high standard. We have to provide appropriate proof of that.

Dr Jeni Tennison: I would say a few things. One is that there are various uses of data, particularly patient data, and various ways in which it is shared. Sometimes we lump those together as though one set of rules is going to be appropriate across them all and it is not. Patients have an expectation that their personal medical record will move with them as they go through a treatment process, but that is very different from bulk access for medical research or access by SMEs for new health applications or access for individuals to their own health record as well. They have different kinds of expectations and knowledge in those different places.

The flows of data through the health system, as in every other sector, are quite complicated. They go through multiple hands, they go through multiple organisations and they are used for multiple purposes. Communicating that is quite difficult. I do not think that patients understand exactly everything that happens with patient health data, but understanding that would be a huge challenge even for those of us on the panel. It is important that communication is clear. We need more public information campaigns around the general use of data. Also, doctors and clinicians need to be equipped to have personal conversations with patients about the way in which data they are collecting might be reused.

Lord Kakkar: How is that being developed at the moment?

Dr Jeni Tennison: I know you have already had pointed out to you the work of Understanding Patient Data at the Wellcome Trust. This aims to assist clinicians and hospitals engaging directly with patients to

communicate with those patients directly, and how to do that and talk about data in a way that is understandable.

Lord Kakkar: Is there any programme of activity that goes into schools that allows pupils to understand questions around their health data so that it becomes part of our strategy in education?

Dr Jeni Tennison: That is a very good question. I have a view that we are somewhat good at educating children how to handle data, for example through the maths curriculum, but not so good at talking about the way in which data is collected and used within society: the cultural ways in which we use data; the power of the census; the reason that medical research is so powerful. That kind of lens—data literacy and critical thinking about the role of data in society—would be excellent to add to a history curriculum or to subjects such as government and politics.

Professor Julian Peto: One thing that would foster public understanding of what data are used for, particularly in relation to research, is a parliamentary debate and the public discussion that would go along with it, where all these issues would be aired. The irreducible minority would have the opportunity to state their case just as we would have the opportunity to state ours. If you walk up to people and say, "Should people have access to your medical records?" they will say no, but if you spend 15 minutes explaining what the question means, 95% of them say yes.

The irreducible minority cannot be allowed to do so much damage to British medical research. NHS data is the medical equivalent of the Large Hadron Collider. It is the best data resource in the world for doing medical research for epidemiology, clinical trials and a lot of other things. Our hands are completely tied by these restrictions, which should be set aside. Public debate is the only way of educating the public. You cannot sit people down one at a time or take somebody and stick them on a focus group or have PPI on every research application, which is a very substantial and pointless part of research costs.

Dr Paola Zaninotto: May I add something about the challenges in using NHS Digital data? In 2009 we requested the linkage for the first time and received the dataset only about two years ago. We are not allowed to share this dataset outside our English Longitudinal of Study of Ageing team. The value of linked data increases enormously when it can be shared with the wider research community. At present, no model for onward sharing has been implemented at NHS Digital. We have the data, but we cannot share it with other researchers.

Q142 **Baroness Walmsley:** May I move to two very specific large datasets, the UK Biobank and the 100,000 Genomes Project? How are those datasets being used for the diagnosis of and prevention of age-related diseases, specifically for the planning of services and support for the ageing population this Committee is looking at? Is the UK Biobank collecting the right data for these purposes? Are there any other data that would be useful?

Professor Julian Peto: One example of data which would be useful is the three-quarters of GP records UK BioBank do not have access to. They have taken legal advice on this. A one-sentence change in the contract between GPs and the companies that manage the databases would suffice. That is a major hole in the data. There is a great deal in GP data that is not captured in hospital data. UK Biobank is desperate to get hold of it. It has got hold only of a subgroup. GP records are not accessible and they should be.

I would like to add a technical point. You asked what age they cover. The upper age limit for the UK Biobank cohort is now 83 and the upper age limit for the Million Women Study, which is an even larger cohort of women recruited during breast screening, is now 89. They are well into the age which is relevant. A very nice example has just been published on the Million Women Study which shows that inactivity, which is very highly correlated with dementia, looks as though it is an effect rather than a cause[1]. When there is a 20-year follow-up you see that the huge effect seen at recruitment has disappeared. When you look at high BMI, which was apparently protective because people with high BMI had significantly lower dementia rates, you see that it crosses over at 10 or 15 years and, by 20 years, high BMI in middle age is significantly predictive of dementia, but only of vascular dementia and not Alzheimer's.

So, you have a very plausible finding, which is that obesity and probably any other factor which causes vascular damage will cause vascular dementia and that Alzheimer's works by a different mechanism. That result was not available even after follow-up at 10 years and is the opposite of the conclusion that most people believe. There was somebody on the "The World at One" on Sunday saying everybody knows activity prevents dementia. The evidence for that is very weak, and BMI has the opposite of the effect it is generally thought to have.

Dr Paola Zaninotto: Biobank is a great resource, but it comes with limitations. It is not representative of the general population and is biased towards more educated and affluent parts of the population. It is not a suitable dataset to explore inequalities in health or healthcare. We know there is a strong social gradient in health in the UK and this is not the best data to explore that. In ELSA, we are now collecting the 10th wave of data—so about 18 years—and it is representative of the English population. If we continue to collect data, we will be able to look at the ageing process from many different aspects because we collect information related not only to health but to socioeconomic and psychosocial aspects of people's lives.

Baroness Walmsley: Is your information being used to plan services?

Dr Paola Zaninotto: To look at healthcare access, yes. There are many publications from the data. It has been used a lot. It is also used by policymakers.[2]

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[1] Floud et al (2020). Neurology – in press

[2] DHSC does use ELSA as the base population in their Funding Reform Model that they

Q143 **Baroness Penn:** I want to follow up on the data on the social gradient and whether the datasets are representative of the broad range of social backgrounds in the UK. In some of the larger longitudinal datasets, is information routinely collected about socioeconomic background or status to inform that research? Does that tend to be included in some of those larger datasets that are used?

Dr Paola Zaninotto: If I talk specifically about ELSA, we collect a wealth of information on social and socioeconomic aspects of people's lives. The information is more limited in the UK Biobank. We know the education, occupation and class, but less information is available on income, wealth, pensions, debts and other characteristics that are quite important, especially in those who are older.

Baroness Penn: Beyond those two datasets, is this kind of information collected or is it not seen as relevant?

Dr Paola Zaninotto: Understanding Society, which is another large sample of individuals across all ages, collects information on socioeconomic characteristics because they are important when you are studying health and other aspects of people's lives.

Dr Jeni Tennison: There is one particular gap. We have just done a piece of work with the Legal Education Foundation on the collection of data from digital public services about who is accessing websites and other public services that have been made digital. In those cases, those socioeconomic or other characteristics that you might want to monitor to be able to tell who is using those services are not being routinely collected. We have a paper with the Legal Education Foundation that has more detail about that.

Q144 **Lord Mair:** In our previous session we heard about the potential for artificial intelligence. What are your views on new processing and analytical tools that could be brought to bear in the context of ageing?

Charles Lowe: There are some very exciting artificial intelligence start-ups among our membership. They have done some exciting analyses and come up with interesting connections that were not apparent previously. One of their issues is finding data they can use. In particular, there appears to be a constraint on the labelling of data and the cleaning of data. Much of that requires very skilled clinical knowledge. One of my many part-time roles is as an assessor of investment proposals. One thing that crops up regularly is the explanation of the need for a significant amount of expenditure just to clean and catalogue data before it can be analysed for machine learning and artificial intelligence purposes.

There is one other issue. Matthew Gould specifically made mention of developing the sufficient regulation of artificial intelligence. There is one wrinkle that this Committee might like to do something about, which is

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use to model the effects of different funding reforms on the public finances and individuals. The IFS conducted an independent review of their modelling back in 2018, the report is available here: https://www.ifs.org.uk/publications/13336

the concept of CE certification. The Medical Device Regulation is going to replace the medical devices directive on 26 May. If an app or service that is being offered to patients directly is considered to be involved in activities like "monitoring", "treating" and "curing", it risks becoming a medical device. If it becomes a medical device, our members will have to shell out at least £50,000 more, and quite possibly a good deal more.

Unfortunately, many of them also do not yet realise there is a number of standards they need to obey from the start of their development. When they say, "Now I think I need CE certification", occasionally you need to go back and say, "Well, you have not followed this ISO or that ISO". They will then have to tear up their work and start again. Essentially, this creates a cliff edge. You have a lot of SMEs close to that and they tinker around with their intended use explanation to ensure they are not seen as a medical device. In America, the FDA has a much more gradual process and it is possible to approach the concept of a medical device gradually. In the UK, it is very much a cliff edge. That is a significant constraint on the development of artificial intelligence by SMEs.

Lord Mair: As I understood your earlier point, there is a difficulty with uniformity of description or coding. Is that right?

Charles Lowe: Yes.

Lord Mair: Clinicians need to describe particular medical conditions but that has to be understood in a uniform way for the AI to be effective.

Charles Lowe: Yes. If AI is going to analyse a series of pictures of a particular type of tumour, you have to ensure it is that type of tumour. In order for the machine to understand it, it has to be described very precisely for the machine subsequently to be able to say, "I recognise that as a tumour of this type".

Lord Mair: What about dementia? How is that problem addressed in something more difficult to define, such as dementia?

Charles Lowe: I am involved with and am a patient on the CHARIOT trial, which is trying to pick up early physical appearances of dementia. At the end of every quarter, I undergo some extremely detailed intelligence and memory tests. They take various bits of my body every six months and analyse them to see if there are any changes. Those will be appropriately labelled so that they can be put through an artificial intelligence device.

Lord Mair: The labelling is rather crucial, is it not?

Charles Lowe: It is. You are absolutely right. There is a particular issue of making sure there is no bias in that labelling.

Q145 **Baroness Manningham-Buller:** My question has largely been answered by the previous panel and some of the comments you have made about barriers to the use of health data. We have covered a lot of them: legal, ethical, public opinion, communication between different datasets and so on. Are there any that we should have considered as relevant that we have not touched on? Is there anything in the list that we have heard in

the previous session and from you that is incomplete?

Charles Lowe: I can offer you a trivial one which nevertheless is important. I sit on a number of prize committees for pitches for SME start-ups. I have noticed that information start-ups have a much harder time gaining approval than ones that have a device that will measure a particular function of the body. There are one or two organisations, one of which is Faculty, which do an extremely good job of making information start-ups successful. Typically, what you find is they stress qualities and not benefits. For the average person who does not understand the detail of what is being proposed, it goes over their head. If they could be encouraged to be a little more focused, that would be good news. I suspect it will be of no interest to this Committee, but it is an observation.

Baroness Manningham-Buller: You would be surprised what interests us.

Dr Jeni Tennison: May I highlight two things which I do not think you have heard? One is around the licensing of data and the legal constraints on the way in which it can be reused and shared. We highlight at ODI that open licensing of data, where appropriate, is necessary to let us combine different datasets with the minimum of friction, which enables that to be used in much more flexible ways.

The other one is ongoing and repeated access. My thinking is influenced by the work of Ben Goldacre at DataLab on Open Prescribing. In a paper that he wrote that was published about a month ago, he spoke of barriers that they have found in getting access to open prescribing data where the location of the data moves around and is coded in different ways over time. It is about consistency of access.

Baroness Manningham-Buller: I think in Scotland they have cracked that one on prescribing data.

Dr Jeni Tennison: His paper was based on England data. There may be differences.

Baroness Manningham-Buller: Does anybody want to fill any gaps? I have a supplementary to bring us back to the subject of this inquiry, which is ageing, where we had a very clear steer from the previous panel that it was better to have data on everybody rather than data relevant to ageing. Do you agree with that?

Dr Paola Zaninotto: One of the challenges is digital access for older people. Health research that is based mainly on collecting data digitally is missing out on the most vulnerable people in the population. There are people in their 70s, 80s and 90s who do not use computers or smartphones, or they have them but do not feel confident using them. It is important to continue to collect data face-to-face or by telephone interviewing of vulnerable people otherwise we will miss out on a large chunk of the population.

Professor Julian Peto: We did a randomised trial of vitamin D in people aged up to 85. Up to age 80, the majority chose to be contacted by

email. Even for those aged 80 to 84—this was five years ago—it was 37%. You can do large studies very cheaply with older people who are tech savvy. There are very few medical discoveries which are true in a subgroup of patients but are not true across the population. The bodies of people who use email work in the same way as those who do not use email. For research purposes the primary objective should be to get the best data we can easily and cheaply. There are lots of very expensive other things we could do but sending people emails is a lot cheaper than interviewing them.

Lord Borwick: You have explained the barriers and how they could be changed. To what extent is this a worldwide problem? Could you do research in different parts of the world that you cannot do in the UK? Can we see that research money being spent in other parts of the world as a result of these barriers?

Professor Julian Peto: Nowhere in the world has our combination of a large population, a national health service and very good records. We are in a unique position to do the best research in the world in relation to epidemiology and clinical trials. We do not know how to prevent dementia. We do not know how to make people live longer and healthier. The way to discover that is by research. We know how to do the research, but we are enormously obstructed. The answer is simple. As we have the best data in the world we may as well use it.

Lord Borwick: Is there no other country with anything remotely achievable?

Professor Julian Peto: Scandinavian countries—some are better and some are worse—are less restricted and produce very useful information on extraordinary questions such as whether women who have children by different fathers have higher or lower breast cancer risks. They link social data to medical data in a way which is sometimes extremely informative.

Baroness Sheehan: You mentioned that we hold very valuable data. What is the risk that that data might be used for commercial purposes abroad or sold to Google, et cetera, before the NHS and medical researchers in the UK have the opportunity to capitalise on it?

Professor Julian Peto: If Google discover something that we cannot that is all to the good. The danger with Google is they link with Facebook and start running elections with it.

Baroness Sheehan: It was an example.

Professor Julian Peto: If they discover something before we do that is great.

Dr Jeni Tennison: We need to recognise that the private sector has a strong role to play in getting value out of data. That includes things such as Google Health but also pharma companies and so on. Communicating that and the role of the private sector in gaining those benefits is one of the challenges we have about communicating the benefits in general of using health data to patients and the populace at large. Part of that is needing to have better ways of sharing that value and understanding how

that is shared back to society. You heard from the previous panel that most people are quite happy with data being used if they view that as being a public benefit, but there is a lot more concern when that value is fed into profits. Getting that value shared is going to be tricky.

Baroness Sheehan: There is the issue of public trust and I think that is still a live issue. In the public's mind there appears to be a blurring of commercial interests via non-commercial interests in the way their data is used and exploited. Is there a quick answer to that challenge?

Dr Jeni Tennison: My observation is that trust in the way that data is used is infectious. Unfortunately, distrust over the use of Facebook data and other social media data infects the way the public perceive the use of health data. We need to level up all our trust around all use of data to take advantage of it.

Baroness Sheehan: Do you think that public perception drives the policymakers?

Dr Jeni Tennison: I think so. If you look at the places where money is invested and the bodies that are set up, particularly around data ethics and those kinds of areas, you see investment going into places where you see public distrust.

Professor Julian Peto: If there were to be legislation to facilitate medical research, the first and easiest target would be non-commercial research. A law should be passed on non-commercial research and a further question asked as to what extra regulation should apply to commercial research. There are grey areas. Very large clinical trials are often funded by the pharmaceutical industry but run entirely under academic control. They have to be classified as non-commercial. As a basic principle, non-commercial research should have much lighter-touch regulation in relation to access to data.

I want to come back to one other point which Lord Winston raised. The issue of tissue is separately regulated, and it is very unfortunate because stored tissue is enormously informative. If you are giving Google DeepMind the job of predicting which cancer will develop, it is extremely useful to know exactly which cancer is which when they are trying to develop the software. Modern methods of tissue analysis can do extraordinary things in terms of surface markers and genetic sequences. Far more refined classification of cancers, for example, can be achieved with access to stored tissue samples. It is not practical to get patient informed consent. Many of them are dead. It is not possible or desirable to get informed consent to use that material. The Human Tissue Act needs to be amended.

Q146 **Lord Browne of Ladyton:** The irony is that people may distrust Facebook but, for some bizarre reason, it does not stop them giving them all the information they can amass. My question is about integration between health data collected by private organisations and data collected in the NHS. It has already been answered, or at least the issues raised were answered in response to Lord Kakkar's question. Unless anybody wishes to add to what Charles Lowe has already said or to the evidence

we have heard from other people, I do not think there is a need for me to ask that question other than in the following way. Is there some international example of a country comparable to ours that that does not have this problem, and where there is integration between private sector data and health service data where the health service is provided by public resource? If so, we could learn from that.

Charles Lowe: Not that I am aware of. I work very closely with an American organisation and they have many problems in America. I cannot think of one. That does not mean to say it does not exist; I just do not know it.

Dr Jeni Tennison: The methods and organisational or institutional structures we need for having data collected by the private sector shared back for public benefit are very much in their infancy across the world. We have been doing particular research on the notion of data trusts and other data institutions to get that working better, but we are in very early stages of getting that working well.

Lord Browne of Ladyton: We have the healthy ageing grand challenge. Have any of you had an opportunity to be involved with the grand challenge to make the points you have made to us?

Dr Paola Zaninotto: Not directly. May I go back to your previous question on integrating data? There are different ways of integrating data. We have two examples in our study where we have been integrating data collected through wrist-worn accelerometers to monitor physical activity in older people. Measuring physical activity from self-responses in older people is quite difficult and you do not get a reliable response. This has proved to be very valuable. Wrist-worn accelerometers produce a large amount of data. The analysis is facilitated by machine learning. We are going forward with that and will apply these monitors to the whole sample because it is important to integrate this type of data with the data that we collect.

Lord Browne of Ladyton: The essence of the question is: is that data accessible to and accepted by those who are looking at the same issues from a national health perspective?

Professor Julian Peto: I have one personal anecdote. The strongest candidate for a cheap way of improving health in old age is vitamin D. There is very strong epidemiological evidence that it has all sorts of benefits in relation to prevention of all sorts of diseases and infections, even prevention of dementia. The evidence is all epidemiological and deeply suspect because cause and effect are easy to confuse. The only way of answering the question is a very large randomised trial where older people are given vitamin D for the rest of their lives and followed for the rest of their lives. In its wisdom, the NIHR gave us nearly £1 million to do a feasibility study, which we duly did very successfully. We went back to them and said, "Will you now fund the main trial?" and they said, "No, we've lost interest in that". That is a trial which ought to be done and would be very easy and cheap to do with automatic follow-up through NHS records.

Baroness Young of Old Scone: Mr Lowe, have any of your SMEs had any access to the challenge fund?

Charles Lowe: I was involved in assessing for the first round the so-called Trailblazers. I can report back that I was hugely impressed by the quality of the proposals, but I cannot discuss details. We publicised it widely within DHACA. To the best of my knowledge, a number of our members have applied for it. We are waiting to find out what the results of the first round are. I am not aware that it has come out, but maybe it has. It looks very promising and is very exciting.

Baroness Young of Old Scone: How directed was that? Is it a thousand flowers blooming or are there some key lines of research that are being funded?

Charles Lowe: One or two of the proposals that I was sent to analyse, and I cannot tell whether that was a representative sample, focused on specific aspects of healthy ageing. One or two took the view that they were going to develop a portfolio of projects with a particular connection.

The Chair: Are any of you familiar with NHS apps?

Charles Lowe: Yes, I am. Absolutely.

The Chair: We had a question from a member of the public who was watching this panel and the previous one. They asked whether you think there is enough testing of NHS apps by the public rather than those who set it up? Do you have a comment?

Charles Lowe: I am aware that there is a proposal to encourage increased user involvement in the development and subsequent enhancement of apps approved for the NHS Apps Library. In a previous role, I assessed about half of the apps currently on the NHS Apps Library. At that time, we were using the NHS's digital assessment questions, otherwise known as the DAQs. There are 500 or so of those questions. One section, for example, covers Usability and Accessibility - this specifically requires the involvement of patients and, to a lesser extent, of clinicians in the development and testing of the app. There is therefore already a significant amount of patient input. If you look at some of the third-party systems, such as ORCHA, you see that it has an additional rating specifically from patients—the five-star feedback-type rating that everybody is familiar with on Amazon and such like. I think there is a proposal to increase that.

The Chair: I want to thank all of you for coming today to help us. It has been most helpful.