HOUSE OF LORDS

Select Committee on Science and Technology

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

Tuesday 25 February 2020

10.20 am

Watch the meeting

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

Evidence Session No. 15 Heard in Public Questions 131 - 138

Witnesses

Dame Fiona Caldicott, National Data Guardian; Matthew Gould, CEO, NHSX; Chris Roebuck, Chief Statistician, NHS Digital; Dr Jem Rashbass, Executive Director of Master Registries and Data, NHS Digital.

USE OF THE TRANSCRIPT

Examination of witnesses

Dame Fiona Caldicott, Matthew Gould, Chris Roebuck and Dr Jem Rashbass.

Q131 **The Chair:** Good morning, Dame Fiona and gentlemen. Welcome and thank you for coming today to help us with this inquiry. There are some familiar faces to me; it is nice to see you. Before we start, would you mind introducing yourselves for the record from my left? If you want to make an opening statement, feel free to do so. If you have any interests to declare, please do so at the beginning.

Chris Roebuck: I am the chief statistician at NHS Digital. I am accountable for the nearly 300 sets of official statistics we produce each year. These cover a range of health and care data, predominantly in England, including administrative data, clinical data and survey data. We release them to encourage transparency, to help with local and national decision-making and for public accountability. Typically, statistics and the wider statistical service can make available quite granular local information and demographic breakdowns as well, so what is particularly relevant is most of our statistics can be broken down quite granularly by age.

Dr Jem Rashbass: I am a medic by background. I am the executive director for disease registers in NHS Digital. I have been there for about four months. Prior to that I was the national director for disease registration and cancer analysis in Public Health England and I ran the disease registration services for cancer, rare diseases and congenital anomalies. My role in NHS Digital is data collection, curation, quality assurance and linkage of data.

Matthew Gould: I have been the chief executive of NHSX since July last year. It might be worth taking a second to explain NHSX. It is a new non-statutory body that was set up to try to unify the different levers around digital transformation in health and care. We are part of both DHSC, where I am director-general for technology, and NHS England and NHS Improvement, where I am the national director for digital transformation. The idea is in a single place we are able to do policy, budgets, strategy, standards, et cetera, and we are the single point, the Secretary of State describes it as the "guiding mind" on these issues. We have a convening authority which we use in areas such as information governance and the regulation of AI in health and care to bring together all the interested parties.

Dame Fiona Caldicott: I have worked as a psychiatrist for many years and have worked in the NHS all my professional life. Jeremy Hunt conceived the role of the National Data Guardian in 2014 when I had been doing some work on health and care data and its use, particularly the sharing of it as opposed to an emphasis on confidentiality. I have been in the role for the last six years, and one of its principal aims is to be the advocate for the public's interest in how their health and care data is used, how it is safeguarded and how their rights to privacy are protected. One of the key themes for us is trust, because at the centre of

the work is the confidential conversation between a person who is a patient with a clinician.

The other thing that is very important about the role and my panel, which became statutory in April last year, is that we are independent, so we are able to give advice and to scrutinise the work of the department and other bodies concerned with health and care data. It has been very important to us in having the trust of the public that we are thinking about their interests alongside all the authoritative bodies.

Q132 **The Chair:** Thank you very much. Of course, we are all familiar with Caldicott guardians, the army of guardians, but which are not to guard you, Fiona. By the way, I should have said we are being livestreamed and this morning's session is also on the Parliament Live channel, so if you have any private conversations they will be picked up.

Let me start off with the first question which is about the use of data that the NHS has and particularly its use in planning and designing services not in healthcare generally but for older people. I would like to hear from you whether the data is used specifically to plan services and track diseases for older people. Within it, what is the role of NHSX and NHS Digital?

Matthew Gould: As you have said, data is informing management decisions particularly by commissioners right across the NHS all the time. At an aggregate level you have CCGs looking at data to try to work out how best to use their resources. At an individual level you have clinicians using patient data to identify risk and best treatment. What I would say is this: at its best there are some fantastic examples of data being used really effectively to improve care, particularly care of the elderly. You have parts of the country which are doing really brilliant things with population management. For example, Frimley in Surrey has really got its act together in terms of pulling together data across different providers, health and care, to be able to identify what issues its population are facing, to risk stratify the people it is looking after and to ensure that its resources are used to best effect. You have a good number of places where data is being shared across silos. In places such as Manchester and Liverpool, for example, you see data being well shared across health and care. You have some good examples starting to happen of commissioners and management across NHS and care identifying those who are most at risk. In Nottinghamshire there is a really nice example of leadership which has done well in setting up systems to use data to identify those who most need attention and care.

It is also worth saying at the outset that the use of data in this way is not consistent and there are a number of systemic issues which get in the way of this happening. One is the well-known siloisation of health and care and the fact that data does not for the most part flow easily between the two sectors.

Secondly, I would say there are issues around technical interoperability, so systems not being able to speak to each other. That can be within individual providers, between primary and secondary and mental health

and other parts of the NHS, and then between health and care, so there is a technical issue.

Thirdly, there is an issue around what you might call semantic interoperability, so people describing things in different ways, which makes it difficult for the data to be used and to flow effectively and to get the most value out it. If, for example, a medicine or a dosage is described differently in one part of the system to another it makes it difficult for the data to be maximumly valuable.

Lastly, but by no means least is a concern across much of the system that if data is shared wrongly they will get into trouble, so there are concerns around information governance inhibiting the flow of data in the way that we would like to see.

The Chair: Are there examples where the data is specifically used for planning of services or tracking of disease for older people?

Matthew Gould: I would say Nottinghamshire is a really good example of local leadership which has done exactly that. It is using data from health and care to identify those older people who are most at risk and most need the services that they have to offer.

Dr Jem Rashbass: I can talk from the perspective of NHS Digital and Public Health England and perhaps give the example in the National Cancer Registration and Analysis Service where we have done a specific piece of work looking at access to chemotherapy in older patients. It is called ABC—Age is no Barrier to Chemotherapy. In this country we have one of the most sophisticated data collection systems for cancer and cancer therapies and we are able to identify every individual who receives chemotherapy. On the basis of that we can look to ensure that individuals with the appropriate conditions are given the right treatment and we can look to see whether age is in fact a discriminator by tumour site, by individual hospital site, by individual consultant. That piece of work is very informative. It is about to be published. It shows that we are very good at not discriminating against older patients for chemotherapy in appropriate centres but that there is some unequal distribution.

One of the most important uses of data in the elderly population is to highlight variation: variation in access, variation in practice and variation in outcome. Each of those are things we need to be able to look at. To be able to do that we need to be able to follow a patient over the entire care pathway and between sectors, and that is where the real challenge is. We are getting increasingly good—not perfect—in some diseases at collecting data in the healthcare sector, but it is the spill into and transfer between health and social care where we see challenges.

NHS Digital has been working on an adult social care programme for the last five years to try to improve that join between health and social care, particularly around not creating a digitally disadvantaged community of the elderly population. We are very taken by the use of new technologies and smartphones, but they are not always the way that an older population wants to interact with a healthcare service. We need to ensure both that we train those people who wish to take part and provide

supplementary mechanisms to allow individuals to be captured into the system.

Viscount Ridley: May I ask a question about the objectivity of data? One of the principal interests of this Committee is the Government's aim of shrinking the gap between healthy lifespan and total lifespan. In one of our very first evidence sessions we heard from the Chief Medical Officer, Professor Whitty, that the problem with that is defining health span, the point when you are no longer a healthy ageing person, is extremely subjective and very difficult. Is there any work being done on trying to put an objective measure on that and ensuring it is consistent so we can tell whether it is changing? Does Mr Roebuck have a view on that?

Chris Roebuck: We do a lot of work around capturing survey data. In the Health Survey for England, which is a big survey, we ask patients and a sample of the public to respond to a range of health questions, including their health status. There are various measures such as whether people need help with bathing, dressing and other daily activities, and that is one approach we can take. It also looks at other support they need with other tasks. There is a degree of subjectivity in that some people with similar conditions may want to be more independent than others, but, ultimately, that subjectivity is important to a degree, because if someone feels that a condition is restricting them and because of that they are not doing the daily tasks they could be doing, that is affecting their healthy life and their full participation. Our data shows there is a strong link between depression and anxiety and the extent to which people can fulfil daily tasks.

Lord Winston: Could I ask Matthew Gould a question? In a cash-strapped NHS where you have chief executives looking over your shoulder, as you suggested, to what extent is one problem trying to improve the relationship with chief executives of trusts in understanding the needs of older people, because it seems to me that here there is a real risk we are not getting the messages across that are being promoted? Do you think that is true?

Matthew Gould: One of the things that I have observed in my time in the job as I go across the system speaking to providers, GPs, clinicians and hospital chief executives, is in a system which is under a degree of strain and where bandwidth is limited, the ability of people across the system to identify and make use of and deploy technologies which might help relieve some of that strain is an issue. NHSX, together with colleagues in NHSD and elsewhere, is trying to make that easier and help those bits of the system which probably most need the benefits of this technology but, because of that, have the least bandwidth to deploy it to be able to do so. For example, the operational guidance that has just gone out from NHS England makes clear for the first time that there are a number of applications which are essentially now proven at both secondary and primary level to relieve burden and improve productivity. There is an expectation on providers to make use of them. NHSX will maintain guidance about which applications have been so proven and we will stand up and resource to be able to help providers with the deployment of the applications. It is no good just giving bits of

technology to bits of the system that do not feel they have the bandwidth or the capacity to be able to deploy them. They need more active assistance. It is a generic answer to the question, but I think it is also true in relation to care for the elderly that providers will need a certain amount of guidance and support to be able to use the technologies that might most help them.

Lord Winston: I have just one interjection. You mentioned chemotherapy and of course that is great, but the care of old people in general in the health service has not been of a very high standard. There are huge numbers of old people who still feel very isolated in hospital. The question is whether the attitudes towards old people are now changing in the health service, because that seems to me to be pretty critical if we are going to improve data collection.

Dr Jem Rashbass: Yes, I agree, but I think it is more important to keep old people out of hospital as best we can. It is the support of the social care sector and allowing people to be in their own homes and their own environments and avoiding the destabilisation, which many of us feel at any age on going into a hospital environment, which really causes alienation when old people end up in hospital. Again, one of our focuses is to help the acute care sector to best look after patients they have, to treat acute medical conditions that have to be seen in hospital, but to ensure that the discharge process, the ability to pass medications out of hospital, to take somebody back into their own home environment, with that supportive environment around them. That is where technologies really give us an opportunity, both to ensure that we move the data between the sectors so that people are not lost and falling through gaps and that the home environment they go back to is potentially digitally enabled to detect when they fall over and to provide an environment which is safe and as best as it can be.

The Chair: I have a brief question from Lord Browne and then I will move on to Baroness Rock.

Lord Browne of Ladyton: This is a question specifically about one of your systemic barriers, Mr Gould. We have four of these, siloisation, lack of interoperability of systems, and people speaking a different language, the semantic issue, but the one I am really interested in is fear of making a mistake in handling data. People who work in health regimes all over the country delivering healthcare are not alone in having this, but, presumably, either the people of Nottingham are less risk averse, which is unlikely, or they have managed to manage that culture of fear or solved it. How have they done it?

Matthew Gould: From what I have seen, where you have bits of the system that have done this effectively they have devoted a good amount of time and energy both to clarifying the rules for themselves and creating a coalition of clinicians, social care workers and others who are willing to buy into whatever data-sharing arrangement they have put in place locally. I could make a couple of observations on this point. First, it is something Dame Fiona and I discussed at length together with Elizabeth Denham, the Information Commissioner, and Sarah Wilkinson,

chief executive of NHS Digital, and others. Collectively, we are clear that we have a job to do. NHSX can play a useful convening role in this by bringing together the parties that are most involved that have at times been individually putting out guidance, and starting a process to try to create for the system more coherent, unitary straightforward guidance. One of the issues which people have come across is there is a range of different codes, laws, common law and so forth, and a fear that unless you are a world expert in this stuff navigating between them is difficult and so the rational thing to do is to take the path of least risk.

That comes at an enormous human cost when patient information which should be shared is not. I have seen some heart-breaking examples in the system where concerns around information governance and the consequences of getting it wrong have got in the way of patient data being shared for the benefit of that patient. Recently, I visited a hospice outside of Manchester. I sat in on the weekly clinical meeting and it was a group of clinicians who were caring for patients in the last weeks of their life, so right at the most vulnerable end of the spectrum, and there was a technical ability to share data but it required the agreement of the clinicians who were the data controllers for that data to be shared, and in a number of those cases that agreement was not given. I am sure it was out of concern for the consequences if they got that decision wrong, but what that meant was clinicians in the hospice, who were trying to care for these patients at the end of life, lacked some of the information that might have eased that process. That was absolutely heart breaking to see. Between us, we are confident we can create guidance which is more simple, straightforward and coherent.

Q133 **Baroness Rock:** First, could I declare my interest as a board member of the Centre for Data Ethics and Innovation? Could I expand on the theme of data sharing a bit more to the panel? To what extent is healthcare data from the NHS shared outside the NHS? There are particular challenges associated with that. Could you expand a bit more on what those are, particularly as there has been some controversy over recent years over the sharing of data with private companies, and I think DeepMind would be at the forefront of that? Could you also expand a little on the control that patients have over use of their data currently and where you think this is likely to evolve in the next five years? Lastly, could you give me a little bit of insight into why care.data was unsuccessful and what lessons have been learned from that?

Dame Fiona Caldicott: It is difficult to measure the extent to which data is shared outside the NHS, phrasing it in that way, but I would like to comment on the fact that because of the failure to take the public with us on these issues, we have a public generally which does not know very much about how the healthcare or social care systems work and when they are confronted with clinical needs within the service they are quite surprised by some of the issues to do with data. We think there is a big public education need, which is one of our priorities now. It is not just about induction programmes for staff when they come into a post; it is how we keep them up to date as they go through their careers.

Linking back to the question before, the word that comes to my mind is leadership. If the leadership in the organisation you are looking at understands that the governance of health and care data is just as important as clinical governance in its benefit to the patient, and to the community from which they come, there is a very different approach compared to what some people have just looking at technical issues, as opposed to those central to the care of the individual.

From the public's point of view, there is a hierarchy of approval, I would say, about who might have the data. Most of the public, when we talk to them or survey them, immediately understand what their individual care involves. They share their data with the clinician, they know it might have to be shared with another clinician and they accept that. Once we start talking to them about issues such as population care and research the public is less knowledgeable, and therefore have more questions to ask and have answered. However, they are very altruistic in general. Our public, once they are given the information, see the benefit there is for others in knowing more about the conditions they have suffered from. It involves a process. You have to take the public with you, I would say. They do not just know these things, and we find it very difficult when what they know is from the page of one of the newspapers, if I can put it like that.

They have a hierarchy of worry and when they read about data being shared with commercial companies, even pharma, because they know that can lead to the benefit of new drugs, it is the word "profit" that is the most difficult. Again, it is a matter of education and discussion about the benefits that come from the sort of work that Matthew has been describing with the technology. If you put artificial intelligence in front of an average member of the public they will be very puzzled. To take them through how that can benefit them, even if it is through a commercial company that is developing software, is not a quick process. We have to think about how we can best do that. I think we can take the public with us, but we cannot do it overnight and the media stories are not always very helpful.

The Chair: Are you always aware of who is using the data?

Dame Fiona Caldicott: That is a very good question. If they go to their GP and ask, they will hear a certain amount about who is using the data, and the same when they go to the secondary care, the hospital, but often that is a puzzle. If they look on websites, they are not as informative and easily accessible for the average member of the public to see. How we put very accessible information about these issues in front of the public should be part of our educational campaign. We have not been good at that and keeping pace with the technology.

Matthew Gould: May I add to that? I agree with everything Dame Fiona has said. In answer to your question, Chair, as a general principle the more we can tell people about how their data is being used the better and the technological means now exist for us to be able to do better and better at that.

I want to go back to the point Dame Fiona made about the commercial use of data. All the evidence—and there has been a good deal of research into this that I have seen—suggests that the public are altruistic, and between 70% and 75% will support the use of their data for secondary purposes where they see sufficient benefit accruing back to the NHS, and that is key. We need to bring the public and clinicians and expert professions with us. Core to that is doing it in a transparent way and being able to demonstrate that this is to the benefit of the NHS.

As part of that we have done a few things to try to lay the ground work for that. We have established five principles for the use of data which have been published. We have written to all providers to make it clear that no one should be doing any arrangements on data which gives exclusive use of patient data to anyone. We are in the process within NHSX of setting up a centre of expertise precisely to provide support across the system to anyone who is doing or thinking about doing a deal or an arrangement around data so that they have expert support so they can get this right

Lord Kakkar: To come back to this point about public education, what form practically can that take? How should it be mobilised and organised and paid for? How might it be tailored to deal with the different demographic ends of the spectrum in terms of younger and older people. Bearing in mind our inquiry is specifically into the question of ageing, how might one persuade populations that are at the further end of the spectrum of age that this is a good thing for them to participate in?

Dame Fiona Caldicott: One of the things that worries me about these sorts of conversations is our tendency to generalise. I have certainly been ticked off by a member of the public in giving a presentation for an assumption that somehow elderly people were less likely to be interested in the use of technology than other generations. Obviously, I should have declared an interest at the beginning on the topic that you are studying.

We have to bear in mind that we are talking about individual people even though we have to talk in the shorthand of the elderly or the young. I have been interested doing one or two train journeys recently seeing people who are clearly quite a lot older than me using their smartphones and seeming to enjoy that, and I am sure they do because it gives them a whole range of opportunities that they would not otherwise have, particularly if they are lonely, for keeping in touch with whatever they choose. We have to be very innovative about all the ways we understand communication now for the different groups we wish to relate to and tell them more.

A point I want to make is that my experience is that the public tend to be only interested in health and care data when they have a reason to be. If you try to aim at the public you are trying to talk to many people who think, "This is nothing to do with me. I use my banking data, my holiday data, but I am not so interested in health and care data." I am generalising myself in this answer because some people are interested, but I think we have to bear in mind it is usually when people have a reason to be interested in it. We need to use all the means—notices,

websites, videos, everything—for those who are interested in those particular approaches to knowledge.

Lord Kakkar: Is that happening? Is there somewhere that this is all co-ordinated and there is a proper strategic approach to this type of communication, targeted, as you suggest, at the time when our fellow citizens are going to be most interested in accessing it?

Dame Fiona Caldicott: I am afraid the short answer is no, but there is a lot of work going on to develop this, as we have all been saying from our different perspectives. One of our particular aspirations for the immediate future is more public education along the lines that I am describing and finding the funding to do that because it is extremely important.

Matthew Gould: Could I add to the answer? I think another channel which is incredibly important is between citizens and their healthcare professionals. The conversations that they have with their GPs or their care workers and so forth ought to be an important channel of understanding for citizens to get an appreciation of their data and how it is being used. I agree that we have some way to go before we have a coherent single effort on public education and information.

Baroness Walmsley: Mr Gould, you mentioned that 75% of people are happy to have their data used for legitimate purposes. I am interested in what the other 25% are afraid of or against. Do we have any information about that? What are the reasons?

Matthew Gould: The research is there and has been done by the Understanding Patient Data project at the Wellcome Trust and other places. As for the other 25%, I would not presume to speak for them, it goes back to what Dame Fiona said about concern around people profiting from patient data. There is always a small irreducible core of people who do not want their data to be used for anything because they have strong privacy concerns. One of the reasons we set up the national data opt-out was precisely to give people an ability, if they do not want to be part of this, not to be part of this.

Q134 **Baroness Manningham-Buller:** I declare an interest as the chair of the Wellcome Trust. Thank you, Matthew, for referring to that paper. The other thing I wanted to ask about was our research shows that the public do not just want to be informed and educated; they want to have a say, and they want to be listened to and to share in the development of policy. From that aspect, how are you addressing that particular message which we got quite firmly from the work we have done?

Dame Fiona Caldicott: We had a meeting yesterday at which we had a young woman who has experienced cancer and who feels strongly that the patient is not at the centre of the use of data. She was a very articulate person. One of the difficulties is hearing enough from patients who can explain more of exactly what it is they want.

Baroness Manningham-Buller: They think they want.

Dame Fiona Caldicott: They start by wanting one thing but perhaps gradually come to want different and other things. We just have to keep

working at it and involving patients in all these discussions. I do not think the health service traditionally is patient centred but it is trying to be much more patient centred. GP patient participation groups are much more active than they were and trusts have patient participation groups on particular illnesses and so on. The difficulty is getting a breadth of views, given the different interests of the community. It is work we have to do more of, and listen and then act on it. It is not just the listening. That will show the difference that the patients have made to the way the policy is unfolding.

One of the conversations I want to have with Matthew in the near future is how we put this up the agenda of all the work we are doing in health and care, because I do not believe the patient voice is loud enough, but it is not an easy thing to solve. Anything you are able to say in your report on your thoughts about this, particularly for the elderly, would be really helpful to us, because it is a difficult issue to tackle and solve.

Matthew Gould: There is some emerging good practice on this. I have seen for example the use of citizen panels around the use of data in places such as Liverpool to good effect where the citizens have a chance to be informed and to debate, discuss and influence the approach. We are trying very hard to ensure that the patient voice is heard in everything we do. We are in the process, for example, of recruiting some patient advisers to sit on my senior leadership team. I have regular meetings with my senior leadership team and we ensure that there are patients heard in all the projects we have set up. The point that this needs to include the elderly in particular, who have particular concerns on particular issues and particular angles, is an important one.

Q135 **Baroness Young of Old Scone:** We have some large databases such as the UK Biobank and the 100,000 Genomes Project. How effectively are they being used for planning services for assessing prevention technologies and for diagnosis of age-related diseases? An earlier answer we had on whether data was being used for older people's issues seemed to indicate that it was a bit of a researcher-based decision. Researchers could seek access to that data and use it, but if the researchers did not decide to research age-related stuff it would not be accessed. How effective are those two and any of the other large databases at prompting age-related inquiry?

Dr Jem Rashbass: UK Biobank and the 100,000 Genomes Project are extraordinary world-leading, essentially initially research-driven data collections. They have huge potential and a lot of that is about the longitudinal following up of patients who are part of those cohorts. As you have said, they are largely research driven at the moment, but as the datasets get richer and we get to understand more of the longitudinal outcome of patients, plus in the case of UK Biobank as the patients get older, because they were recruited 20 years ago and were quite young patients in those early days, they are obviously moving on like the rest of us, that becomes more informative. You are right to observe they are not routinely used for service planning and evaluation, they are research driven, but they are hugely valuable in that research question because it

is not just about research planning but about diagnosis and recognition of conditions earlier, optimising treatment and outcomes, all of which are very important in the healthcare process.

When it comes to more operational research and being able to look at the longitudinal care of patients, we are seeing emerging datasets. In NHS Digital we have Hospital Episode Statistics, which is increasingly improving as a dataset that gives the comorbidities of patients and the ability to link that to prescribing information so you can begin to understand a couple of the things that really affect the older population. Those are multiple comorbid conditions and the complications of being on large panels of medications and their interactions. Those sorts of datasets are beginning to emerge, but they are not heavily used yet. There is an opportunity to improve that. UK Biobank and the 100,000 Genomes Project are really at the cutting edge of research as opposed to operational delivery at the moment.

Baroness Young of Old Scone: If you were having birthday and Christmas rolled into one, is there some other major database that you would want to see created to help with the elderly issues?

Dr Jem Rashbass: I have to return to my roots, which is building the national cancer registration service. We have had huge support from the cancer community, and reflecting back on Dame Fiona's comments about respect, trust and transparency you need to collect healthcare data to support a population. The patients who are part of the cancer registry have allowed us to have a very good longitudinal dataset on what happens to cancer patients from the time of diagnosis until their death. That ability to have a longitudinal record where you can see what happens to an individual as a result of treatment, where you can do long-term follow-up years later to see people bouncing back into secondary care, where there are complications of procedures or operations, it is that sort of model that we need to envisage for the future. One of the reasons I am now in NHS Digital is to be able to begin to investigate how we build that longitudinal view of healthcare for an individual so that we can ensure that there is no variation.

The Chair: The question was though: is there such a database being built for older people?

Dr Jem Rashbass: I do not think we would see it as specifically for older people. We would see every individual as being a contributor to it and that includes older people. You can then do that analysis. We all start not old and we all become old. The opportunity is to ensure that that entire life course as best we can is collected.

Baroness Young of Old Scone: If we were going to try to force the pace of that sort of data being useful, would we throw money at the research agenda for older people so that researchers were demanding that or would we have some person in the NHS trying to drive that from the centre?

Dr Jem Rashbass: Ultimately, these things have to be a partnership. You do not build datasets in isolation. You build them starting with a

question and a need. It is not just for the researcher and for the NHS, but for the whole community to recognise, and perhaps driven by this Committee as well, what value can be achieved by a good not primarily a research dataset but a longitudinal dataset that allows us to track the outcome of patients over time.

Viscount Ridley: I declare an interest as a victim of UK Biobank, sorry, that is the wrong word, as somebody who is behind on their latest consultation, but never mind. What age group does it span and how long before that age group is starting to tell us interesting things about the end of healthy living? I cannot remember whether I am in the middle of the age group or at the top or bottom end of it but I am 62.

Dr Jem Rashbass: I do not have that data to hand. Chris might know otherwise we can come back to you.

Viscount Ridley: It feels to me that that cohort is going to move into an interesting age relatively soon and start falling apart, if I can put it bluntly. Is that soon enough to inform policy or are we going to have to wait 20 years to get the data?

Chris Roebuck: I do not have the specific answer on UK Biobank. There are other similar research datasets. There is one run by UCL, the Whitehall II study, which is a cohort of retired civil servants and, again, consented.

Viscount Ridley: These are much smaller, are they not?

Chris Roebuck: They link to a variety of administrative dataset so lots of analysis is being done on that and they are aged 90. I can get back with the specific age range for UK Biobank.

Matthew Gould: May I make one point and return to something Jem said? I would really caution against an approach that said any group of people—old people or young people—are important and therefore they need their own dataset. We want to get to precisely the opposite because much more value is gained out of a unitary approach, which involves us breaking down barriers, establishing standards, setting up a data architecture that works and solving the information governance issues so that the data that is of use in allocating care and doing research for older people is available from that longitudinal approach, not from a series of individual datasets set up for individual populations.

Chris Roebuck: Jem mentioned the Hospital Episode Statistics dataset which has been going 30 years. Last year 80% of people over 85 were seen in hospital in one setting or another, so you are able to build up a very rich and comprehensive set of data that can be used as a backbone for lots and lots of research. We disseminate that and make that available for many researchers who meet the legal criteria for the benefit of health and care.

Lord Kakkar: I declare my interest as chairman of the board of UK Biobank. I wanted to ask one question: are you content that across the spectrum of the different datasets that need to be mobilised and co-ordinated to bring true value to something, such as the 100,000

Genomes Project or UK Biobank or something else, we are now in a position where those data in terms of longitudinal interaction with healthcare services, with broader services provided in the community and so on, has now been achieved?

Dr Jem Rashbass: I am sure we are not there but, as Matthew said, that is a vision to get to. We have huge opportunities to do that. At a very basic level the unique NHS number provides an opportunity to join datasets together. A large amount of the modernisation programmes that are going across the NHS and in social care at the moment are mobilising the ability to get data out of systems. The ability to harmonise the information governance systems behind that allows us to begin to pull data into the appropriate format and share that data. We are some way from getting there, but we are beginning to see a common understanding of what we need to achieve.

The cancer registration service, as you probably know, already provides data on every case of anyone in the 100,000 Genomes Project and anyone who is on UK Biobank, and we are seeing increasingly that linkage with Hospital Episode Statistics and with a range of other datasets. Linkage is always a challenge. It is happening, but we are certainly not there yet.

Lord Mair: Dame Fiona mentioned artificial intelligence—AI. Could I explore that and ask you about what new processes and analytical tools can be used to make better use of data, specifically for ageing? Are we anywhere near using AI yet or is it a bit of a pipe dream?

Dr Jem Rashbass: I think we are in an extraordinary place, potentially, for artificial intelligence. We have always had challenges in the past with looking at groups of patients statistically. Artificial intelligence allows us to take disparate datasets with different properties—imaging datasets, pathology datasets, hospital interaction datasets—and bring a view on to that dataset that allows us to produce new analytical views. What we are seeing at the moment is largely vertical where we are taking the skills of a doctor, say, interpreting an image, learning that and reapplying it to other images. Over time and what we are beginning to see at the cutting edge of artificial intelligence is the longitudinal analysis of patients. If you have these events in the past, what does that predict for the future? That is what I think will change medicine fundamentally. Where we struggle as doctors is in part making the diagnosis, "How do I group you as a patient into a diagnostic bin where I can treat you appropriately?" but as treatments become more refined and focused on an individual, so as an individual they become rarer, and, therefore, it is very difficult to predict what is going to happen to them next. Where AI is beginning to open those doors is to be able to say, "I can look across very large and complex datasets and intuit and work out what will happen to you next as a patient".

To me, the gold standard for medicine is to be able to predict for the patient sitting in front of you asking, "What is going to happen to me next, doctor?" and to be able to understand that and to allow someone to make an informed decision of, "If I take this choice now, what is the

outcome and how will it affect my life and what are the other options I have now?" I think that is what AI will eventually do for us. That is why building this longitudinal record is so fundamental because it underpins that ability to do what every doctor wants to be able to do, which is to tell the patient about what is going to happen to them next.

Matthew Gould: It is not purely a hope for the future. We are starting to see some really interesting examples of AI and machine learning being used in different parts of the system. For example, Barts and UCLH are both deploying AI to identify risk of stroke and heart attack in people. The London Borough of Bexley is using machine learning to identify which people might need particular social care packages, frailty scores, and to understand risk of admission to hospital. The potential for the future is enormous, but we are already starting to see some nice concrete examples of AI making a difference in the provision of care to the elderly.

Lord Mair: What are the barriers? We have heard already several of you have spoken about the difficulty of linkage across different systems. If the AI is really to be effective that problem has to be overcome.

Dr Jem Rashbass: Yes, and I think we are working towards that. The Government have made a very significant investment in the AI Lab and investment in the technologies and skills sets. There is a competition out at the moment for people to bid for projects to use datasets. We need to get the underlying datasets right. We need to sort the information governance. We need to recruit the best brains in the country to solve these really hard problems, but we are in a very good position. The ability to link operational data to UK Biobank data to genome data to imaging data is impressive and the opportunity to do this is some way off but not that far.

Chris Roebuck: At a national level we hold rich and comprehensive data on secondary care. In areas such as social care we do not routinely capture client level data at national level to do that linkage, so there is a need to routinely capture—with appropriate legal basis—client level and patient level data from other settings to build up that really rich dataset.

Matthew Gould: As well as the data we need to get the regulation right. We have not yet put in place a comprehensive set of regulations for artificial intelligence in health and care and until we do that it creates an inhibiting effect on people, who will be concerned either by innovating or making use of innovation in the absence of sufficient regulation that they might incur some liability or risk. We are actively engaged in this and it will be a key part of the AI Lab, precisely to bring together all the different regulatory organisations involved, to ensure we have a common approach and a plan. A few weeks ago Dame Fiona joined me and the heads of 16 other organisations and we spent three hours together precisely to think about this question, and we came up with a plan for ensuring we put in place the regulation that is needed.

Q136 **Baroness Sheehan:** What are the barriers facing the wider and more effective use of health data? Could you address specifically ethical and privacy considerations, data fragmentation and lack of sufficient analysis

skills? Could I also ask you to address the challenges thrown up by issues of public trust? In her question Baroness Rock mentioned the controversy around care.data and the DeepMind issues. I would be very interested to know how we are going to try to overcome those challenge of public trust. Could you also address the question of whether there are particular barriers to the use of data to address conditions of older age? We have already covered that last one a bit.

Dame Fiona Caldicott: Shall I start by commenting on care.data because I think it illustrates a stage in a process of our engagement with the public on some of these issues? It had good intention. That was about accessing general practice data and working to join it with the data that has been described by my colleagues that comes out of hospital care and that would have created longitudinal records of patients.

I think the particular difficulty was that there was insufficient discussion with clinicians about the project, because the first person, as Matthew has already been said, that a patient might go to if they are interested in this area is their general practitioner, so what we witnessed was a group of general practitioners up and down the country who had not been involved in the planning of the project and were very upset because they are responsible legally for the data that they hold in the practice. They are known as the data controllers, and this project was suggesting that that data could just be taken out of the practice and sent to NHS Digital to be joined with other hospital data. I think it was an omission of the importance of understanding the clinical relationship with individual patients that led to the difficulties.

Of course, the public heard about it and they were very upset too. In the end it did not have enough strength in its rationale, to explain to the key people who would have to implement it, for it to be achievable, which is why I think the Government decided it should be ceased. A lot has been learned from that and I know one of the issues we have taken particularly seriously is working with the general clinical population and the social care providers regarding their relationship with the public on these issues, so that we recognise the trust that is in that relationship and how important it is for those individuals who are delivering care to be able to explain projects to their patients. That is the starting point.

The building of trust is about being transparent on all these issues and in all the work. This is why it is so important to have people representing the views of patients involved in the discussion so we can say the development of policy and the implementation of policy has these contributions from people who have seen it from the patient's point of view. For me, that is the starting point. Much has been done since care.data and we are now regarding that trust we have built with the public as a very precious thing not to be damaged by our failure to communicate, let us say, with the media, which may, if they are not kept informed about what is happening, put out a different point of view, which then has a deleterious effect on people's trust.

Lord Winston: Dame Fiona, I bow to your great experience in public engagement. What we see on the web increasingly are a number of quite

major websites such as What Doctors Don't Tell You, which you are probably aware of and which I subscribe to because I learn quite a lot about what the mistrust is. Should we not be doing more on the active side and using the web much more effectively than we do? At the moment there is a huge amount of information we should be rebutting, which would help that issue of trust.

Dame Fiona Caldicott: I agree with that and reference has been made to Understanding Patient Data which has produced some very good material on the web to inform patients about how data is used and how they can understand more. We should be doing much more of that and that work is going on at the moment.

Lord Browne of Ladyton: I am interested to ask a question that goes back to the last part of the evidence about artificial intelligence. Are you engaging patients in this discussion about a potential comprehensive set of regulations for artificial intelligence?

The Chair: Briefly, Matthew.

Matthew Gould: Yes.

The Chair: Do you want to expand at all?

Matthew Gould: In the session we had of the regulators involved we reached a series of core understandings, one of which was explicitly the need to engage and communicate with the public, and that none of this will stand or work unless we did that. In the very top lines of the plan is a determination to try to engage the public as we produce this.

Lord Browne of Ladyton: I just want to understand that answer. Is that your intention or are you already engaging patients in the conversation?

Matthew Gould: I would say at this stage it is a determination.

Q137 **Baroness Hilton of Eggardon:** You have said quite a lot about the problem of sharing NHS data with the commercial world, but there is the opposite problem of the commercial world sharing data with you, not only from their research but because they run nursing homes and care homes which presumably could be a rich source of information for you. I wondered what your views are on that.

Matthew Gould: I absolutely agree. It is useful in the respect that the remit of the NHSX extends to social care as well as to health. The most important thing we can do here is establish standards; technical standards so that systems can speak to each other and semantic standards so that things are described in the same way. If you can get both those elements right data can flow more effectively between nursing homes and hospitals, for example. A large part, probably the core part of the work of NHSX is precisely to try to establish and find ways to propagate and enforce those standards.

Baroness Hilton of Eggardon: How willing are they to share information with you, which was really the point of my question?

Dr Jem Rashbass: Very willing. I think everyone recognises that you get substandard care if you do not share data across boundaries. The private

sector recognises that as well as the NHS. NHS Digital works very closely with PHIN, the Private Healthcare Information Network, to share data on private patients and NHS patients, and we are looking at how we join that data.

The challenges in social care, though, should not be underestimated. There are 18,500 care providers with over 39,000 establishments. Some 62% of those organisations are small with fewer than five staff in them. Some 58% of these organisations are non-residential and about half of them are private. It is a huge logistical challenge to do this, but it is clearly one we need to address. Both sides are willing. Most important from the point of view of confidence of patients and the public is that we have secure robust systems that transfer data safely using the sorts of standards that Matthew has just referred to.

Viscount Ridley: There was an article recently by Professor Tim Spector and Professor Barbara Prainsack in *The Conversation* complaining that there are cases where patients had already given their consent to data being used, but research ethics committees decided the researchers needed to go back to them and ask them again for consent before doing specific further research project. This added a huge administrative burden and potentially meant the research would not take place. Does anyone have any comments on whether sometimes we are going too far in asking for consent here?

Dr Jem Rashbass: This is a difficult area. As we have said, we hold very dear information governance and our duty to protect patient confidentiality and respect of individuals, and I think we may have gone too far and, as Matthew has said, we need to have that open conversation and to not just hide behind bureaucracy where there is benefit to be had. On occasion, we find ourselves with a changing landscape where the consent was taken some time ago, and there is a concern that that consent may no longer be valid. Of course, it is very frustrating if you are a researcher not able to get data and we need to reduce those barriers, but at the same time maintain public confidence with honesty, transparency and openness on the use of data. I think it is a balance, but I am not surprised to have heard that. Occasionally we might go too far and it is something we need to address.

Q138 **Baroness Penn:** This inquiry is focused on recommendations to the Government in the context of their Healthy Ageing: the Grand Challenge, and specifically their target for five years of extra healthy life expectancy in 15 years' time and, importantly, their target to reduce the gap in healthy life expectancy. We have heard a huge amount in this session, but to bring it back to those specific targets, what would be the things that we need to do that we are not yet doing in the world of healthcare data and the use of healthcare data to help deliver them?

Matthew Gould: If we get this right using all the things we talked about—improving the quality of data, making data more consistent and making data flow between silos and across the system and so forth—there ought to be six benefits from it. They are: more effective system management, so the use of resources on those who most need it; joining

up between different theatres of care between health and social care in particular; identifying those most at risk and ensuring they get the support they need to prevent admissions, in particular, wherever possible; making sure that healthcare is personalised so people get the care that they as individuals need; using data to support the prevention agenda and in the process empowering people to drive their own care; and, finally, to support research into new therapies and new techniques. These are all potential prizes of getting this right.

Baroness Penn: Do you think we are on track to do that or are there gaps in what we are doing at the moment that will affect the delivery against that target from the data point of view?

Matthew Gould: There are definitely gaps now and we are doing our best to address them. We have a plan and we are working very closely with NHS Digital and colleagues in partner organisations to do that, but it is not a straightforward task. It needs lot of parts to come into alignment. It is a work of years.

Dame Fiona Caldicott: I would add that there needs to be more emphasis on patient centredness. That would make a lot of difference because I think that would build the trust of the public if they could see examples of ways in which we are involving them in the development of policy and the work we are doing to use the benefits of the wonderful technological achievements but without damaging the precious relationship that they wish to have in a confidential environment.

The Chair: In terms of use of data and monitoring success or otherwise, to follow on from Baroness Penn's question, are you involved with those who are driving the strategy of the Grand Challenge?

Dr Jem Rashbass: Yes.

The Chair: In what way?

Dr Jem Rashbass: Certainly in NHS Digital we are responsible for collecting the data and quality assuring and linking it. The other thing that is important about this dataset is we have examples of where there is success. We are looking at the difference between areas where there is that success and elsewhere. That gap analysis gives you opportunity. It does not make the problem simple or easy to solve because many of these things are not as simple as just joining data, they are the wider determinants of health and all those are bigger system things that we need to address. The elegance of having good measuring systems allows you to begin to target interventions, test interventions and see change, and I think that is what I see out of data.

Baroness Penn: To pick up on that point about a lot of this can be about differential outcomes and the areas that are doing this best, as it were, are already delivering substantially better outcomes, is your involvement in the Grand Challenge also ensuring that where some of this work needs to be done first, or the areas leading the way, are the areas that will help close that outcome gap in terms of healthy life expectancy?

Dr Jem Rashbass: Grand Challenges are by their nature grand and have a wide audience. We play a role around data, quality assurance and advising on data systems. Matthew is involved in policy and we also have information governance. There is a big picture around this which involves many parties. We are there but I would not say we are the prime determinant of it.

Baroness Young of Old Scone: Could I ask a supplementary about that because there is a lot of money attached to this—£300 million for the Grand Challenges so far? How much of that is coming to the priorities that you have been identifying for us today?

Matthew Gould: I cannot put a figure on that.

Baroness Young of Old Scone Small, middling, large.

Matthew Gould: Can I undertake to write to you to set that out?

Baroness Walmsley: Could I go into an area we have not really talked about, which is skills? What is the situation in relation to skills: inputting, understanding standard ways of doing things, analysis and so on? How are we doing in this country in relation to that, at every level?

Dr Jem Rashbass: You can always have more skills, but I think we have some impressive resources. At the input end it is extraordinary that we have 7,500 data coders distributed across the NHS inputting data at a local hospital level. There is an opportunity for artificial intelligence and other things to support more accurate data collection. At the linkage level inside national bodies, such as NHS Digital or Public Health England, there are curators who quality assure and link data and there are initiatives supported by the Office for Life Sciences and the life sciences strategy to increase our ability to curate and quality assure and link data. At the analytical level we have created Health Data Research UK as an academic/NHS/industry partnership that is focused on increasing skill sets for data analysts and data scientists. It has built a number of digital information hubs and research centres across the country focused on specific diseases and the analysis and output. Chris, you may want to talk about analysts and national statistics.

Chris Roebuck: There is a variety of analysts in national bodies including in NHS Digital, and we are rapidly upskilling to build new data science skills and bring in data scientists. One of the great challenges is automating the core data processing work, the repeatable processes, so we free up the capacity of humans to do what only humans can do. I think that is a challenge in every part of the NHS and a big challenge centrally.

Matthew Gould: As Jem has said, we have a lot of very talented and committed individuals. What we have not done but are now trying to do is create professions within the NHS to try to give analysts and clinicians involved in technology and technologists the training, accreditation, kudos and rewards that go with being part of a profession, and the sense of there being a head of profession, support for what they are doing, and an agenda that is helping them as professionals, whether it is analysts or

chief clinical information officers or whatever. I think there is an important agenda of creating professions around these skills.

There is a further element which Chris's remarks alluded to which is too much of what is being done is done by people figuring it out for themselves rather than sharing across the system. The more we can do the analytics of some of this in an open manner, in ways that protect patient data, so we are not in any sense risking patient confidentiality, so there is sharing of code and sharing of workbooks, the more I think we will get exciting results out of this.

The Chair: Do any of you feel you should have a bigger involvement with the Grand Challenge or delivery of it than you already have?

Matthew Gould: No.

The Chair: Let me phrase it another way: should you have a bigger involvement with the Grand Challenge?

Dame Fiona Caldicott: Yes.

Matthew Gould: We are clearly a key part of meeting the Grand Challenge. I do not think we will meet it unless we use data and technology more effectively. We are trying to do that and I think we are reasonably well lashed up. The creation of NHSX allows a more unified approach than was possible before.

The Chair: Thank you very much all of you for coming today to help us.