Dr Sarah Wollaston (Totnes) (Con): I love medical data. They have undoubtedly saved my life and the lives of almost everybody in the House. Medical data, particularly big data, allow us to identify which drugs and procedures work and which do not work. They enable us to pick up the rare side effects of medications that have recently been released on to the market before they can wreak the kind of havoc that we have seen in the past. They enable us to identify which are the good hospitals and which are the failing hospitals. They allow us to identify which clinicians need serious retraining and from which clinicians the public need protection.

I would argue that evidence-based medicine is one of the greatest advances of our age. Evidence-based medicine works a lot better if we have access to big data. I state for the record that I do not intend to opt out. I hope that the Government will use the six months that we have to mount a clear campaign to the public that sets out just what the possibilities are.

I also feel that some of the concerns about releasing big data to pharmaceutical companies are misplaced. We need our pharmaceutical companies to be able to access those data, and there is a virtuous circle. We know that if we attract more research to the UK, not only will that benefit our universities, it will create more employment.

Barbara Keeley (Worsley and Eccles South) (Lab): My honourable colleague from the Health Committee mentions pharmaceutical companies. Does she feel it is appropriate—we touched on this in the first part of the debate—that insurance companies have access to hospital data? As I said yesterday, BT now has access to our hospital patient data on the cloud systems in the United States. Does she think that those uses are concerning, and what should we do about them?

Dr Wollaston: That is absolutely correct and I will come to those points later in my remarks. The public did not expect to see their records uploaded to insurance companies, specifically where that resulted in higher premiums for many people. We have a virtuous circle of improving access to data for our universities and creating high-quality jobs within the industry. If we can attract research to this country, and it is carried out among the UK population, the results from that research will be more relevant to the British population. Also, less research will be carried out in circumstances that are ethically questionable or with oversight that may not be up to the standards we expect in this country, or that sometimes exploits people in developing countries and where we cannot be sure of the accuracy and reporting of that research.

This is a virtuous circle, but I am afraid it has unfortunately been broken by the oversight and some of the arrangements that have taken place in NHS England and the Health and Social Care Information Centre. It is frankly beyond me that nobody has assumed responsibility for destroying the trust in what should have been the most exciting advance that would have benefited countless hundreds of thousands of people, not only now but in the future.

On the six-month delay, I call on the Minister to set out clearly how we will campaign to
inform the public of the benefits of the proposal, but also of the risks. We have seen a rather patronising approach that has assumed the public will not notice or care about those small risks, but they are there and we must set out clearly what they are and how they will be addressed and minimised. There is much more we can do to minimise those small risks.

Of course we need transparency about past errors; the performance of NHS England and the Health and Social Care Information Centre in the Health Committee was disappointing. I am glad that on its website, NHS England has now clarified that Sir Nick Partridge, former chief executive of the Terrence Higgins Trust, will conduct an audit of all previous data releases by the NHS information centre—the predecessor body. We are also expecting the release on 2 April of all the data released by the current body. I understand that that will set out the legal basis for those releases, but also their purpose, and that goes to the heart of my amendment.

We must have clear penalties for breach, not only in the provisions in the Bill, but across the whole NHS and social care sector. The Minister will know that in practice, if somebody wants to snoop on someone’s personal medical data, there are far easier ways to do it. He will also know that the penalties are derisory. In a well-publicised case in December 2013, a finance manager at a general practice had been deliberately snooping on the records of thousands of patients within the practice, and focusing “rather disturbingly” on one young woman he had gone to school with and her family. Those were repeated breaches of her and her family’s privacy in a really toxic way. That individual was fined only Â£996. The public need to be clear that there will be severe penalties not only for individuals who deliberately breach privacy, but for companies. A fine of Â£996 for an insurance company or a large body is laughable.

Mr Jamie Reed (Copeland) (Lab): The hon. Lady makes an excellent case. The maximum fine for an individual breaching the data clause in the situation she describes is Â£5,000. Does she agree that that is inadequate?

Dr Wollaston: I thank the shadow Minister for making the point that Â£5,000 is woefully inadequate. The financial penalties “significant ones on a sliding scale commensurate with the wealth of the individuals or organisations concerned” should be set out, but I believe that people should go to prison for such data breaches. Organisations should be clearly held accountable. It should be made clear to them that, should such breaches occur, requests from them will not be looked on favourably. There should be a clear penalty. Currently, those penalties simply do not exist.

How do we explain to the public the small risks and how we will address them? One significant risk has not been covered: the powers of NHS England to direct the Health and Social Care Information Centre to collect information when it is considered "necessary or expedient". That could include full identifiable, confidential data. Will the Minister address one point on that? I have been told that NHS England has, in meetings with senior researchers, discussed the fact that, in the next releases of care data, it plans to include free text. Free text takes us into an altogether different area, so will the Minister give categorical reassurances on it? I support the principle of a default opt-in, but might not support it if the data included free text. Free text is deeply and intensely personal data and is not coded, and the public need specific reassurances on it.

Paul Burstow (Sutton and Cheam) (LD): Given that the intention, as I understand it, is to create wholly anonymised data, surely the use of that contextual information creates the possibility of re-linking to an individual’s identity. The hon. Lady is right to make that point, and I hope the Minister can reassure us, but surely that is a step too far.
Dr Wollaston: I agree with my right hon. Friend. Free text takes us into a different territory. People say things in free text to their doctor knowing that it will not appear in a coded form.

There are other ways in which we can improve reassurance for the public. Perhaps we could pseudonymise data before they leave the practice, which would introduce another important layer of protection. That suggestion has been made to the Minister on a number of occasions.

Barbara Keeley: The hon. Lady was in the Chamber yesterday when I talked about the cloud systems using NHS patient data launched in the States. What disturbed me about that was that the commercial companies involved said that the data—our patient data that they were using—included clinical data, demographics, education and income. That provided a context, and the companies could link episodes throughout a patient's life. People would be disturbed if they understood that companies charging for usage in another country had linked their data in that way and had almost a lifetime's coverage of people's medical records.

Dr Wollaston: Linking primary and secondary care data is so important, but the purpose to which it is put is at the heart of the matter. To whom are the data released? If data are uploaded to Google—27 CDs of our database—and leave the premises, we have no control over them. We could not apply in the States the controls and sanctions I have described. It is simply not good enough to be reassured that the data will not be handled by Google staff. What is to stop them accessing the data when they have gone offshore? The hon. Lady is right to make that important point.

My amendments are about improving the situation in two ways, the first of which is on the purpose of the information. Will the Minister consider adding the word "improving"? He might be concerned that, if the wording is "improving health and adult social care", the Bill could restrict open research. I do not agree. He will know that improving the care of patients is fundamentally the purpose of research. The amendment would therefore not restrict open research. The amendment would put beyond doubt the fact that the fundamental purpose of releasing data to, for example, insurance companies or Genomics UK, is improving care. People would see that the data release is not for a fundamentally commercial purpose to benefit a commercial organisation without a necessary link to improving care for people in the UK. Those questions should be asked at every stage of the process.

It was reassuring yesterday to hear the Minister clarify that insurance companies will be specifically excluded. However, there is no reassurance in the existing wording in respect of other organisations, including, for example, the Department for Work and Pensions. We can see how the case could be made that disseminating information to the Department for Work and Pensions is for the purposes of "the provision of health care or adult social care" or "the promotion of health", which is the existing wording of new clause 34. As he knows, the longer somebody is off work with, say, lower back pain, the less likely it is that they will ever return to work. The Department for Work and Pensions could argue that disseminating information is all about improving care, but in fact, the fundamental purpose might be altogether different. If the principle in the Bill is that information dissemination is clearly about "improving" care, it would focus people's minds on the underlying purposes when they make appraisals about whether their information should be given out. That could happen without disadvantaging primary medical research access to the information—the principle of improving care would clearly be at stake. I hope the Minister considers adding the word "improving" to the Bill.
My amendment (b) would mean that there is a reassurance in the Bill on how the data are handled by the person receiving them. We have the reassurance of the confidentiality advisory group, but including a responsibility and a duty in the Bill not just for those giving out the information but for those receiving it would be helpful. I ask anyone following this debate to hold their fire and not to be distracted by those who are rather jumping on the bandwagon on this issue and seeking to undermine the fundamental principles behind care.data. Those principles are important and we could save countless hundreds of thousands of lives in the future by having good access to medical data. But it simply will not do to gloss over the very real concerns that have been expressed. We will see the same problems arising six months down the line unless those very real concerns are addressed. To those who are following the debate, I say, “Do not opt out.” Let us give the Government, NHS England and the Health and Social Care Information Centre the opportunity to address those real concerns and to put them beyond doubt. I will not opt out and I hope that others will join me.

To read further:-

Hansard