Speech: Building public trust for the use of patient data

I am delighted to be here. As many of you will know, this is an agenda which has personal significance for me.

Although it may feel to us that data ethics and health data sharing are 21st century challenges, it is hardly a new concept that human progress is built on our ability to gather accurate information, share it ethically and, finally, critically analyse it so we can transform raw data into actionable knowledge.

Since before the establishment of the NHS in 1948 we have sought more and better ways to record, share and structure health data for patient benefit.

Indeed, many of the scientific, ethical and regulatory challenges we are debating today in relation to patient data have their heritage in the evolution of clinical trials in which UK researchers have always been world leaders.

From James Lind’s famous 1747 scurvy trial, which already contained most elements of a controlled trial.

To the Medical Research Council’s (MRC) first double blind trial of patulin (for common cold) in 1943.

To its first randomised control trial of streptomycin in 1946 – which was a landmark trial for its systematic enrolment criteria and data collection compared with the ad hoc nature of other contemporary research.

We should be proud to have led the way in so much groundbreaking medical discovery.

But we must do more than celebrate our successes. We must recognise these highly meticulous and ethical standards that have become deeply ingrained in our medical research and clinical systems is an exceptional national asset.

And they are principles which stand us in good stead to realise the huge potential of patient data to improve health, care and services across the NHS.

Long Term Plan

And that is exactly what the Long Term Plan recognises. Developed with frontline staff, patients and their families, it calls for targeted investment in health data infrastructure and analysis to help deliver better prevention, earlier diagnosis and more targeted treatment.

But it’s easy to forget that a key benefit of using health data more effectively though is safer, more responsive services to enable clinicians to spend less time administrating and more time treating patients. What they were actually trained to do, in other words.

This is why:

- the Health Secretary’s tech vision has laid out a road map for interoperability and better digital standards
- we are investing in the digital infrastructure at different levels in the NHS from Local Health and Care Record Exemplars (LCHREs) to digital pathology and radiology

And why we are building on the great success of the 100,000 Genomes Project – which crucially translates into clinical care with the Genomic Medicine Service – with a National Genomic Strategy to draw together our world-leading strengths from the UK biobank to the commitment to sequence 5 million genomes in 5 years.

Even with all this activity though, we all know we are just at the beginning of this journey and that is why we are so determined to start on firm foundations.

One thing we have learnt through long, hard experience since that first 1747 trial though, that we have heard clearly today, is that the precondition for all medical innovation and clinical care is patient trust.

National Data Guardian

That is why I am so pleased to be here today to mark the role of the National Data Guardian being placed on a statutory footing.

This is an enormous achievement. It was a longstanding government commitment, but there were some challenges along the way to getting here and we would not be here without all of you – so I want to thank every one of you who played a role in getting us passed the finish line.

Placing the National Data Guardian on a statutory footing strengthens the role as an independent and authoritative voice for the patient on how their data is used across the health and care system. It is right that patients are confident they have a strong champion, not only to advise them, but also to challenge the system and ensure that confidential information is safeguarded and used appropriately.

In establishing this role, Dame Fiona has firmly rooted the National Data Guardian within the health and care system as an essential building block for building public trust for the use of patient data.

Public trust

As Dame Fiona says, the 10 principles have been a key step in moving us forward in public and clinician trust for health data sharing.

We remain absolutely committed to ensuring that the public have trust in how their data is used, that it is used effectively to support better health and care outcomes, and they understand there are robust safeguards in place to ensure it is used for purposes which they recognise as appropriate.

Patients should have a clear explanation of how their data may be used for purposes beyond their individual care and of the security and legislative controls that are in place to protect their data.

People want to know their privacy and rights are safeguarded and to understand how and when data about them is shared, as well as how and when they can make an informed choice about whether to share their data.

We must continue the conversation we have started with the public, to build and maintain trust and confidence, recognising that there is no ‘one’ public and also that people’s views on patient data will naturally evolve depending on their personal experience and of course the advances in technology.

That is exactly why the role and independence of the National Data Guardian is so vital.

Cybersecurity

But of course, our ability to unlock the benefits of using data relies not only on the public having confidence in the health and care system’s appropriate and effective use of data but also in their confidence that their data is held securely.

Cyber threats to patient data are constantly evolving and always present. Health and care organisations must remain prepared and ready to respond.

This isn’t just about protecting patients’ confidentiality by making sure that their data is secure, though of course that’s essential. It’s also about making sure the systems on which patients’ data is held can’t be disrupted or corrupted, because we want the right data to be available at the right time.

For this reason we’ve worked with our arm’s length bodies to provide a range of specialist services that help organisations manage cyber risk and, if the worst happens, respond quickly in the event of an incident.

Since the 2017 WannaCry attack we’ve invested over £60 million to make significant improvements in the cyber resilience of local infrastructure and we have a stronger regulatory framework to impose harsh penalties on organisations that allow data breaches to occur.

We can never be complacent when it comes to ensuring the cyber security of our hospitals, ambulance services, or any of the many organisations that handle patient care and data, and there is still work to do.

But this work to toughen up the cyber protection of the NHS is an essential enabler of better care, to ensure that data can be available where it’s needed, and that the public can trust that their data is secure.

Role of NHS staff

But as Dame Fiona so clearly laid out, we all know this isn’t only about trust. The role of NHS staff is critical.

Unsurprisingly, we’ve found that the public are most likely to listen to information about the benefits of, and their choices around the use of their data if it comes from frontline NHS staff.

Medical researchers and secondary care clinicians are obviously on board with health data sharing, but the wider picture is more mixed. The Your Data Matters work highlighted that certain groups of NHS staff were less positive than the public about the benefits of data sharing. Others are unclear on how the rules apply to them. It goes without saying that if we are to realise the full potential of health data sharing – for patients, for our health system, indeed for those very NHS clinicians – this must change.

Patients like me with complex illnesses and co-morbidities are crying out for a health system that shares our data better so we don’t have to explain our medical history at every appointment.

Patients like me with rare diseases, who have battled through a decades-long diagnostic odyssey, are desperate for advances in data science to be applied to our anonymised health data so that others don’t have to suffer as we did and can be diagnosed and treated earlier.

Patients like me want to have more control over our health data so we can manage our own long-term conditions more effectively and reduce unplanned GP and A&E visits, not to mention improve our quality of life.

We are looking to the whole health and care system – including clinicians – to help us do this.

Of course there are challenges. But that is the case with every medical innovation in history. The ‘challenges’ didn’t stop Lind’s scurvy trial or the MRC’s streptomycin trial or the 100,000 Genomes Project.

All those achievements involved overcoming great odds and discovering new clinical standards, new protocols and effectively disseminating them – setting up new ways of working right across the whole health and care system.

No health system in the world is better at this than us. We are more than equipped to respond to the challenges that health data sharing creates.

And I know that because of all of you and the work you have already done.

Conclusion

Today I have referred to a few examples of clinical trial success, but the Understanding Patient Data website is awash with case studies of outstanding practice from across the country. Clinicians, industry, researchers, charities and government working together – all in accordance with the rules set out by the National Data Guardian – to improve patient care, patient safety and NHS services.

To all of you Health Data Leaders here today – I want to offer my personal thanks. I look forward to working with all of you.

I look forward to working with the National Data Guardian. Not only to ensure we keep building trust. But also that data saves more lives.