

Sustaining Public Trust in Health Data

A speech by Kingsley Manning, Chair of the HSCIC

at

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As I'm sure many of you know the HSCIC was established in April 2013, as independent statutory body, an arm's length body of the Department of Health, bringing together the NHS IC and CPfIT to which has been added the regional LSP functions and NHS Choices.

Therefore we are now 2,200 people. Our key responsibilities are:

- national statistics
- national infrastructure
- major IT programmes
- be the technical Design Authority for the system as a whole, leading the development of the technical strategy
 - provide a safe haven
 - reduce burden

And our primary task over the last 9 months has been to:

- ensure the continued publication of the key national statistics
- keep key national infrastructure systems working
- sustain progress on the major programmes
- and transform the organisation

I'm very proud of what my colleagues have achieved over the last ten months.

One of our key measures of success might have been that we were safely below the radar of public attention.

Clearly the last few weeks have been therefore quite interesting.

Whilst we did not seek it, in many ways the publicity of the last month and the debate it has engendered is very welcome.

Because a key element in our strategy has been to sustain public trust on the collection, analysis and use of health care data.

Indeed as I have said the HSCIC was created specifically to be a trusted, safe haven for the nation's most precious and personal data.

In the light of these recent events, I would therefore like to take the opportunity to review some of the key issues and outline our current thinking and intended responses.

But first I would like set out why the issue, why the future of healthcare data is so important.

At the core of the concept of the NHS is the notion of a social compact between the citizen and the state, whereby the community as a whole takes on the risks of individual ill health, in return for the state providing free care at the point and time of need.

Data, information, and knowledge are critical to the operationalisation of that compact and for the sustainability of the NHS as we know it.

Sharing risks is only possible on the basis of accurate data and subsequent knowledge.

Sustaining taxpayer support for paying for services is only possible if the taxpayer, who increasingly is not an immediate user of the service, knows their money is being used efficiently.

Sustaining patient support is only possible if they are assured that the services being provided are appropriate, safe and effective.

A shared NHS, is dependent on shared data,

And until recently it was perhaps reasonable to believe that this view was overwhelmingly supported by the general public.

And yet now we find this notion questioned and for a number of reasons.

First, the public is become less trusting of a wide range of institutions, whether the police, the banks or big government, fuelled by a constant stream of scandals.

Second, large sections of the public fully understand the power of information, and have a genuine concern about how their data is used by large institutions.

Third, there is a general perception that those institutions aren't very good at keeping your data safe, as evidenced by Snowden and Bradley Manning.

These concerns, are widely held, and have been fuelled by increasingly active groups and individuals, who utilise the new technologies, not least Twitter, to provide a 24 by 7 stream of exposure, comment and debate.

And given the scale and sensitivity of that data, is it both appropriate and welcome that those organisations that handle health care data, not least the HSCIC, should be subject to stringent scrutiny of their actions and plans.

And given the potential power of the data, the debate as to how it should be used, is also both apt and welcome.

It is particularly important given the promise that the use of data and technology holds out for the future of healthcare services.

Whether it is in personalised medicine, for example the individualisation of cancer treatment or enabling citizens to manage their own chronic conditions.

Or in the redesign of services, underpinning the transformation of productivity.

The combination of data and technology constitutes our major hope of making the NHS affordable and sustainable.

But that potential will only be realised if the great majority of the public continues to trust us with their data and to be clear it has to be the overwhelming majority of the public.

Because we should be under no illusion as to the impact of even a sizeable minority opting-out, of refusing to share some or all their data.

As with immunisation, unless we sustained data coverage of the overwhelming majority of the population then the utility and impact of our data resources will be substantially reduced.

Those who actively encourage patients to opt out of data sharing should be equally clear with those patients that such a decision has costs or consequences, both for them as individuals and for the wider community.

But we cannot and we should not rely on the easy acquiescence of the past, we must quite rightly earn the public's trust, both the HSCIC as an organisation and the wider system as a whole.

To do that we and the wider system need to focus on 3 areas

- Transparency
- Effectiveness, and
- Security

In each of these areas we will be announcing new initiatives over the coming months both for the HSCIC and for the wider system. In doing so we are recognising that the present arrangements, instituted both by our predecessor organisations and the wider system, are no longer adequate, they are no longer 'fit for purpose'.

With respect to **security**, and in this I include not just cyber security but also the physical and human security threats, we are facing a fundamental shift in the level of threat. When I became Chair of HSCIC, 9 months ago one of my first actions was to institute a review of our security arrangements. For more than 20 years I've been running organisations that have been handling sensitive data and I have lived in fear of a major security breach.

Despite that experience I was shocked by the pace and the scale of the developing security risk. Whilst I had been concerned with the lost disc or the stolen laptop, I had failed to appreciate the extent of the risk now posed, whether it's by highly organised, criminal hackers, extremely proficient and motivated activists, or foreign states or ideologically motivated interlopers.

The NHS is reliant on core national information infrastructure and dependent on highly, valuable data assets; we are not immune to these threats.

In the next few weeks we will therefore announce a major strengthening of both the security and IG frameworks for the whole health and social care system.

Whilst we can never guarantee the absolute security of data we must give the public a guarantee that we as a system have taken all reasonable steps to protect and keep safe their data. We have no defence if we are found not to be compliant.

Nor do we have a defence if having collected a citizen's data we fail to use it **effectively**, both to enhance their personal care and to improve the care for the community as a whole.

A common and quite reasonable assumption made by service users is that the NHS is a joined up organisation. That their information, their records, will be shared across care locations so that the care they receive is informed, safe and effective. The presumption in favour of sharing information was a core recommendation of Dame Fiona Caldicott's review and of our Guide to Confidentiality published last October.

And the Secretary of State has set us the challenge of enabling the sharing of information between GPs and A&E departments, between patients and the GPs and between social care and healthcare professionals.

Yet we know the formidable technical barriers to achieving this. Despite many years of preaching interoperability, progress has been painfully slow. And I recognise that the organisation I now chair bears a significant responsibility for this.

Both as the providers of the core national infrastructure and now as the Technical Design Authority for the system as a whole, we recognise that we need to take a radically different approach to ensuring that patients can be confident that their data will be accessible, accurate and reliable whenever and wherever it is needed to support their care.

Citizens also have the right to expect that we use their data to deliver efficient and effective care. As a system we have invested billions of taxpayers money in IT over the last decade. Whilst we all know of the difficulties of the National Programme we should also recognise its successes in such things as PACS and the Spine. But we have to recognise, how by comparison to other industries, we have failed to make the progress that is needed.

Both professional and patient expectations of information systems, are sadly too often, and too rightly, very low. Whilst the requirement for patients to give the same information multiple times is now legendary

It still comes as a shock, however, that in fulfilling our statutory responsibility for tackling the administrative burden across the NHS, we found in a recent audit of 16 acute trusts, that 77% of records are hand written before being subsequently typed into the computer and that junior doctors are spending two thirds of their time looking for and dealing with patients notes.

In the coming months we will be extending our work on burden reduction and with our partners NHS England, working to use the investment available through the TechFund to support data effectiveness and productivity across all the healthcare sectors.

Whilst the use of the data to support commissioning is not well understood by the public, it is crucial to the effective allocation of resources, to monitoring service quality and for powering the transformation of clinical services.

We recognise that the current arrangements for supporting CCGs and CSUs could well seem confused, and are often frustrating for our partners in those organisations. Over the last 9 months we have been working to ensure these arrangements operate within the existing IG framework.

We are now working with NHS England to establish what data flows are required by commissioners, and how these services can be provided and how we can meet the requirement that patients should have an opt-out option. Working with NHS England we will be coming forward with a series of proposals as to how meet the local needs of local commissioners.

One of the great and outstanding aspects of the NHS is the intimate relationship with research. We can be extremely proud of the contribution that has been made over the last decades to clinical science, much of which has been critically dependent on the collection of and access to health records.

All the evidence suggests that the public are overwhelmingly willing and enthusiastic supporters and contributors to research, both in their own interest, but just as importantly in contributing to the health of the wider community and of the generations to come.

Since our establishment we have been working with the research community to improve the way we support them and demonstrate for patients the direct contribution they are making to solving the great clinical challenges.

One the major areas of controversy over the last few weeks has been the sale of health data to commercial organisations. Some observers are unhappy that we provide data to information intermediaries and indeed to pharmaceutical companies. Some commentators are also unhappy that we charge too much or too little for the data. In reality our fees are set in accordance with Treasury guidelines, to ensure that we recover our costs, no more and no less.

Ultimately what we do with the public's data is and will be determined by Parliament and we very much support the Government's proposed amendments to the Care Bill.

It is however timely to point out that there is not necessarily any contradiction between the aims of a commercial organisation and the advancement of the nation's health and social care services. Many of the commercial information intermediaries who make use of our data releases are supporting NHS organisations to plan, transform and deliver their services.

With respect to the pharmaceutical industry, not only does it represent a major contributor to the UK economy, but they are also critical in developing new treatments. It would be perverse if we weren't to support their activities and their endeavours. There could be no better evidence of the effectiveness of health data, shared with us by the patients, than the contribution it makes to crucial break-through in treating deadly diseases.

Quite rightly however, the public are suspicious that these arrangements are in some way unfairly tipped in favour of the profit makers. This suspicion has been fuelled by our innocent lack of transparency. I have no doubt that HSCIC's predecessor organisations were intent on operating in the best interest of the patients of the NHS, but they were working at a different time and without the glare of public interest.

If we are to sustain public trust we not only need to demonstrate that their data is secure and that it is used effectively, but we need to be transparent in everything we do. The current arrangements governing the release of data are undoubtedly confusing and there is inadequate representation of the public voice in our decision-making.

We have already announced that we will be publishing the details of all the data releases we have made since we were formed in early April. We are also undertaking a review of all the data releases made by the NHS Information Centre, and this will be published in the early summer.

To strengthen the public participation, as already announced, we will be establishing this year a joint professional/ public advisory council, with an independent chair.

And we are working with our colleagues in the Department of Health on the implementation of the proposed amendments to the Care Bill, not least on strengthening the scrutiny of the processes governing the release of data.

The HSCIC was established in the recognition that data is fundamental not only to the running of the NHS and the wider health and social care service as we know it, but that

together data and technology, are central to the future of healthcare and for sustaining the NHS.

So, let me conclude by reiterating that we very much welcome the current debate and the current level of public interest, even if it can be uncomfortable. It is vital that we establish a level of trust with the public and with care professionals, not only for the HSCIC but also for the system as whole. I have no doubt as to the critical role that data will play in the health and care system of the future: we can't afford to get this wrong.