

## Governance of a Digital Economy in the medium term: AI, blockchain, genomics, and beyond

Writing this document, we cannot know what industry you are in, the country of your local hospital, how it performs, or how it uses medical records today, let alone in a decade's time. However, what we do know is that how it uses medical records in 100 months' time will be very similar to how it uses medical records in 98 months' time. Things will evolve; change is compounded upon change – and if citizens receive information on how data about them was used yesterday, they will be in a good position to make informed decisions about tomorrow.<sup>1</sup>

Organisations that wish to hide how they use citizens' data, e.g. how they use medical records, are disproportionately likely to be the ones to abuse public trust. Regulators cannot prejudge innovation, but they can ensure that those involved can make informed choices.

The debate about population-scale genomics rumbles on; companies have tools to sell. But as research continues, it is now clearly evident that a population-scale genomic database does little for health interventions for previously healthy citizens who have become ill.<sup>2</sup>

When a person becomes ill, it is necessary to take a new blood sample to run tests. Knowing a person's blood chemistry from last month is not particularly helpful for diagnosing a condition they didn't have at that time. While there may be good reasons to have research datasets of genetic data, direct care of the identified conditions of those patients is generally not one of them. Direct care requires rapid proteomics, genomics, and analysis of the patient's current 'body state' – not a previous one.

As AI and machine learning move beyond the technologically exceptionalist claims of their infancy and into wider utility, they too should deliver greater public understanding. The best way for a citizen to begin to engage with such issues is through an event about which they already have a high level of understanding, because it was something they were involved in.

This also highlights the difference between research for improving knowledge, available to the world, and operational decision-making which may adversely affect individuals – or which individuals may feel is adverse to them, even if others take a different view.

medConfidential does not oppose the use of AI or genomics in healthcare. It is simply necessary that *all* data uses, including AI, are consensual, safe, and transparent. In providing that transparency to patients and related organisations, reputable organisations can demonstrate their trustworthiness – and in refusing to do so, disreputable organisations make it equally clear that they are not.

If individuals understand how data about them was used yesterday, they are in a position to have an informed conversation about how that may change tomorrow – and about how any new proposal would change the lived experience the person already has.

Anything else is just asking for trouble.

---

<sup>1</sup> NHS GPs already do <https://medconfidential.org/for-patients/your-records/>

<sup>2</sup> Q130 - Genomics England <http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/science-and-technology-committee/genomics-and-genomeediting/oral/48729.html>

medConfidential  
sam@medConfidential.org  
May 2017

## **About medConfidential**

medConfidential is an independent non-partisan organisation campaigning for confidentiality and consent in health and social care, which seeks to ensure that every flow of data into, across and out of the NHS and care system is *consensual, safe, and transparent*.

Founded in January 2013, medConfidential works with patients and medics, service users and care professionals; draws advice from a network of experts in the fields of health informatics, computer security, law/ethics and privacy; and believes there need be no conflict between good research, good ethics and good medical care.

[www.medconfidential.org](http://www.medconfidential.org)