

GenomEthics Blog

Chat about genetics and impact on people

Articulating the contract between science and people: DNA data sharing

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A new deal on data: are you with us?

For most of us it is hard to unpick the various declarations, assurances and guarantees made regarding the sanctity of our data. Even the General Data Protection Regulation still feels quite far removed from the everyday lives of ordinary people and is seemingly absent of any consultation with them. **People need to both see and hear proof that they've been listened to.** And they will act against anyone who seems to wilfully dismiss or disregard them – with every right to do so. With Facebook recently under the spotlight, there is tangible alarm about the use of our personal information by others. A breach of confidence or inappropriate access to data becomes really sensitive when we consider our most precious and personal information. **In a health sense, what is more personal than our DNA? It's what makes us 'us'.**

We broadly know that scientists, clinicians and academic institutions collect, store, research and share DNA and medical information as part of the global endeavours to understand human health and treat human suffering. As part of this endeavour DNA information bounces around the Internet on an unbelievably massive scale, in ways unknown to the person who donated the data.

We probably expect 'science' is gathering, storing, analysing and sharing our data with respect, transparency and integrity. Whilst we hope that there is choice in this and we hope that we have actively consented, have we ever really discussed this as a collective society? Is this even possible?



Is it widely known that particularly for genetic research it is only possible to interpret what a glitch in DNA means if there are hundreds of thousands of DNA glitches from other people to compare it to. So, Big Data and DNA go hand in hand and are necessary for genomic medicine to deliver on its promises.

But, if science is truly going to serve humankind in the best way possible we need to be clear on the terms of the interaction and transaction with people, *on their terms*. And to

do that we need a simple and clear conversation; to be certain that we can fulfil their demands or at least understand their desires and concerns.

The need for a **PEOPLE POWERED** conversation

The Why

A: The world of data is leaky

B: ‘Society’ hasn’t yet been part of a clear conversation

When thinking about A we have to be honest. Nothing is perfect. No data is 100% secure. No system is flawless. No regulation is absolute. No cache of information is 100% bullet proof – and if anyone promises that, they’re over promising.

This is a given that we have got to accept.



The type of data we are talking about here is the purest most precious kind, fundamental to our identity and existence. DNA and linked medical data – the foundational stuff that makes us who we are. Whilst our data might be ‘de-identified’, i.e. our name and address has been uncoupled from it, ‘anonymity’ cannot be absolutely guaranteed, because health information can always be linked to other personal information that is also on the web, and in our increasingly data-connected world, it is entirely feasible that we *could*, in theory, be identified from

our DNA alone.

Which brings us to the B.

There are a lot of companies and regulatory bodies that broadcast commitments and assurances about data use. But as there has been no collective societal ‘sign up’ – so the pronouncements and commitments could be seen as one-sided. Aside from (relatively small scale) targeted engagement initiatives, there hasn’t yet been a global two-way conversation. No complete consultation. No reciprocity. No serious voice given to the most important people and the principal recipients of the good works undertaken with their data.

This is especially problematic when it comes to trying to get more people to share their precious DNA – their genome – to advance medical research and progress healthcare. Which is why the scientists need to ‘go first’ with starting this conversation.

The Crunch...

To move forwards we need:

- the medical, clinical and academic institutions and the policy makers to clearly articulate the assumptions behind ‘people’s best interests’ and make this available for debate
- society to accept the tiny risk inherent in sharing their data with individuals and organisations

We need the people on both sides to be in this together – mutually accepting and supporting the power of precious data sharing to make life better.

Drawing up the New Deal

Simplicity is key. Two clear parties. Two clear beneficiaries. And equally mutual rewards.

Consultation

This is a *reciprocal people-powered deal* that brings both sides together for better. And the people's voice must be consulted, heard and written into it.

This will require a comprehensive consultation process involving ordinary people from all walks of society.

This should involve Qualitative and Quantitative explorations and interrogations of the topic and the terms of the deal. It should involve experts in large-scale, population engagement techniques.



But how do we start the conversation?

We need a starting point for that conversation – an ‘in’; and starting with the genome isn’t it. We know from our own research that the vast majority of the broader public have not yet encountered the term. However, more than 90% of the public are online and feeding their data into the grid. Thus ‘data’ is the conversation starter that can take us to DNA.

The binary algorithms that once sat invisibly inside tech tools that serve humanity -- have now become visible – data has become a ‘thing’. Something we can point at, hold up, scrutinise and hold accountable. Data and its big brother, Big Data, are now discussed, interrogated and judged everywhere from the Senate Commission to Mumsnet.

So, Data; our relationship with it; and with those who harvest, explore and administer it ‘on our behalf’ gives us a rich area from which to begin.

The conversation needs to focus on how science and humanity collaborate and win, together.

Communication

Language and Tone are everything. Pub and school gate rules apply (i.e. it can be discussed anywhere and everyone can participate). ***This is a People Powered Deal. Not a Protocol.***

This is a simple deal that respects and honours every human’s right to control their own data destiny. And confidently go into an agreement where they believe that the terms will be upheld to the best of everyone’s ability. Which means it must be couched in clear simple terms.

Distribution

We need the New Deal to be visible to all at every level. This will require a robust channel strategy – so we would also need to test best channels for spreading the word. And answer some pretty simple questions: Is it an event based news worthy event? Is it a web based platform for commitment with visible partners? Is it a socially driven call for better – a clarion call where we give the New Deal to the people and get them to use it as a lever to agitate for better – a movement.



We feel it is time for science and policy to scrutinise their direction of travel – with less rhetoric about the benefits of research and delivery of science (i.e. going in one direction from them to us) and more about serving humankind, recognising that we are all in this together. We, collectively are a partnership and we need the people of society to feel they sit with the scientists so that the journey into human discovery is one made together.

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