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A new deal on data – articulating the contract between science and people

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A NEW DEAL ON DATA – ARTICULATING THE CONTRACT BETWEEN SCIENCE AND PEOPLE

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

Today Anna Middleton ([Wellcome Genome Campus Society and Ethics Research \(https://societyandethicsresearch.wellcomegenomecampus.org/who-we-are/\)](https://societyandethicsresearch.wellcomegenomecampus.org/who-we-are/)), Vivienne Parry (Head of Engagement, [Genomics England \(https://www.genomicsengland.co.uk/\)](https://www.genomicsengland.co.uk/)), and Julian Borra (Citizen, Founder of Thin Air Factory, London) have launched a manifesto asking for a people-powered conversation around the collection, storage and use of biomedical data, so that the journey of human discovery can be pursued collectively and democratically.

Introduction: Are you with 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.

Read the full article [on the GenomEthics blog](#)

(<https://genomethicsblog.org/2018/06/20/articulating-the-contract-between-science-and-people-dna-data-sharing/>).

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