

Introduction

“ *Genomics is all about human identity.*”

Christine Hauskeller

No doubt you're sure about who you are, but how did you arrive at that knowledge? The ways in which we construct our identity are complex. At one level, how we choose to describe or represent ourselves (and others) might combine information about our age, gender, appearance, faith, nationality, ethnicity, language, accent, occupation, status, family or where we come from. But on another level, how you feel about being 'you' might embrace more complex issues like your personality, mood, mental state, illness, or relationships.

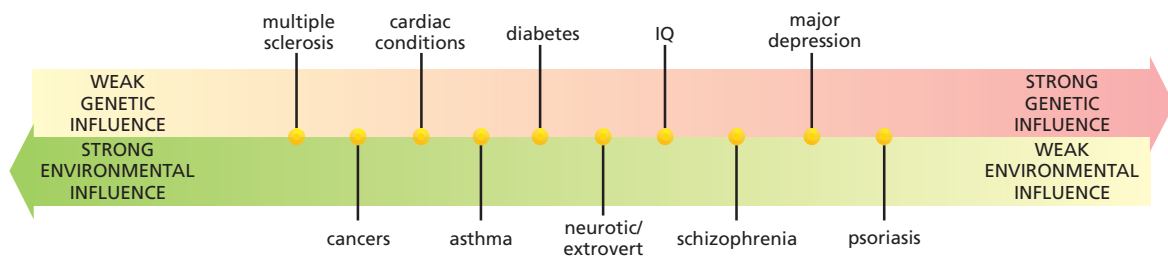
Some of these factors are influenced by our genes, while others are probably not. At yet another level, in the eyes of the state, your identity may reside in your name, a driving licence, a passport, a photograph, or genetically related biometric data such as fingerprints, iris scans or even DNA profiles!

The photographers in this exhibition reflect on some of these complex issues of personal and social identity, within a context that explores how recent information about our human genome affects how we, and others, will think about and use identity in the future.

The human genome project has changed how we and the state think about who we are. We might define ourselves by our ethnicity, belief, age, gender, language, or nationality, but subtle genome-wide variations in our common genetic inheritance are increasingly being drawn on to define us as individuals, not just by the medical profession, but also by agencies and companies, and more importantly by the state. The ethical and social issues that this gives rise to are a counterpoint to, and context for, the work of the commissioned photographers.

Nature and Nurture:

The whole issue of identity and how it is constructed is immensely complex, with both confusion and disagreement rampant in the literature, frequently depending on whether the author is a politician, a sociologist, a psychologist, a writer, a philosopher or a geneticist. Personal identity is



Nature and Nurture:

Some human traits are strongly influenced by the environment, others less so. Studies of identical and fraternal twins have indicated the relative genetic and environmental contributions to different human traits. (from Alberts B. et al. Essential Cell Biology 3rd Ed. Garland Science, N.Y. 2010)

often distinguished from social identity and from cultural identity and from genetic identity. But taking our own personal sense of identity, or who we think we are, we could, broadly speaking, claim that there are two key ways in which that identity is constructed, through Nature and through Nurture, and it is together that these contribute to the final version of who we think we are. Whether we are male or female and where we ultimately come from, i.e. our ancestry, are essentially products of nature, of our genetic inheritance, while the social or cultural identifiers of where we live, our nationality, class, language, accent, and faith, are all largely products of nurture. What relative roles each of these play in our construction of identity remains unclear. In the last few years, driven partly by the availability of DNA genealogy tests, proliferating databases of human genomic variation and the increasing interest that people have in their family's origins, our engagement with the power of genetics and its claim to define identity has mushroomed. But along with this has come a plethora of difficult ethical, social and political challenges that genomics work has thrown up. Indeed the list of questions that link identity and genome biology grows ever longer.

The Human Genome

My friend Peter Walter is seen here examining the 118 volumes in the Human Genome Library in the Wellcome Trust gallery, London. This contains the entire human genome printed out as a sequence of tiny As, Gs, Ts, and Cs. The volumes are numbered to correspond to the human chromosomes 1 to 22 together with the two sex chromosomes X and Y. Designed by Kerr Noble, produced by Moore Print.



What variation exists in the human genome? In what respects is genomics a bureaucratic tool? Is DNA really a gold standard for identification? How much of our identity is inherited? What is the relationship between identity and identification? How can we know where we come from? How useful could our own personal genome be? What are the links between our human genotype and our human phenotype? What do the links between our surname and our genome mean? In what ways does genomics diversify and amplify identity? What impact does our personal genome have on our personal identity? Are racial groupings only bio-socially defined? How can genome wide variation help medical practice? Should DNA ancestry firms be regulated?

Genome-wide Variation:

Despite the daunting length of the DNA in the human genome and the Herculean efforts required to determine its sequence, there are now several completed whole human genome sequences and even more partial sequences where particular regions of interest are sequenced from many individuals. When the same region of the genome, from two different people, are compared their DNA sequences differ on average by about 0.1%. That may not seem very much, but when we consider the size of the genome it actually corresponds to about 3 million genetic differences in a single set of

chromosomes between any two individuals. It is estimated that about 100 of these small variations is enough to unambiguously identify an individual.

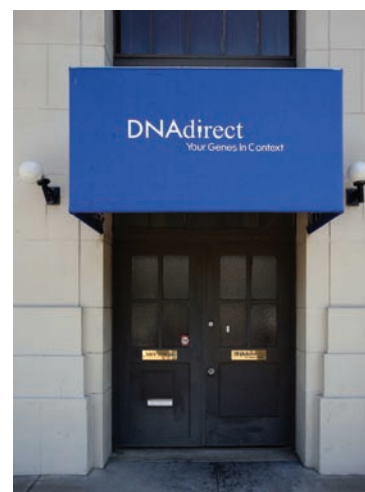
The bulk of these variations were present early in human evolution, perhaps 100,000 years ago, meaning that much of the genetic variation we see was inherited from our early human ancestors. Analysing the patterns and distribution of these variations in different individuals has become big business. Although many of these variations in the DNA sequence will fall in non-essential regions of the genome, and will not contribute directly to our individual traits, they have become useful by identifying their inherited association with particular traits. This kind of DNA analysis is now used for at least three rather different ends.

The first is to find associations between genes and particular diseases or conditions, both physical and mental (the article by Jennings later in this book addresses some of these issues). The association of particular gene variants with autism is a recent example. Companies can test for genetic variants related to cystic fibrosis, Hemochromatosis, breast and ovarian cancer, and various drug susceptibilities. This approach is being extended to search for associations with particular behaviours. The second is in the field of forensics, and the related area of paternity testing, for the correct *identification* of an individual. The third, perhaps most controversially, is in ancestry and genealogy services, which use variations in the mitochondrial DNA (for the female line) and the Y chromosome (for the male line) to follow ancestors, ethnically or geographically.

Genetic genealogy is now approaching a billion dollar market, with a seemingly insatiable interest, particularly in the US, in ancestors, origins, ethnicity or just family membership. Despite the very flawed methodology (Looking at an ancestry going back about 300 years the method would look at a single maternal or paternal ancestor at the expense of the more than 4,000 others who contributed to your genome today!) the take up is huge and the promises glowing. Who asks for such an analysis? Who provides it? Who monitors what it all means? A sequencing act is a political act. The knowledge that emerges is hard to control or manage and it has implications for group membership, ethnicity, tribal membership, land claims and faith issues. Genetic ancestry is often directed to finding Native North American ancestry or African roots, as well as claims about ethnic, political and religious identities. People tend to believe in the permanence of such 'scientific' knowledge, compared with the ephemeral nature of other identity markers like nationality or citizenship. Cultural determinants of identity perhaps need to be further forward in this mix. At present there is no legal licensing or operating framework for such companies, but California recently banned them. (The article by Hausekeller later in this book addresses some of these issues)

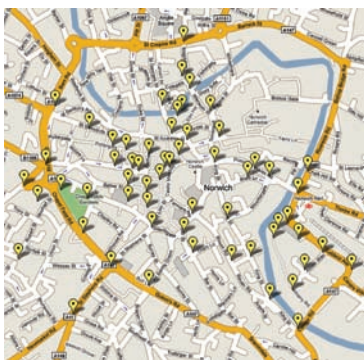
Identity and Databanks

The data from genome analysis lies in DNA databanks. And most of the other data collected about us, which might or might not relate to our



DNA testing companies:

*DNA Direct in San Francisco:
"Our Mission is to bring the power of personalized medicine to patients, consumers and healthcare professionals - enabling access to genetic expertise, reducing health risks, preventing disease, and better targeting therapies."*



Norwich Police/Norwich City Council CCTV Cameras:

Locations of CCTV cameras operated by Norwich City Council and used by Norwich Police for crime detection. (tinyurl.com/n5hrr6)

identity, but certainly serves to identify us, is also held in data banks. There are many problems associated with large-scale centralized depositories of data both in terms of viability and security, let alone the problems of who uses and controls them. The Decode project to link medical, genealogical and genetic information in Iceland collapsed. Insurers, employers, relatives, police and medical staff may all want information about crime scenes, gender, paternity, surveillance data or ethnicity. Crucial aspects of our identity may be available, stolen or locked up? I find, allegedly, there are more police surveillance cameras per head of population in Norwich than in anywhere else in the UK!

A report on the legality and operation of key databases in the UK was commissioned in 2009 by the Joseph Rowntree Reform Trust Ltd. Stimulated by the loss of 25M child benefit records by HMRC, the report, called *Database State*, said in its executive summary, "This report surveys the main government databases that keep information on all of us, or at least on a very substantial minority of us, and assesses them using a simple traffic-light system. Red means that a database is almost certainly illegal under human rights or data protection law and should be scrapped or substantially redesigned. The collection and sharing of sensitive personal data may be disproportionate, or done without our consent, or without a proper legal basis; or there may be other major privacy or operational problems." Red-badged databases on the list included the National DNA Database, the National Identity Register, the NHS Detailed Care Record and the database that allows information to be shared between EU member states.

Identification .v. Identity

Identity is a fluid and complex set of overlapping and sometimes contradictory properties and assertions. Take my own 'identity': I find I am British (but also European), an East Anglian (but born in London), middle aged (but feel younger), a scientist (but engaged with the arts), a father (but also a son, and a step-father), male (XX, but I think I may have a sensitive side!), an atheist (but I believe in the miracle of evolution), white (but I don't know the haplogroup of my Y chromosome), an English speaker (but with a tiny smattering of French). I am also right handed, an omnivore, a non-smoker, left wing, and take a size 7 1/2 hat. And the culturally or socially determined part of my identity could so easily have been very, very different! Each circle overlaps with all the others and only a core area where they all overlap feels as though it's about my own identity. The bits of partial identity that hang over are partly mine, but they also overlap with, and are shared with, the circles of my friends, colleagues and relations contributing to new labile social and cultural identities.

It is very important to distinguish, and not confuse, the idea of *identity* and the idea of *identification*. Identity is a set of characteristics that, as in my case above, are attributable to an individual. Many of these features of my identity are shared with others. In contrast, identification is something

that is done to a person with the express aim of removing those overlaps, to uniquely differentiate that individual from all others. A name is not enough and typically this is done digitally; a National Insurance number, a passport number, a NHS number. But iris-scans, fingerprints and DNA profiles are increasingly how we are identified now.

Surnames

What's in a name? Our name might seem, historically, a crucial part of who we think we are. Your surname, or family name, is a surprisingly recent idea. It came to the UK from France, along with the Normans, but it took until the 13th or 14th century for us in England to routinely adopt surnames, and a century more in Wales. Names were largely plucked from the father's first name (Johnson, Robson), a nickname, a village, a trade (Smith, Wright) or from a place (Wood, Ford, West). Many names arrived more recently, with many featuring in the top 100 surnames (Patel at 20 and Khan at 66).

The Top Ten British Names:

1 Smith	6 Davies
2 Jones	7 Wilson
3 Williams	8 Evans
4 Brown	9 Thomas
5 Taylor	10 Roberts

Our surname certainly helps the state identify us, but it is also an important part of our own personal identity and sense of family.

We might think that social mobility would lead to names being pretty evenly distributed across the country. But surnames, even common ones, are not; instead most are very regional, at least ten times as common in their heartland than in Britain as a whole. Maps of family names can be useful for studying family histories and our ancestry, and such maps can be found on the National Trust website at www.nationaltrustnames.org.uk. Compiled from data in the UK census, you can look up where people with your surname live currently (1998), and also about a century earlier (1881).

Two surprising facts emerge from the maps. The first is that almost all names are regional. The second is that, despite some migration, things don't change that much between then and now.

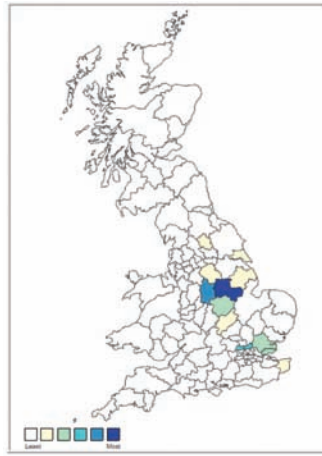
Surnames and Maps

Compare the distribution of people with the familiar (but actually quite rare) surname Attenborough. Centred firmly on Nottinghamshire in 1881, the distribution only spreads a bit in the next century.

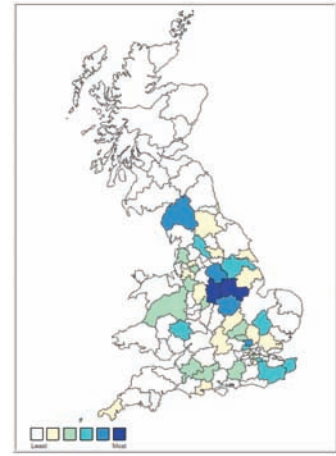
The photographers in our exhibition come from many countries but here are the 1881 maps for some of their names: Two have clear roots for their



Sir David Attenborough

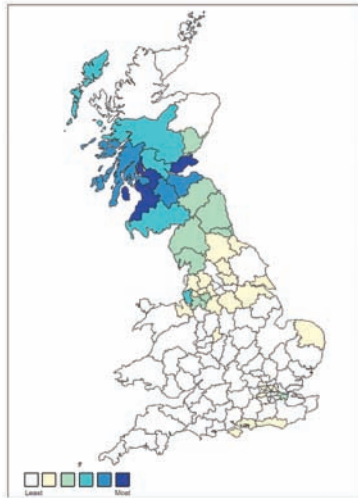


Attenborough, 1881

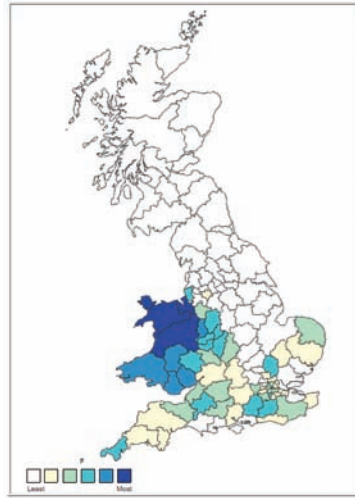


Attenborough, 1998

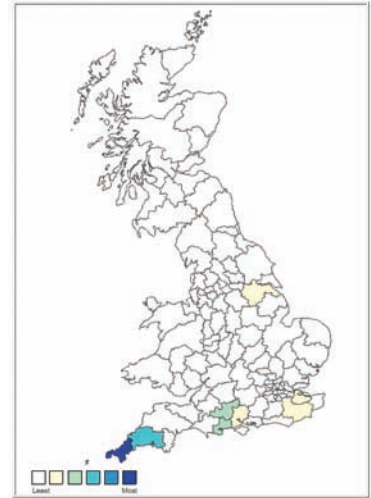
names in Scotland, two in Wales and two in England (even though Simon Terrill hales from Australia and Dave Lewis's parents come from Grenada, West Indies).



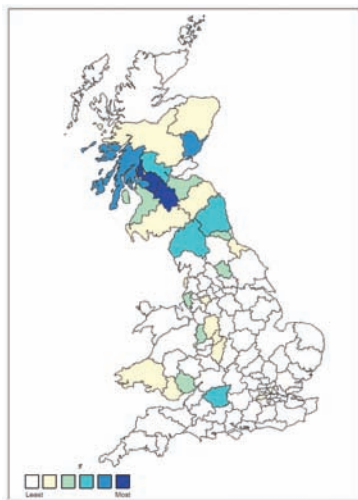
Cunningham, 1881



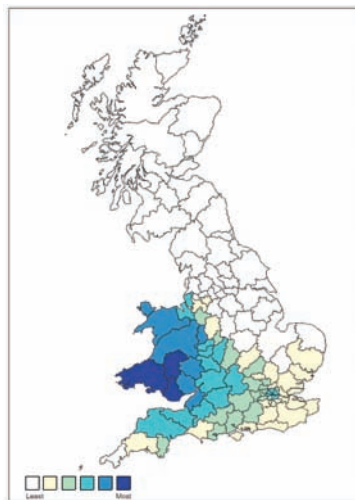
Edwards, 1881



Terrill, 1881



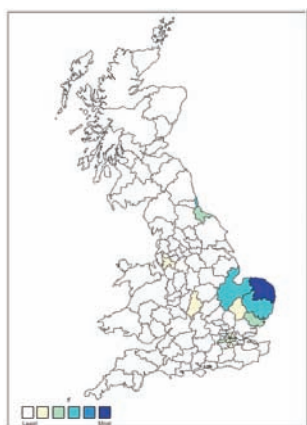
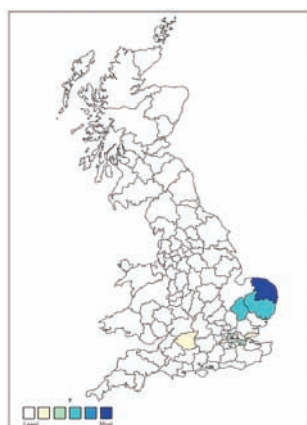
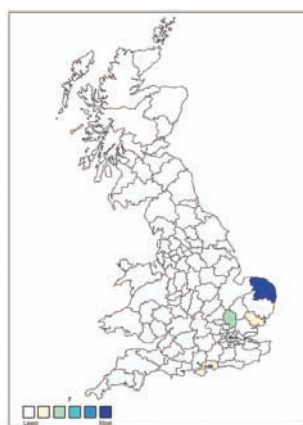
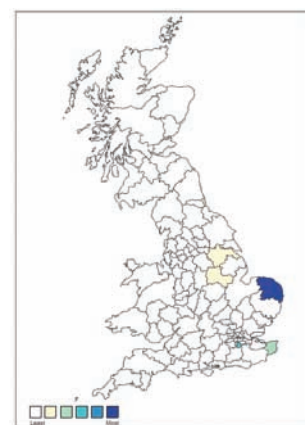
Kane, 1881



Lewis, 1881



Jaycock, 1881

**Skipper, 1881****Kett, 1881****Grapes, 1881****Pilch, 1881**

And what about local names in Norfolk? Here are some names, probably familiar to those in Norwich, which have deep roots in the county. Even people with quite common names, such as Moore and Wright, are more concentrated in Norwich than anywhere else.

Surnames and Sex

Family lineages, defined by their surname, are also defined by the male sex, or Y, chromosome. This, like their surname, is also passed down from father to son. With few exceptions, such as adoption or non-paternity, a man's Y chromosome is passed along down the generations along with his name.

In addition to the 22 pairs of chromosomes they share in common, each woman has two X-chromosomes and each man one X and one Y-chromosome. Only if a Y-chromosome is present does an embryo develop as a male, without it a female results. So Y-chromosomes and names go together.

Over time, as small changes build up in each Y-chromosome and these are passed along the line, each lineage begins to build up its own identity. Scientists can now study bits of the DNA making up the Y-chromosome sequence and compare them between people with different names. Sequences from thousands of different Y-chromosomes support the idea that there is a link between our surname and our Y-chromosome!

The link is closer with less common names (common names had many founder ancestors). About 85% of men with the rare name Attenborough, for example, share a particular set of markers on their Y-chromosomes suggesting that they are essentially one giant family of distant relatives. The Smiths of this world, however, are as different from each other as the rest of the average population. This does, incidentally, raise an ethical challenge; if you have a rare name and your DNA is forensically examined, they might be able to make a good guess at your surname simply from your DNA, whereas if you are a Smith that will not be the case! You can use this website (www.nationaltrustnames.org.uk) to find out where people who share your surname lived in the UK in the years 1881

and 1998. Information about the distribution of surnames across the UK was worked out, using the census records for those two years, by researchers based at University College London. The National Trust now hosts the site.

In the seventeenth century identity papers were introduced where previously you just had to rely on your name or a letter to say who you were. Since then two key events have radically altered how we represent both our identity and ourselves. The first was the arrival of photography in the early nineteenth century and the second was the human genome sequence at the start of the twenty first century. We cannot tell how these will interface and accommodate in constructing and representing identity in the future, but the photographers in Photo-ID have made a contribution to that debate.

But a cautionary tale: Henry Mayhew, writing in *London Labour and The London Poor* in the 1850s recorded the ease with which people could be persuaded by a jobbing photographer that a stock image of someone else was in fact an excellent portrait of them! Of a sailor customer, he records the photographer saying, "I persuaded him that it was his blue Guernsey which had come up very light, and he was so pleased that he gave us 9d. instead of 6p. The fact is, people don't know their own faces. Half of 'em have never looked in a glass half a dozen times in their life, and directly they see a pair of eyes and a nose, they fancy they are their own."