BIG BROTHER, MEET BIG GENOME

WHY BRITAIN'S BABY DNA PLAN FEELS STRAIGHT OUT OF 1984

By Alan Cross

22 June 2025

Neurohaven.co.uk

Big Brother, Meet Big Genome: Why Britain's Baby DNA Plan Feels Straight Out of *1984*

By Alan Cross – 22 June 2025

When the government recently announced that all babies born in England could soon have their entire genome sequenced at birth, the message was one of progress. It was presented as a bold stride into the future of healthcare — an enlightened policy designed to prevent suffering, deliver personalised care, and modernise the NHS. On the surface, the idea is compelling: catch hundreds of devastating but treatable conditions before symptoms emerge, offer immediate intervention, and reduce the burden on an already overstretched health service. Who wouldn't want that?

But for those of us who grew up reading George Orwell, something about the plan feels deeply familiar — not in the sense of medical innovation, but in the cold, systematic logic of surveillance. Because underneath the clinical language lies a stark reality: the UK is preparing to become the first country in the world to collect, decode, and permanently store the full genetic blueprint of every new citizen from the moment they are born. It is not hyperbole to say this represents the creation of a nationwide, identity-linked biometric register — and that the consequences of such a move will echo across generations.

In Orwell's *Nineteen Eighty-Four*, the omnipresent threat of Big Brother was not simply that he watched, but that he knew. He had the power to erase, rewrite, and categorise a citizen's entire identity from above — a state not just of surveillance, but of total control. What we are witnessing now is not fiction but prelude: a government building the foundations of a system that can know not just where we live or what we think, but who we are at the cellular level.

We are told this is about care, not control. But DNA is not like other forms of data. It is irreversible. It is permanent. And it is deeply revealing — capable of exposing not only our risk for disease, but our mental health vulnerabilities, our ancestry, our kinship ties, our susceptibilities to addiction, and even our likely responses to stress, trauma, and environmental stimuli. Unlike a credit score or a postcode, a genome cannot be changed. It cannot be deleted. It is the last word in identity — and soon, under the current plan, it may become the first word too.

The sequencing programme is being run by Genomics England in partnership with the NHS, building on the earlier Generation Study which tested the model in 100,000 infants. Under the full-scale rollout, DNA will be extracted from blood taken at birth and decoded into a complete genome — all six billion base pairs. That data will be securely stored and permanently linked to each baby's NHS medical record. Supporters argue that this is simply an extension of existing screening practices, only more sophisticated and inclusive. But the difference is profound. Traditional screening tests look for a handful of known disorders. Whole-genome sequencing reads the entire book, often for chapters we haven't even begun to understand.

Consent is another illusion in this system. Newborns cannot consent, and while parents may be acting with the best of intentions, they are effectively volunteering their child's body for lifelong participation in a state-run database. When the child turns sixteen, they will inherit a record they had no say in creating — and no way of erasing. That record will be accessible to NHS professionals, and potentially, to researchers and commercial partners. We are told that the data will be pseudonymised, but in reality, a genome is not pseudonymous. It is a fingerprint — not just for one individual, but for their relatives. In practice, there is no such thing as truly anonymised genetic data.

The risks of mission creep are not theoretical. Britain already has a chequered history with genetic data. The National DNA Database, initially created for criminal investigations, quietly expanded over the years to include hundreds of thousands of individuals who were never charged with any crime — including minors. It took a series of legal challenges and a judgment from the European Court of Human Rights to force the deletion of many of these profiles. And yet here we are again, only this time the data will be richer, deeper, and collected from birth with no suspicion of wrongdoing at all.

Supporters of the new policy argue that it will be a voluntary, opt-in system. But we know from history that "voluntary" systems often become de facto compulsory through social pressure, administrative policy, or simple inertia. If everyone is doing it, can you really opt out? Will schools, GPs, or insurers begin to view non-sequenced children as "data deficient"? Will parents who decline be quietly marked as non-compliant? These are not idle concerns. They are the logical outcomes of normalising surveillance under the banner of care.

The social implications are equally troubling. We risk entering a world where the genome becomes a proxy for potential. Where individuals are judged not just on what they have

done, but on what they might do — or might become. Genetic scores could be used to predict everything from educational attainment to behavioural risk. If that sounds dystopian, remember that data brokers already sell predictive profiles based on browsing history and purchasing behaviour. Imagine what they could do with your genome.

In *1984*, Winston Smith's rebellion was not to overthrow the regime, but to insist on the existence of objective reality — that two plus two equals four. In our world, objective reality is now something we can decode. But once decoded, it becomes something else: something that can be used, and misused, by systems far larger than ourselves. The genome may begin as a medical tool, but without ironclad safeguards, it becomes an instrument of classification — and control.

None of this is inevitable. It is possible to build a system that truly puts care first. We could mandate that children be re-consented as adults before their data is used for anything beyond immediate clinical need. We could write into law strict, enforceable firewalls preventing genetic data from ever being shared with insurers, employers, or law enforcement. We could ensure that commercial use of this data, if allowed at all, returns value directly to the public, not just private shareholders. Most of all, we could treat the genome not as a public asset, but as a private inheritance — one that should never be collected without explicit, reversible, informed consent.

The technology is powerful. The science is remarkable. But power must never outpace ethics. If we do not put safeguards in place now — at the very beginning — we risk creating a system that no future government can dismantle, no citizen can escape, and no society can fully trust.

Orwell warned that the future might look like a boot stamping on a human face — forever. In our version, it may look more like a lancet piercing a newborn's heel, while a sequencer hums softly in the background.

The machinery of the future has already been switched on.

The question is: who will control it?