



An image created by Don Cooper himself, to illustrate his view on the debate around genetic privacy. Don Cooper described the image as follows: "A project I'd like to see would be a large 3D model of DNA chromatin where an observer walks in and around it."

Policy advice by Don Cooper

As I attempt to understand this rapidly changing field, I try to drill down to a few essential elements in this discussion. Let's first start with contrasting an individual's sense of identity, and our collective identity as humans. Then let's look at our ability to limit the dispersion of genomic data to institutions who are doing the critical medical research that will be of benefit to our world.

A case can be made that our modern need for privacy is no more than 150 years old. Privacy contrasts an individual's sense of identity to a collective identity. A definition I've seen says "Privacy is the genuine state of separateness from others, which also includes psychological separateness from others." Do we pit autonomous individuals against the rapidly increasing interconnectedness of humans with the environment and with each other? Hearing the concerns of pregnant mothers to be, and recognizing how adhering to cultural tradition and narrative can conflict with science, I recognize that each person must have a right to request rigid limits on how his/her genetic data is distributed. Therefore, a basic policy requirement is that any individual can freeze availability of his/her genetic data at any time.

So how do we control the availability of genetic data? A first step is to require that only recognized scientific organizations be allowed to share the data. All data would be heavily encrypted, and decryption codes would be frequently changed and updated to limit hacking by unauthorized groups or individuals. A world council, possibly under the UN, composed of representatives from the major scientific organizations doing genetic research would be responsible for licensing all organizations that have access to a worldwide genetic data bank. This process would prohibit the insurance industry and those involved in employee hiring practices to access the genetic data.

Drawbacks to a world council approach includes limiting inputs from "outlier" scientists, since historically so much of paradigm shifting science has been via serendipity. Fool proof? Of course not, especially in our rapidly changing world. But we need a viable way to encourage and promote genetic research and development.