

Is your genetic information safe? Questions emerge over California and other states' DNA collection programs

Nintey-eight percent of all babies born in the United States have a tiny prick of their blood screened for a few serious diseases within the first few days of their lives. This test has been hugely successful at catching and beginning early treatment for inherited diseases such as sickle cell anemia and severe combined immunodeficiency.

Pressure is now mounting on multiple fronts to take advantage of this wellspring of potential genetic information. In the past, some states, [most notably Texas](#), have gotten in trouble for their willingness to give it up for uses with which many parents are uncomfortable.

Now, attention has turned to California. In [an article](#) in U-T San Diego, the Council for Responsible Genetics' Jeremy Gruber points out that while 19 states store these samples for more than two years, only California and a few other states keep them permanently and rent them out to researchers for a fee.

While the state's Department of Public Health asserts that the samples are anonymous, we've been learning over and over again that DNA is rarely truly anonymous.

For example, the UK Department of Health finally acknowledged in correspondence with [The Guardian](#) that the genomic information in the 100,000 Genome Project will not actually be anonymous, but "pseudonymised" – though they have continued use of the former term publicly because apparently "the term 'pseudonymisation' is not widely understood."

Read full, original article: California and your DNA Is it a healthy relationship?