

Government needs proper advisory committee to make ethical decisions in genetics policy

I served on the Human Genetics Commission (HGC) as a lay member from 2006 to 2012. If there's one thing that the experience taught me, it was the importance of debate. Crucial to that debate was hearing the voices of others – those affected by a development, but also those not so obviously affected, because genetic developments and other advances in science are not just about those of us directly impacted; they have an impact on us all.

But the HGC is no more. In its place, the government set up ESBAC – a committee of experts whose job was 'to provide expert advice to support policy development and priority setting in healthcare science'.

ESBAC's remit was wider than the HGC's – it covered 'new scientific developments'. But it was not intended to cover 'ongoing issues' unless there were new developments, so areas tackled by the HGC (such as advice on first cousin marriage and over-the-counter genetic testing) were out of bounds. And now ESBAC too seems to have fizzled out. Its last recorded meeting was in September 2013, and it formally disbanded in May 2014.

Does this matter? Does the government need ethical advice about new developments in the sciences, and genetics in particular? I think so. Progress is inevitable and, good or bad, there will be far reaching implications for us as individuals and for society as a whole. Given the fundamental nature of the impacts that we could see on the human race, regulation is needed. It's the government that has the job of deciding how draconian or light touch it should be.

The GLP aggregated and excerpted this blog/article to reflect the diversity of news, opinion and analysis. Read full, original post: [Who's advising the government on human genetics?](#)