

Combatting the discriminatory use of genetic data

Marc Willers¹

Garden Court Chambers

There have been tremendous advances in genetic science that will bring enormous benefit to the human race.

But there are concerns that genetic data could also be misused as a tool to discriminate against groups, such as ethnic minorities or people with genetic dispositions to health problems. Such discrimination could occur in a variety of areas, e.g. employment, health-care, education, the police and justice system and the provision of goods and services (such as insurance).

The concern that genetic data could be used for discriminatory purposes are borne out of bitter and painful historical experience. Crimes against humanity based upon racism litter our collective history, including: the murder of 1.5 million Armenians in the Genocide in 1915; and the murder of more than 6 million Jews and 500,000 Roma in the Holocaust during World War II (known by Roma as the ‘Porajmos’).

¹ Email: marcw@gclaw.co.uk.

Discrimination against Black people and people from ethnic minority groups has its roots in discredited theories about ‘race’ such as those advocated by the Eugenics movement in the 19th Century. Nevertheless, discriminatory practices have persisted in many States – including, for instance, the forced sterilisation of Roma women and the ethnic profiling of minority groups by the police.

In 1997, UNESCO issued the Universal Declaration on the Human Genome and Human Rights which stipulates in Article 6 that: *‘No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.’*

In my view there is a need to update equality and discrimination legislation in States to include a prohibition on the use of genetic data to discriminate which complies with Article 6 of the UNESCO declaration.

In the meantime, there is an urgent need to educate the judiciary, lawyers and the public on the risks associated with the use of genetic data and the safeguards that must be in place to ensure that its retention and distribution is lawful.²

In the absence of up to date legislation, the courts can develop caselaw to protect individuals and groups from discriminatory practices using existing laws – though such developments can take time and lead to inconsistencies and anomalies. That said, decisions of supra-national courts, such as the European Court of Human Rights, could do much to advance the protection afforded to individuals and groups in a coherent and consistent way.

There is likely to be resistance to the introduction of legislative safeguards from scientists, corporations and politicians who are keen to exploit the use of genetic data to its full advantage within a relatively relaxed regulatory regime, even if that does allow for there to be some scope for it to be used to discriminate. Such resis-

² See e.g. Article 9 of the General Data Protection Regulations <https://gdpr-info.eu/art-9-gdpr/>

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tance will need to be defeated if we are to ensure that the most vulnerable members of our societies are protected from its misuse.