

Is GINA coming to GB?

Susanne Foster asks whether the UK needs US-style legislation to prevent employers from treating people unfairly based on the result of genetic tests



Susanne Foster
is an associate at
CM Murray LLP

The Genetic Information Nondiscrimination Act (GINA) 2008 was ratified in the US in May 2008, with Senator Ted Kennedy referring to it as:

... the first civil rights bill of the new century of the life sciences.

GINA 2008 protects individuals from genetic information discrimination in health insurance and employment. The Title I health-insurance provisions of the bill took effect in May this year and the protections in employment, known as the Title II protections, take effect in November. These protections will apply to residents of all 50 US states and territories.

Background to the Act

With the continuing rapid advances made by geneticists and the completion of the Human Genome Project in 2003 (providing a blueprint of all genetic data contained in the human genome), there has been much discussion about the possibility of discrimination based on a person's genetic make-up. As Andrew Sullivan wrote in *The New York Times* in 2000:

Men and women will increasingly be judged not by the color of their skin but by the content of their chromosomes.

Genetic discrimination has been defined in various ways, but broadly speaking it is a difference of treatment (to an individual's detriment) based on information obtained from genetic tests or their family history.

In the US, concerns about genetic discrimination were prevalent in two areas:

- in the workplace, where genetic testing prior to offering employment was becoming more commonplace; and
- in the health-insurance industry, due to the worries that those who represented higher risks would be denied employer-subsidised health insurance.

Many felt that existing federal and state laws were inadequate to protect the most vulnerable. The answer to these concerns, after a decade of debate in Congress, was GINA 2008, introduced as a specific effort to combat genetic discrimination.

Details

In brief, the Title II employment protections under GINA 2008 mean that it will be unlawful for US employers to discriminate on the grounds of an employee's genetic information by:

- failing or refusing to hire, or terminating, any employee, or otherwise discriminating against any employee with respect to the terms of their employment;
- limiting, segregating, or classifying employees in any way that would deprive or tend to deprive them of employment opportunities or otherwise adversely affect the status of that employee; or
- preventing an employee's admission to, or employment in, any training or retraining programme (s202 GINA 2008).

In addition, and subject to specific exemptions, an employer is prohibited from requesting, requiring or purchasing an employee's genetic information or that of a family

'Genetic discrimination has been defined in various ways, but broadly speaking it is a difference of treatment (to an individual's detriment) based on information obtained from genetic tests or their family history.'

member of the employee. However, the proposed regulations make clear that inadvertent discovery of genetic information does not violate GINA 2008 (s202).

GINA 2008 explicitly states that a claim of disparate impact (which is broadly equivalent to English employment law protection against indirect discrimination) is not available under the genetic discrimination legislation. However, s208 GINA 2008 does provide for the establishment of a Genetic Nondiscrimination Study Commission in order:

... to review the developing science of genetics and to make recommendations to Congress regarding whether to provide a disparate impact cause of action under this Act.

The statute defines genetic information as including:

- an individual's genetic test results or those of family members;
- the manifestation of a disease or disorder in family members (ie, family history); and
- any request for, or receipt of, genetic services or participation in clinical research.

Genetic information does not include information about an individual's sex or age (s201 GINA 2008). A genetic test is defined as an analysis of human DNA, RNA (ribonucleic acid), chromosomes, proteins or metabolites that detects genotypes, common mutations or chromosomal changes (s201). Routine tests that do not measure DNA, RNA or chromosomal changes, such as blood counts, cholesterol tests and liver function tests, are not protected under GINA 2008, according to guidance issued in April by the US Department of Health and Human Services (HHS).

The law will be enforced by various federal agencies, with the Equal Employment Opportunity Commission taking responsibility for the enforcement of Title II. Remedies under GINA 2008 are consistent with the remedies under Title VII of the Civil Rights Act 1964, which include reinstatement, hiring, promotion, back pay, compensatory and punitive damages. According to the HHS guidance, individuals may also have the right to pursue private litigation.

Other jurisdictions

Turning to other jurisdictions, Australia is currently considering regulating this area and, closer to home, in May the upper house of the German Parliament provided the final stage of legislative assent to laws designed to prevent the misuse of genetic testing. This law prevents, among other matters, employers and health-insurance companies from requiring an employee or potential client to undergo a genetic test or from accessing the results of previous tests.

The general consensus in the UK remains that genetic discrimination does not pose a significant threat to individuals in an employment context.

UK position

Given that UK discrimination law tends to be influenced by the discrimination protections of our American cousins, the question is whether such protections will now be considered necessary here or whether existing legislation offers adequate protection.

In 1999 a report by the UK government's advisory body, the former Human Genetics Advisory Commission (HGAC), chaired by Baroness O'Neill, found no evidence of employer-driven genetic testing. This led the government in 2007 to confirm in its Green Paper, *Discrimination Law Review – A Framework for a Fairer Future: Proposals for a Single Equality Bill for Great Britain*, that although it would keep the situation under review, it did not propose to legislate against genetic discrimination at that time. In 2005 the Information Commissioner's Office (ICO) (the UK's independent authority with powers to enforce the Data Protection Act 1998) affirmed this position, stating in The Employment Practices Data Protection Code that genetic testing in the UK is 'rarely, if ever, used in the employment context'.

At the time of the HGAC's 1999 report, the only exception to employer-driven genetic testing was the Ministry of Defence (MoD). The MoD reported that it did have a formal policy covering a specific use of genetic testing in employment: all applicants for air-crew training were screened for sickle-cell disease. The purpose

behind such testing was to protect the individual and others from the potentially fatal effects of low oxygen pressure in flight. It is understood that this testing is no longer carried out, but the MoD does carry out selective testing where there is a clinical indication of the disease.

In 2002 the Human Genetics Commission (HGC), the successor body to the HGAC, looked further at issues relating to genetics and employment. Its 2002 report, *Inside Information*, concluded that at that time there

was no evidence in England of any systematic use of predictive personal genetic information in employment.

So the general consensus in the UK remains that genetic discrimination does not pose a significant threat to individuals in an employment context. However, it remains to be seen whether the protections due to be enforced in the US later this year will reignite the debate on enacting specific legislation in the UK. In the meantime, certain piecemeal protections are already in place, which are examined below.

Current protection in the UK

The UK does not currently regulate genetic testing in relation to employment. An employer can lawfully require a prospective employee to undergo genetic testing as a precondition to offering employment, and can refuse to offer employment to an individual based on the results of that test. However, under English law the employer is still restricted as to how it processes that information, and is accountable for the fairness of any decision it makes on the basis of genetic information.

Data Protection Act 1998

The Data Protection Act (DPA) 1998 implements the EC Data Protection Directive (No 95146/EC) and sets out conditions which must be met before certain data can be processed. The ICO has powers to enforce DPA 1998 and to issue codes and guidance. The results of a genetic test would fall into DPA 1998's

definition of sensitive personal data, meaning that its collection, storage, organisation, retrieval, alteration, disclosure or destruction has to meet the eight principles set out in schedule 1 and at least one of the conditions set out in schedule 3.

The ICO has issued the Employment Practices Data Protection Code (the Code), which deals with the impact of data protection laws on employment relationships. The Code has four parts, and Part 4 concerns medical information

serious safety risk to others or where it is known that a specific working environment or practice might pose specific risks to workers with a particular genetic variation; and

- ensure that if a genetic test is used to obtain information for employment purposes, it is valid and subject to assured levels of accuracy and reliability.

The Code also suggests that the HGC be informed of any proposals

be either because no companies are asking employees to take genetic tests or because companies are choosing not to follow the guidelines set out in the Code.

Enforcement

A breach of the Code does not in itself result in any penalties or enforcement action. However, if a breach of the Code results in a breach of DPA 1998, or there is a breach of DPA 1998 itself, this could result in enforcement action by the ICO. Enforcement notices can require an employer to take or stop taking specified steps or to refrain from processing certain data. However, the ICO is not obliged to take action on each occasion there is a breach of the DPA 1998, and it will normally only do so where it is a serious contravention or one that affects a large number of people (s47 DPA 1998). A breach of DPA 1998 could also result in the affected individual bringing a civil claim for compensation in a county court or the High Court (and in genetic data being destroyed) if the individual suffers damage and/or distress as a result (s13 and s15 DPA 1998).

Access to Medical Reports Act 1988

AMRA 1988 provides employers with a right of access to medical reports provided by medical practitioners for employment purposes, and employees with the right to withhold their consent to their own doctors providing certain information to their employer. Employers are only permitted to apply for a medical report that is covered by AMRA 1988 if:

- they have notified the individual concerned in writing that they intend to make the application; and
- the individual has provided their explicit consent to the application being made.

An individual who has been asked to provide their consent can:

- withhold this consent;
- consent to the application for the report and agree for it to be sent directly to their employer; or
- consent to the application but indicate that they wish to see the report before it is supplied to their employer.

Therefore, AMRA 1988 does offer an employee some control over the dissemination of confidential medical

Under English law an employer is accountable for the fairness of any decision it makes on the basis of genetic information.

and sets out specific recommendations on genetic screening. It advises that genetic testing of individuals should only be introduced after very careful consideration, if at all. Key statements which the Code makes include:

- do not use genetic testing to obtain information that is predictive of a worker's future general health;
- do not insist that a worker disclose the results of a previous genetic test;
- use genetic testing to obtain information only where it is clear that a worker with a particular, detectable genetic condition is likely to pose a

to use genetic testing for employment purposes. In April this year, Jonathan Montgomery, chairman of the HGC, wrote to the ICO to find out if it considers this mechanism to be:

... sufficiently robust to ensure that the HGC is informed of all companies who are asking employees to take a genetic test for employment purposes.

Mr Montgomery confirmed that the HGC had not been contacted by any companies declaring an intention to use genetic testing for employment purposes. As he suggested, this could

Reference point

- The Genetic Information Nondiscrimination Act 2008: www.legalease.co.uk/gina2008
- 'Promotion of the fittest', Andrew Sullivan, *New York Times* www.legalease.co.uk/sullivan
- 'Fearing Fear Itself: The Proposed Genetic Information Nondiscrimination Act of 2005 and Public Fear about Genetic Information', by Rivka Jungreis, *Journal of Law and Policy*: www.legalease.co.uk/jungreis
- Human Genetics Commission Secretariat Report: www.legalease.co.uk/HGCreport
- Employment Practices Data Protection Code, Part 4.5: www.legalease.co.uk/goodpractice
- Letter from the chairman of the Human Genetics Commission to the ICO: www.legalease.co.uk/HGCletter
- *Inside Information*, Human Genetics Commission: www.legalease.co.uk/insideinformation
- Nuffield Bioethics consultation: www.legalease.co.uk/bioethics

reports that may contain genetic information of interest to an employer. However, it does not prevent an employer from trying to obtain this information from other sources or from discriminating against an individual on the basis of that information.

Employment legislation

Less direct protections against genetic discrimination are also offered by the Disability Discrimination Act (DDA) 1995, the Sex Discrimination Act (SDA) 1975 and the Race Relations Act (RRA) 1976.

Individuals who suffer from conditions that occur primarily in one sex (such as haemophilia, which manifests itself almost entirely in males) or in a particular race (such as thalassaemia, a blood disease which is particularly prevalent among Mediterranean people) may be protected by SDA 1975 or RRA 1976 against less favourable treatment on the ground of such a condition or a predisposition to it.

Under DDA 1995, an employee who is known to have a genetic disorder and is deemed disabled will attract the normal DDA 1995 protections. However, the definition of disability does not cover people who are susceptible to a future disability. This appears to be a lacuna in the legislation, leaving those with a genetic disorder or family history of a genetic disorder potentially exposed to detrimental treatment.

In addition, employees who have over a year's service (subject to a number of exemptions) may have unfair dismissal protection if they are dismissed because they refuse to undergo a genetic test or because of the results of a genetic test.

However, these discrimination protections are not aimed at preventing genetic discrimination and offer no protection to those individuals who are susceptible to genetic discrimination but whose genetic disorder is latent.

Human Rights Act 1998

Another piece of legislation which may be of assistance in preventing genetic discrimination is Article 8 of the Human Rights Act (HRA) 1998. This came into force on 2 October 2000 and provides that:

Everyone has the right to respect for his private and family life, his home and his correspondence.

Although not an employment case, *S and Marper v UK* [2008] illustrates the courts' willingness to apply Article 8 to prevent the abuse of an individual's right to keep genetic test results private. In this case, the European Court of Justice found that the retention by the police of the applicants' fingerprints, cellular samples and DNA profiles was in violation of Article 8. The information had been retained even though neither applicant had been convicted of a criminal offence.

Although the UK courts are required as far as possible to interpret all legislation, whenever enacted, in a way that is compatible with the European Convention on Human Rights, the provisions of HRA 1998 are only directly applicable against public

individual's right to privacy and of personal data than its US counterparts. However, the UK is clearly some way behind the US in protecting against genetic discrimination.

It seems improbable that no UK employers are currently using, or at least planning to use, genetic information in the employment setting when its use in the US has become more prevalent over the last decade, culminating in the implementation of GINA 2008. Employers in this country are either unique in not using genetic testing or are unwilling to declare its use openly.

As illustrated above, English law is yet to provide comprehensive protection against genetic discrimination. Rather, the current

Employers in this country are either unique in not using genetic testing or are unwilling to declare its use openly.

authorities. Therefore, the protections offered to employees in private employment may be somewhat limited, as they will not have a standalone claim under HRA 1998.

Other protections

A number of other principles control the use of genetic testing. These are currently not binding on the UK but may have some persuasive force.

Article 6 of the UNESCO Declaration on the Human Genome and Human Rights provides that no one may be subjected to discrimination based on genetic characteristics if this has the effect of infringing human rights, fundamental freedoms or human dignity. This international instrument was adopted by the General Conference of UNESCO in 1997 and endorsed by the General Assembly of the United Nations in 1998.

The Council of Europe Convention on Human Rights and Biomedicine, which came into force in 1999 and was drafted by the Council of Europe, also explicitly prohibits any form of discrimination on the ground of genetic heritage (Article 11).

The future

It is arguable that UK legislation has always been more protective of an

protections are a patchwork of various laws whose origins stem from other concerns far removed from the fear of genetic discrimination – indeed SDA 1975 was implemented ten years before the laboratory development of the first genetic test.

However, genetic testing advances day by day, to the extent that individuals can now buy their own paternity tests on ebay for under £100. Separate ethical concerns have already been raised about consumers' ready access to such information, and earlier this year a consultation was launched by the independent Nuffield Council of Bioethics, which looked at this and other issues.

As genetic tests become more readily available, they could force our legislature to reconsider the current employment protections against genetic discrimination, in which case we will be able to refer to the invaluable work of our US counterparts on this point. It is to be hoped that any such legislation will fill in the gaps that currently exist in our fairly piecemeal laws and that expose to detriment those most susceptible within society. ■

S and Marper v UK
[2008] ECHR 1581