

## ARTICLE

# Exploring the Regulation of Genetic Testing in Sport

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This article investigates the legal implications of the use of genetic testing in sport, that is, the analysis of human DNA to detect particular genetic traits and variations, or susceptibility to conditions. As science makes significant strides in the understanding of our genetic information, the search for the genetic components which separate winners and losers in sport follows. Although the practice of genetic testing in sport is not currently commonplace, there are some examples of genetic information being used by sports clubs and governing bodies to make decisions about an athlete's capability to perform. This article examines how this practice could disproportionately interfere with an individual's human rights and result in genetic discrimination if information is used for selection and employment purposes. It reviews some of the hard and soft law measures that regulate genetic testing at an international, regional and domestic level. The position of sport within this regulatory framework is uncertain, given the unique way in which sports regulation functions and interacts with the law. Nevertheless, the article concludes that the tendency of the law to treat discrimination in sport differently to other areas of society could leave athletes vulnerable. Whilst genetic information may be useful for understanding genetic traits and their relationship with athletic performance, going beyond this to select athletes on the basis of genetics is discouraged and the interests of sport should be fairly balanced against the human rights of the athlete.

**Keywords:** Genetic testing; discrimination; human rights; sport regulation; sports law

## Introduction

In 2003 the Human Genome Project achieved its primary goal of completing the sequencing of the human genome. This represented a new age in the understanding of the human body and, as a result of the findings, a greater interpretation of how an individual's genotype can explain particular traits and conditions is anticipated. Information about our genetic make-up, individual susceptibility to certain diseases, responses to certain drugs or nutrients are readily available through the process of genetic testing. There is no consensus definition of genetic testing, but it broadly involves an analysis of human DNA to detect particular genetic traits and variations, or susceptibility to conditions.

This genetic revolution in medical practice is leading to better healthcare provisions, improved patient choice, increased research and effective treatment for disease in the future (Gostin and Hodge 1999). Genetic test services are now even offered by many companies directly to the consumer (DTC) post-2012. Genetic testing is becoming increasingly popular and accessible to consumers who may be curious about their genetic information for health or ancestral reasons.

That said, there is often incongruence between scientific capabilities and ethical boundaries (McNamee et al. 2009: 341). Genetic testing raises a number of ethical and legal concerns around genetic discrimination, privacy and consent in employment and in insurance. There is a potential conflict between the progression of science to further human knowledge and improve health, and the protection of human rights and autonomy. These issues are gradually being explored in the literature, as attention focuses on the effective regulation of the use of genetic testing and genetic information (Quinn et al. 2015).

The competing issues surrounding genetic testing manifest themselves in the context of sport where advances in medicine, science and technology are at the forefront of understanding human athletic ability. Capturing and analysing biometric or biomechanical athlete data forms a key aspect of sport practice (Osborne 2017). Sports' demand for excellence in athletic performance and competition continues to grow, and as science evolves, so too has the search for what makes an athlete elite and the innate genetic components which may separate winners and losers. The use of genetic testing in sport is not well documented. However, the authors recently explored the current use of genetic testing in UK elite sport, and found that genetic testing related to sports performance and injury susceptibility does take place although it is not commonly conducted (Varley et al. 2018). The study reveals that there seems to be a willingness amongst elite athletes and athlete support staff for genetic information to be used to improve sport performance and reduce the risk of injury. Some athlete and support staff opinions in the study favoured the use of genetic testing for

selection/employment and talent identification. These findings form the basis of this article, which seeks to investigate the legal implications of the potential use or misuse of genetic testing in sport. The use of genetic information to make determinations about selection and employment could disproportionately interfere with an individual's human right to be free from discrimination on the basis of their genetics (Kim, Salman & Joly *in* Quinn et al. 2015: 69).

It should be noted that there is a clear distinction between genetic testing that is based on clinical scientific evidence of a gene influencing a phenotype, and a mere genetic association with a given trait. For example, variants in BRCA1 and BRCA2 genes are commonly used as screening tools for breast cancer due to their clinically proven predictive capabilities. However, no such predictive capacity has been shown in genes researched within a sporting setting, with many associations asymptomatic, without an established cause and effect. The current article focuses exclusively on genetic testing in a sport setting.

The treatment of athletes on the basis of their human traits is commonplace in sport, with sex segregation for instance, historically viewed as legitimate and necessary division for fair competition in sport. The essence of sporting activity is about challenging our physical and non-physical differences by creating conditions which separate athletes on the basis of these differences. However, at times these exclusionary practices are potentially incompatible with core human rights principles, in situations where there is no justification or legitimate basis for differential treatment (Patel 2015a). As a result, unnecessary divisions are being challenged and measured against legal principles of proportionality (Patel, 2015a).

Analyses of the current regulatory framework for genetic testing generally have been made in the literature (Quinn et al. 2015). This article offers original insight by evaluating the framework in the context of sport, having regard for the unique way in which sports regulation functions and interacts with the law.

This article examines the current uses of genetic information in sport. It explores some of the legal provisions that regulate genetic testing at an international, regional and domestic level, and follows with an exploration of how that framework might apply in a sporting context. Concerns about the use of genetic testing generally are being addressed in many jurisdictions through the introduction of soft or hard law measures, but the position of sport within this regulatory framework, and their handling of sensitive athlete data, remains typically unclear.

### **Current Use of Genetic Testing in Sport**

In a recent study investigating the current use of genetic testing in UK elite sport, 72 elite athletes and 95 support staff at UK sports clubs and governing bodies were surveyed. It was found that genetic testing related to sports performance and injury susceptibility does occur, albeit infrequently (Varley et al. 2018). This supports pockets of evidence of testing taking place in sport globally.

#### ***Age Identity***

In Major League Baseball (MLB) in the USA, genetic testing was introduced to verify athlete identity and to tackle misrepresentation. Prospective players were found to be falsifying their age in order to be more attractive to MLB teams for selection (Hebbar 2011: 55; Schmidt and Schwarz 2009; Zitelli 2011). Teams responded to this by testing the DNA of a selection of elite players and their families. Whilst the test does not verify age in itself, the DNA tracks a family line (Zitelli 2011). The MLB defended the testing as a means of protecting its teams, or more broadly protecting the essence of sport (Schwarz 2009). They claimed that it was only used in rare circumstances and on a consensual basis, with identity fraud in mind. However, it is unclear whether the testing is truly consensual and the use and retention of the information gathered from the genetic test could constitute a violation of privacy as well as genetic discrimination (Stevens 2011).

#### ***Doping***

The World Anti-Doping Agency (WADA) are a private international body tasked with creating and maintaining unified standards for anti-doping testing and the imposition of sanctions for doping violations. Their testing processes involve testing athletes as a condition of participation and gathering and storing sensitive information. Although regimes such as the Whereabouts Rule (out of competition testing) have been challenged as an infringement of human rights (*Fédération Nationale des Syndicats Sportifs and Others v France* judgment of 18 January 2018, no. 48151/11 and 77769/13), those challenges have failed and the intrusion of an athletes privacy is considered to be necessary in the global fight against doping in sport.

The Athlete Biological Passport monitors over a period of time, selected athlete biological variables to identify any changes from the potential effects of doping. This relies on regularly updating blood samples records. Significant attention is being paid to the use of gene therapy to enhance performance in sport. Gene doping refers to the non-therapeutic manipulation of genes to augment athletic performance in sport. WADA prohibit gene doping and gene editing and have explored ways to enable accurate detection of such methods. As an extension to the biological passport, it was reported that they are considering requiring athletes to submit a copy of their genetic code in order to monitor any variables in the athletes' sequencing (Niiler 2018). WADA would have to ensure that these potentially intrusive practices are necessary for the protection of the integrity of sport. The entire WADA regime reflects the way in which sport currently relies on genetic information in sport.

### ***Injury and Medical Conditions***

In the previous study, a willingness amongst elite athletes and support staff for genetic information to be used in the hope of improving sport performance and reducing injury risk was also identified (Varley et al. 2018). The study found that the majority of athletes surveyed would want to know if they had a genetic variation associated with sport performance or injury susceptibility. The potential to use genetic testing to reduce sports injuries is slowly being realised (Goodlin et al. 2015). For instance, it was reported that an English football club sent a geneticist DNA samples from some of its players for analysis of how injury prone they are (Collins 2011). Whilst the effectiveness of genetic testing is still largely unknown, the future use of accurate genetic profiles could potentially help managers reduce their players' chance of getting injured, through better informed training schedules and squad selection (Collins 2011; Goodlin et al. 2015).

However, there is a clash between protecting the health and well-being of an athlete, safeguarding the financial costs of teams and clubs and potentially discriminating against athletes by restricting their employment opportunities. For example, athletes' careers have been inevitably shortened by screening for medical conditions such as Marfan's Syndrome, rare heart conditions and the sickle cell trait (Bland 2011: 370; Quick 2009; Roberts et al. 2017; Wagner 2012; Zarda 2010).

In 2005, professional basketball player Eddy Curry Jr was forced by the Chicago Bulls to undertake a DNA test to determine susceptibility to a rare heart condition that could lead to sudden death, particularly for athletes. It was reported that the Bulls added a genetic testing clause into Curry's new long term contract offer and offered him \$400,000 annually for the next fifty years if he failed the test (Anon 2005a; Anon 2005b). Curry refused to take such a test and challenged it as an infringement of his right to privacy (Rice 2006: 6). However, before a legal claim could be brought, in 2005 Curry was traded to the New York Knicks, where he was not required to undertake a test because the medical team at the club were unconvinced by the accuracy of DNA testing, and also because New York State law (NY Executive Law 296(1)) prohibited employers from requiring a genetic test as a condition of employment.

The Bulls objective was to protect Curry's health and well-being (Anon 2005a) which may be legitimate in principle, but imposing testing on athletes and using the genetic information to make decisions on their behalf can have a disproportionate impact upon the autonomy of athletes' life choices and on their right to privacy (Epstein 2013: 256). Genetic testing may be viable in screening to detect hereditary conditions and diseases/illnesses which are symptomatic. However, the majority of genetic testing in sport and the information provided by DTC testing companies is based upon questionable scientific evidence and is asymptomatic (Varley et al. 2018). Currently, there is no evidence base for a genetic origin/causation of increased or decreased likelihood of sporting prowess or injury.

The complexity of this debate is further emphasised by the introduction of mandatory athlete pre-participation screening in some countries. In 2006, American football student athlete Dale Lloyd II collapsed and died during a training session, as a result of complications associated with the sickle-cell trait. He had no knowledge that he was a carrier and had never been tested for the trait. The Lloyd family sued Rice University and the National Collegiate Athletic Association (NCAA) for wrongful death and claimed that the NCAA was negligent for failing to warn Lloyd about the risk of complications due to carrying the sickle-cell trait. Many athletes who carry the sickle-cell trait participate in athletics without any difficulties and are unaware that they carry the trait. However, some evidence suggests that high intensity physical activity can put carriers at risk (Quick 2009: 671).

Following the litigation, the parties eventually settled and the NCAA agreed to formally recommend that its member colleges and university athletic departments test all student athletes for the sickle-cell trait before participating in intercollegiate athletics (Lanier 2013; NCAA 2009). In 2010, the NCAA Legislative Council formally adopted a measure to codify this commitment (Almond 2010). This example highlights the difficulty with assessing who should bear the risk if an athlete with a medical condition competes in sport (See *Knapp v Northwestern University* below).

Mandatory screening has saved the lives of athletes who would not otherwise have had the opportunity to be screened (Briggs 2016). Yet, mandatory screening for medical conditions is not universal and the medical field continue to investigate the most appropriate and justifiable screening protocol for athletes (Borjesson and Drezner 2012). The screening of all athletes for conditions such as sudden cardiac death is not currently recommended in the UK because of uncertainty around the testing and its current lack of reliability (Anon 2015; Briggs 2016). Instead of confirming a genetic condition, genetic tests, 'indicate risk based upon predispositions for common complex diseases, the possible onset of which are influenced substantially by lifestyle and environmental factors' (Soini 2012: 150). It is argued below that the means employed to achieve the aim, may be disproportionate to the aim and this requires a balancing of competing interests (Legg, 2012: 179). Making eligibility decisions on the basis of uncertainty could be a disproportionate interference with an athlete's human rights, even where the aim of protecting the health of the athlete may be legitimate.

### ***Gender Verification***

Genetic traits can also include our sex and gender. Recently, the International Association of Athletics Federations (IAAF) eligibility regulations for female classification (Athlete with Difference of Sexual Development) have been at the centre of sport debate (Sports Hour 2018). The regulations require any female athlete with testosterone levels higher than permitted, to be legally recognised as female or intersex and to reduce her testosterone level in order to compete. These rules have been dressed up in many ways over time, from the historical chromosome sex testing of suspicious looking female athletes, to a range of hormone gender verification policies and the current IAAF hyperandrogenism

rules. Ultimately, these rules have forced female athletes to undergo a genetic test to verify their sex. It was historically viewed as a way of preventing gender fraud and regulating unfair advantage in sport (Patel 2015a). However, the regulations marginalise and exclude athletes with naturally occurring genetic traits such as high levels of testosterone, as evidenced by Indian athlete Dutee Chand who successfully persuaded Court of Arbitration for Sport (CAS) to suspend the IAAF hyperandrogenism rules in 2015 (Patel 2015b). The current eligibility criteria continues to have an exclusionary effect on athletes such as Caster Semenya, who is launching a challenge to CAS, contesting the discriminatory impact of the rules. Analysis of these issues are beyond the scope of this discussion, but this practice demonstrates how rules in sport may continue to be upheld as legitimate for fair competition, even when they lack a conclusive scientific or rational basis.

### ***Talent Identification and Selection***

In sport the recruitment and retention of employees has evolved towards a process of 'talent analytics' where employers use data-based predictive methods to improve the accuracy of athlete selection (Burdon and Harpur 2014: 680). The position of genetic testing within this selection process is based upon the assumption that genetically favourable athletic traits can be traced and future better performance can be predicted. Since early talent identification in sport is of paramount importance, genetic profiling arguably makes the process of selection more exact and quantitative (Roth 2012: 249). For instance, DNA testing and analysis company 23andMe, conducted genetic analyses of both former and current National Football League (NFL) players to investigate how genes impact athletic performance (Bland 2011: 372). In 2008 it was reported that an English football club approached a scientist about 'the possibility of screening players to discover whether they have a genetic predisposition to athletic excellence' (Scott and Kelso 2008). There have been many reports that elite athletes have been working with DTC companies ahead of the Olympic Games as part of their competition preparations (Watts 2012).

The majority of support staff and athletes in the authors' study reported that there is a place for genetic testing in sport though opinion was divided in relation to the use of genetic testing for talent identification (should be used = 67% athletes; 48% support staff) and even selection/employment (should be used = 28% athletes; 14% support staff) (Varley et al. 2018).

For now, at least on the surface, the use of genetic testing precisely for talent identification and selection remains hypothetical. There has yet to be a large-scale study that prospectively identifies athletic excellence as a result of an individual's genotype. If genetic testing were to be conducted for this purpose, it would be without scientific credibility given the lack of current scientific understanding in relation to genetics and sport performance. Although there have been some genetic variations that have been shown to potentially influence sports performance (such as the ACE II associated endurance athletes, and the ACTN3 RR associated with power athletes) (Ma et al. 2013), the precise impact of genetic variations on sport performance remains inconclusive (Varley et al. 2018).

The difficulties in assessing how genes interact with the environment, the assumption that many genes play a role in determining physical attributes, and the lack of understanding about how genetic variants interact, suggest a very limited applied use in assessing current or potential athletic excellence through genetic testing. In light of this, making determinations based upon predictive tests could be a dangerous and potentially discriminatory practice based on the limited and questionable scientific evidence (Collier 2012: 44; McNamee et al 2009).

Over time, genetic or cultural human differences have often been generalised and used as a basis for exclusionary treatment (Tishkoff and Kidd 2004). The consequence of dangerous stereotyping on the basis of genetics has been the deliberate placement or displacement of athletes in particular sports (See Patel 2015a). There is a danger that the less desirable athletes would be weeded out in a sort of modern-day un-natural selection process (Rice 2006: 5). This process may begin from an early age and lead to the exclusion of children from certain sports based upon their genetic information (Miah and Rich 2006).

The imposition of genetic testing as a means of talent identification or team selection also raises issues of autonomy and consent: to what extent the athlete is free to decline to take a test or whether they would feel obliged to participate in order to secure opportunities in sport. Given media attention on sport, there is also a concern of privacy and confidentiality of information if genetic testing were to be widely used (Roth 2012).

Overall, the examples of genetic testing in sport are rare but they do exist. As science advances, it is likely that 'the economic incentive to discriminate based on genetic information' will only increase (Zitelli 2011: 27). Yet the current use of genetic information is based upon inconclusive or only predictive evidence. Even if certainties are possible in the future, there is potential for legal challenge if genetic information is used for selection and employment purposes. What follows is an evaluation of how such practice could infringe genetics regulation and anti-discrimination legislation which seeks to protect individuals from discriminatory treatment on the basis of their genetics. There may also be potential human rights breaches and failures to adhere to medical policies and guidance on genetic testing.

### **Regulation of Genetic Testing**

With genetic testing in sport still in its infancy, formal regulation appears to be minimal, with medical bodies in the field currently presenting position statements on the use of genetic testing (see Vlahovich et al. 2017: 5). Some sports organisations such as the British Association of Sport and Exercise Sciences (BASES) have explored this issue and rec-

ommended that as genetic research becomes an increasingly important aspect of sport and exercise science, research should be conducted in an 'ethically acceptable manner' (Williams et al. 2012). Leading discussions have taken place in Australia and the Australian Institute of Sport (AIS) reinforce the notion that there are 'currently no scientific grounds for the use of genetic testing for athletic performance improvement, sport selection or talent identification' (Vlahovich et al. 2017). On this basis the use of DTC genetic testing by athletes and coaches is largely discouraged unless for research or health-related purposes, where it should then follow stringent ethical guidelines. This reflects the Australia Law Reform Commission recommendation that policies and guidelines are developed by sports authorities on the use of genetic information in sport (Australian Law Reform Commission. 2003).

In the absence of any firm sport regulation for genetic testing, current sport practices have instead been hypothetically measured against legal standards. The relationship between sport and the law is a complex one. Sport is unique because it holds significant global commercial power and has dominated many areas of social activity. Sport influences the shaping of societies and cultures, and contributes to economic growth. Given this stronghold in society and industry, the legal accountability of sports bodies and the external scrutiny of their rules and regulations receives increasing attention (Boyes. 2017).

At the one end exists the interventionist model that is based upon the idea that sport serves a public function and the state has a responsibility to regulate this area through the enforcement of legislation (Lewis and Taylor. 2014: 5). Proportionality and the rule of law is therefore considered essential for the regulation of sport.

In comparison, the model of non-intervention and autonomy is one where sport is considered to be a self-regulating private sphere, which is immune from government responsibility (Harlow and Rawlings. 2009: 235; 239). The sophistication of the internal regulation of sport blurs the boundaries between formal law and normative rules of sport, leading to the emergence of sports law as a distinct discipline (Davis *in* Siekmann and Soek 2012: 1). Sports governing bodies have a general tendency to regard the involvement of the law as a potential threat to the special essence of sport, instead favouring internal sports regulation. It is fair to say that the intervention of law in sports activity is cautious and mindful of the special nature of sport regulation.

Outside of the sporting context, appropriate models of regulation for genetic testing are currently being sought. Key theoretical considerations in these early stages of regulation are around what needs to be protected and whether there is a need to create specific regulation for genetic testing at all (Pinto-Basto et al. 2010; Sequeiros et al. 2012: 122; Soini 2012: 144). Definitions of genetic testing and genetic information in the literature appear to vary considerably and it is recommended that an operational, consensus definition, which is context dependant when drawing guidelines/recommendations in this field is agreed in any policymaking process (Lemke, 2005: 23; Pinto-Basto, 2010: 29; Kristoffersson, Schmidtke and Cassiman 2010: 23; Sequeiros et al. 2012; Varga et al. 2012).

The regulation of genetic testing and the use/storage of genetic information appears to be located in hard and soft law measures pertaining to employment and insurance, anti-discrimination, privacy and data protection, although there is a significant variation of approach between countries and across domestic, regional and international levels. A review of these instruments follow.

### **International Level**

The Universal Declaration of Human Rights 1948 (UDHR) represents the foundation of international human rights law. It was the first instrument that set out internationally accepted basic civil, political, economic, social and cultural rights for all human beings. It serves as a framework for the enactment of a wide body of legally enforceable global human rights instruments that have translated the concepts of the document into law through the formation of treaties, principles, agreements or conventions at a domestic, regional and international level of governance (Patel 2015a: 40).

The rights contained in the Declaration apply universally to every person 'without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status' (Article 2 UDHR). Whilst no explicit reference to genetics is made, attention is given to the human family and Article 1 states that, 'all human beings are born free and equal in dignity and rights.' Article 12 UDHR guarantees the right to privacy.

As discussed below, some countries address discrimination on the basis of genetics within existing provisions for the protection of individuals with disabilities. The Convention on the Rights of Persons with Disabilities (CRPD) is an international legal agreement that broadly categorises persons with a disability. Its purpose is to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity' (Article 1 CRPD).

The United Nations Educational, Scientific and Cultural Organisation (UNESCO) is a special branch of the UN and promotes dialogue between civilisations, cultures and people to achieve global visions of sustainable development encompassing observance of human rights, mutual respect and the alleviation of poverty (UNESCO 2014). They also conduct significant work in the fight against discrimination, using sport as a vehicle for change. Two international instruments exist in the field of bioethics. The Universal Declaration on Human Genome and Human Rights 1997 seeks to balance the advancement of science with the need to protect human rights and preserve human dignity, given that the human genome represents the 'heritage of humanity' (Article 1). The Declaration establishes universal ethical standards for human genetic research and practices. According to Article 2, everyone is entitled to 'a right to respect for their dignity

and for their rights regardless of their genetic characteristics,' and no one should be subject to discrimination on the basis of those genetic characteristics (Article 6). Ethical principles relating to consent and confidentiality of genetic information are also contained within the Declaration.

UNESCO also adopted the International Declaration on Human Genetic Data 2003. It similarly aims to balance freedom of research with the respect for human dignity, ensuring the protection of human rights at every stage of human genetic research (collection, processing and storage of human genetic data). With a need for international guidelines in this field, the Declaration seeks to offer guidance to States in the 'formulation of their legislation and their policies on these issues; and to form the basis for guidelines of good practices in these areas for the institutions and individuals concerned' (Article 1a). However, it continues to be advocated that these instruments have moral, but not legal force (Ibarreta and Hogarth in Kristoffersson, Schmidtke and Cassiman 2010: 246), and to some extent pursue a genetic exceptionalism approach (Soini 2012: 145).

In 2007, the Organisation for Economic Co-operation and Development (OECD) introduced best practice guidelines for quality assurance in molecular genetic testing (OECD 2007). The organisation provides a space for governments worldwide to share practice and discuss global issues relating to economic, social and environmental challenges. The guidelines demonstrate a commitment to ensure international minimum standards for quality assurance systems and molecular genetic testing laboratory practices (OECD 2007).

The World Medical Association (WMA) is an international organisation representing physicians and focused on ensuring high standards of ethical behaviour and care. In official alliance with the World Health Organization (WHO), the WMA provide ethical guidance to physicians through the implementation of its Declarations, Resolutions and Statements. Their statement on genetics and medicine highlights the importance of ensuring informed consent when genetic testing is carried out (WMA 2017).

The International Federation of Human Genetics Societies aims to provide a platform for communication across the international community of human geneticists. Members of the Federation include the American Society of Genetics, the European Society of Human Genetics, the Human Genetics Society of Australasia, the African Society of Human Genetics, the East Asian Union of Human Genetics Societies and the Asia-Pacific Society of Human Genetics.

### **Regional Level**

Europe was first to gain a comprehensive regional treaty in the form of the European Convention on Human Rights 1950 (ECHR). The effect of the Convention has been underpinned by the fact that members of the Council of Europe are required to be signatories to it and to abide by its rights and protective provisions. These are ultimately guarded by The European Court of Human Rights (ECtHR), to whom individuals may take complaints about violations which have not been domestically remedied.

In some circumstances Member States may restrict these rights if that restriction is necessary in a democratic society. Applying the necessity test is very much a case of analysing proportionality (Kumm in Pavlakos 2007: 132). The doctrine of proportionality demands that the restriction must be in pursuit of a legitimate aim and must not go beyond what is necessary. Member States are afforded a margin of appreciation when interpreting the rights (Fenwick and Edwards 2016: 95).

The Council of Europe's commitment to the regulation of genetic testing is evidenced by the enactment of the European Convention on Human Rights and Biomedicine Convention 1997 (The Oviedo Convention), which is considered to be the only international legally binding instrument in the field of biomedicine (Council of Europe 2015).

Core principles of the ECHR are adopted within the Convention, which aims to protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine (Article 1). Article 10 protects the privacy of an individual in relation to his or her health. Article 11 prohibits discrimination on the grounds of genetic heritage. Furthermore, Article 12 states that predictive tests may only be administered for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling. It has been observed that this would therefore exclude tests which were conducted for sport performance (McNamee et al. 2009: 341; Soini, 2012: 146). In accordance with Article 32 of the Convention, an additional four protocols supplement and reinforce the principles contained in the Convention. Despite the symbolic significance of the Convention, only 29 countries have ratified it currently.

In 2016 the Council of Europe produced recommendations for the use of personal health related data for insurance purposes, which included data from genetic tests. The proposal is that Member States take appropriate measures to ensure respect for the fundamental rights of persons, without discrimination, in the context of the insurance contracts (Recommendation CM/Rec(2016)8).

In the European Union, the Treaty of Lisbon which came into force in 2009, has firmly enhanced the presence of fundamental rights in the EU (Douglas-Scott 2011). Article 2 of the Treaty on European Union (TEU) states that 'the Union is based on the values of respect for human dignity, freedom, democracy, equality, the rule of law and respect for human rights, including the rights of persons belonging to minorities.' Principles of non-discrimination are broadly recognised by Article 10 and Article 19 of the Treaty of the Functioning of the European Union (TFEU). Explicit protection from discrimination on the basis of genetic features does not appear in the TEU.

The Charter of Fundamental Rights of the EU 2000 now has full legal status (Article 6(1) TEU) and under Article 6 (2) TEU. The legally binding Charter is the first formal EU document listing civil, political, economic and social rights to which EU citizens should be entitled. Article 3 concerns the right to the integrity of the person and signposts particular attention to this protection in the fields of medicine and biology. In addition, Article 21 expressly prohibits discrimination on the grounds of genetic features and demonstrates an awareness of genetic discrimination at the EU level (de Paor *in* Quinn et al. 2015: 169). The right to privacy is also protected under Article 7 and Article 8.

The General Data Protection Regulation 2016/679 (GDPR) imposes minimum harmonised standards for the handling and processing of data across Europe. It seeks to protect individuals and provide them with more power over their personal information. Article 9 GDPR specifically protects the processing of personal genetic, biometric or health data.

The regulation of health-related genetic testing in the EU is broadly captured under legislation on *in vitro* diagnostic medical devices. In order to remedy implementation and enforcement issues with the current directives (Council Directive 98/79/EC on In Vitro Diagnostic Medical Devices; Council Directive 90/385/EEC on Active Implantable Medical Devices; Council Directive 93/42/EEC on Medical Devices), two new Regulations on medical devices, the Medical Device Regulation (MDR) and the In Vitro Diagnostic Medical Device Regulation (IVDR), were adopted in 2017 and once fully applied, they will replace the existing Directives. They aim to offer better protection public health and patient safety and include predictive genetic tests within their scope. The regulations will prevent consumers from being misled by genetic information by placing obligations upon companies offering genetic tests to ensure that their testing procedures are accurate and correct before they are marketable. This could therefore have a significant impact on the companies relied upon by sports teams and clubs to supply their athlete genetic information.

### **Domestic Level**

The UK Human Rights Act (HRA) recognises the rights of the ECHR as an integral part of domestic law. The HRA gives effect to the ECHR by imposing an obligation on public authorities to comply with Convention rights. The enactment of the UK Equality Act 2010 (EA) harmonised discrimination law by consolidating and repealing previous discrimination legislation. The Act protects individuals from discrimination on the basis of their disability, gender reassignment, race, sex, age, marriage and civil partnership, pregnancy and maternity, religion or belief and sexual orientation. During the consultation process of the EA, genetic predispositions were considered for inclusion. In 2007, the former Human Genetics Commission (HGC) urged the government to add genetic discrimination to the Equality Bill following concerns about the treatment of individuals in employment and in insurance, but this was rejected (Carlin 2007).

The Human Tissue Act 2004 in the UK aims to regulate activities involving the use and storage of human tissue and organs. Under s.45 of the Act it is an offence to analyse DNA of any bodily material, without qualifying consent of the living person (unless for an excepted purpose). Bodily material is material that has come from a human body and consists of or includes human cells. Genetic testing companies are therefore obliged to comply with the provisions of the Act.

The Data Protection Act 2018 is the implementation of the GDPR and aims to ensure that those responsible for handling personal data, follow strict data protection principles.

Much of the policy at the domestic level seeks to protect genetic discrimination in employment and insurance. Non-legislative soft law measures are in place such as the UK Concordat and Moratorium on genetics and insurance which has been extended until 2019 (HM Government and the Association of British Insurers 2014). This is a voluntary agreement which aims to ensure that an individual is not denied insurance as a result of predictive genetic test results. This approach to regulation is considered favourable because it seeks to balance the interests of both the individual and the insurer by offering context dependent flexibility in its application (Davey *in* Quinn et al. 2015: 158).

Some countries such as Australia are yet to introduce any explicit policy on genetic discrimination in insurance and employment and instead amended the Disability Discrimination Act 1992 to include 'genetic predisposition' in its definition of disability. In Ireland genetic testing is also covered within the Disability Act 2005. Extending existing disability discrimination legislation in this way may be deemed a better solution to regulation since practices of genetic discrimination is currently rare.

Comparatively, other countries have enacted specific legislation to directly address the increasing risks and fears of genetic discrimination in insurance and employment. Many European countries such as Germany have banned the use of genetic tests (Human Genetic Examination Act 2010; a comprehensive comparison of EU countries can be found in Van Hoyweghen *in* Quinn et al. 2015: 199). In Canada, the Genetic Non-Discrimination Act (GNDA) 2017 bans the requirement of a genetic test by companies and employers, and prohibits the restriction of services on the basis of genetic test results.

Significant attention has been given to the US Genetic Information Non-Discrimination Act (GINA) 2008 which was designed to prohibit genetic discrimination in health insurance and employment. Prior to GINA, the regulation of genetic discrimination varied across states. At a federal level the Americans with Disabilities Act 1990 (ADA) was in place to deal with any claim for discrimination on the basis of genetic information in employment, although no precedent existed (Prince and Waterstone *in* Quinn et al. 2015: 116). The Health Insurance Portability and Accountability Act 1996 (HIPAA) covered discrimination in insurance but its scope was limited. The HIPAA aims to also protect patient data, but its coverage is narrower than the EU GDPR. GINA was enacted to fill the gaps in this regulation by offering

a more uniform system and setting a minimum level of protection against genetic discrimination (Bland 2011: 360). GINA does not pre-empt state laws which may offer stricter protections.

GINA provides privacy protection by placing restrictions on gathering information, and anti-discrimination protection by limiting employers from discriminating on the basis of genetic information. Title I protects individuals from genetic discrimination in health insurance and Title II makes it unlawful for employers to use genetic information in employment related decisions such as retention and recruitment, or employment opportunities and privileges (s. 202a). GINA also makes it illegal for an employer to request or require genetic information from an employee, although there are limited exceptions to this which are related to consent or compliance with law (s. 202b).

Overall, there is a growing awareness of genetics regulation at the international, regional and domestic levels. The framework is a little complex, which may be a consequence of the lack of consensus definition in the area (Van Hoyweghen *in* Quinn et al. 2015: 207). The EU level of governance has been criticised as fragmented and currently inadequate to regulate genetic testing (de Paor *in* Quinn et al. 2015: 173). However, there is clearly scope for protection in the provisions currently offered, and a willingness to engage in the protection of rights. Various approaches are being adopted as a protective mechanism to prevent genetic discrimination and privacy breaches. There is a general protection offered under human rights principles for the discrimination of an individual on the basis of their human characteristics. Some provisions provide explicit reference to genetic features, others can be broadly interpreted.

There is also a body of medical provisions at all levels seeking to ensure that genetic testing companies use accurate information and do not mislead their customers. Guidance for good practice and good governance in the field is also being developed. Significant updates in data protection legislation introduce strict principles for the use of genetic data.

Centred on insurance, health care and employment, there is country specific legislation prohibiting or limiting genetic discrimination. It is argued however, that existing anti-discrimination and privacy models, as opposed to explicit genetic discrimination provisions, are sufficient to deal with current regulatory needs since there is little evidence of actual genetic discrimination and there is a chance that regulation may instead exaggerate the issue (Rice. 2006).

### Application to Sport

It is unclear how these measures, if any, capture the use of genetic testing in sport, and how they might protect an athlete if their genetic information was used to discriminate against them. Such a restriction would need to satisfy principles of proportionality, namely whether the limitation pursues a legitimate objective, whether the means of the objective is rationally connected, whether the limitation is necessary to achieve its purpose, and whether there is a fair balance between the benefits and the limitation (Husscroft et al. 2015).

There is a general reluctance to hold private sports organisations/governing bodies/employers legally accountable, particularly in the context of discrimination where legislation tends to apply to public bodies (Boyes. 2017; Patel. 2015a). In the UK, whilst the courts have considered that sports bodies may be quasi or hybrid public authorities, that is, private bodies that exercise public functions, the position remains limited and narrow particularly in the context of human rights (Boyes. 2000).

As mentioned earlier, this is not necessarily a new problem, and differential treatment on the basis of human characteristics is an unconsciously accepted practice since this goes to the heart of sport and its very purpose. Yet there is a balance struggle between inclusion and exclusion when this treatment becomes unreasonable (Patel. 2015a). Few cases have been dealt with by the courts, and where they have, the judgment and decision has done little to directly address the obligations of sports governing bodies under human rights provisions. In *Dr Renee Richards v United States Tennis Association* (93 Misc.2d 713, 400 NYS 2d 267), a male-to-female transgender athlete successfully won the right to compete in a female competition. The supreme court held that the USTA requirement to force her to undergo a genetic sex test in order to be eligible, was discriminatory and a breach of s.290(3) Executive Law of the New York Human Rights Law, which declares that the State has the responsibility to act to assure that every individual within this State is afforded an equal opportunity to enjoy a full and productive life. This was a favourable outcome for Richards but the judgment was limited and did not impact upon sport policymaking, since similar exclusionary regulations still continue to apply to female athletes to determine eligibility. Instead of pursuing a legal claim, affected athletes such as Dutee Chand and Caster Semenya, have referred their challenges to CAS who have approached the issue through a sport lens, tackling issues around unfair advantage and fairness in competition, rather than measure the regulations against equality and human rights principles.

Using the courts to challenge sport practices under human rights provisions is not common and usually unsuccessful. For instance, in *Fédération Nationale des Syndicats Sportifs (FNASS) and others v. France*, the ECtHR held that the mechanisms of the WADA whereabouts system do not violate the athletes' private life under Article 8 ECHR. The Court accepted that the protection of health was a legitimate aim for this interference and also that the doping rules seek to ensure the protection of the rights and freedoms of others. The Court held that the restrictions imposed were a necessary and justified part of the doping control process, which struck a fair balance between the competing interests. The retention of DNA information by the UK police was viewed differently in *S and Marper v United Kingdom* [2008] ECHR 1581. Baroness Hale of Richmond, dissenting in the House of Lords decision stated that 'there can be little, if anything, more private to the individual than the knowledge of his genetic make-up' (Para. 71).



An athlete was unsuccessful in his claim of disability discrimination in the US case of *Knapp v Northwestern University* 101 F.3d 473 (7<sup>th</sup> Cir. 1996). Northwestern University prohibited Knapp from competing with the basketball team following an examination of his medical records by the team physician. Knapp was held to be medically ineligible because of his increased risk of cardiac death, even though he was implanted with a cardioverter defibrillator to regulate his condition, his parents were willing to sign liability waivers and his own team of experts deemed the level of risk to be acceptable. Knapp argued that his condition falls within the definition of a disability under the US Rehabilitation Act 1973, and the university had violated their obligations under the Act by excluding him.

The legal decision turned upon whether Knapp was disabled under the terms of the Act. The court concluded that as a matter of law Knapp was not disabled within the meaning of the Act and no violation had occurred. They commented that 'legitimate physical qualifications may in fact be essential to participation in particular programs' (Case, 483). In reaching their decision the court highlighted that the university's decision may not be the right one, but it is not an illegal one under the Act.

The assessment of risk was a key sporting issue in the case. The parties disagreed upon the acceptable level of risk for Knapp to compete. On this point the court held that it is for the team doctors and universities to make its own medical determinations, provided that reasonable consideration of sufficient evidence specific to the individual and the potential injury has been conducted. Although the court affirmed that Knapp is an adult, capable of assessing whether competing is worth the risk to his life, and if that risk is acceptable, this was not a consideration in the final decision, possibly because it was not the legal matter before them. The judges did however highlight that eligibility of athletes who may risk future injury should not be founded upon paternalistic stereotypical concerns, and should instead be based upon objective evidence.

Since its enactment much has been written about GINA's potential applicability to sport, but its current impact is unclear, particularly since no sport case has arisen (Bland. 2011: 366; Wagner. 2012: 94). There is potential for genetic testing in sport to fall within GINA but this is debated in the literature, particularly because the global nature of sport practice could place testing outside the jurisdictional reach of US legislation (Bland 2011; McNamee et al. 2009: 339). Furthermore, in other anti-discrimination provisions such as the UK EA, exemptions provisions exist for sport. Section 195 EA permits sex discrimination in a gender-affected activity to secure fair competition and the safety of competitors (See Patel 2015). In this light, sports bodies may attempt to exempt themselves from GINA (Wagner 2012: 96).

Indeed, one of the consistent themes in some of the discrimination related cases, is that although discriminatory practices are recognised, the breach of human rights is justified as necessary and legitimate for sport, since the essence of sport is about discriminating in a sense. In this context, it may well be reasonable to exclude or treat an individual differently on the basis of their physical differences, in order to protect the essence of sport. It is questioned whether regulation of genetic testing in sport is at all necessary since genetic information is arguably the ultimate identification tool for potential ability (Sellenger 2003: 252). Perhaps sport administrators should be given the freedom to select their athletes by any means to best further the interests of the particular body.

Another justification might be that sport deserves special treatment by the law because of the economic implications of genetic testing. Sport employment may be considered unique in this context because athletic ability, peak health and exceptional performance are necessary employment requirements (Evans 2009: 210), and sports employers may exploit athlete genetic information to protect themselves and the employee from harm (Bland, 2011: 369; Stevens 2011: 820). From the employers' perspective therefore, it is suggested that this is simply economics – teams and clubs are seeking to ensure that they are making good investments (Hebbar 2011: 58).

However, this exclusion can become unreasonable and compromise an athlete's human rights when genetic information/testing is misused to treat athletes differently on the basis of their genetics. In order to satisfy human rights provisions detailed above, sport decision makers need to ensure that they are pursuing a legitimate aim, and the means adopted are appropriate for achieving that aim. Given the current limitations of genetic testing, and the inconclusive evidence of associations between genetic traits and athletic ability, it would be misleading and inaccurate to make decisions about employment and selection on the basis of genetic information (Epstein, 2013: 265; Rice, 2006: 35; Roth, 2012: 250; Varley et al. 2018).

That said, despite the stereotypical assumptions of differences between men and women, including their misconceived suitability to particular sports, the UK EA sport exemption is justified on the basis that some sports are gender affected 'in circumstances in which the physical strength, stamina or physique of average persons of one sex would put them at a disadvantage compared to average persons of the other sex as competitors in events involving the activity' (s. 195(3) EA). The law would also need to play a role in ensuring that misconceptions about genetics and sport are not used to treat sport differently in genetics regulation.

Even if a stage is reached where certainty is guaranteed and the research investigating genetic associations with sporting traits improves so that genetic testing is based upon reliable evidence, this leads to wider theoretical questions about the heart of sport and to what extent the essence of unpredictability is to be eliminated from the activity, if athletes begin to be selected on the basis of their specific genetic traits. Placing importance on genes in sport, ignores the many other factors that contribute towards success and performance. From a discrimination perspective, conflicting issues would still remain.

## Conclusion

This article has reviewed the growing body of international, regional and domestic regulation in place for genetic testing. Both hard and soft law measures exist to address our fears about potential genetic discrimination. The protection of human rights is at the heart of this framework. In the search of the qualities of a great athlete, it is likely that genetic testing in sport will advance considerably in the future and this will certainly challenge the boundaries of human rights. This article has provided examples of how genetic information is already broadly used to influence current sport practice and how those challenges already present themselves.

In principle, if genetic testing were to be introduced to determine employment or selection, from a legal perspective this would constitute an interference with human rights. Even if the sporting aims of protecting the health of the athlete or ensuring fair competition constituted legitimate aims, the lack of scientific accuracy around genetic testing in sport, would render the human rights restriction disproportionate. If firmer evidence for differential treatment on the basis of genetics is available in the future, the rights of the athlete will still need to be balanced since it would be an intrusive act.

However, in practice, this article has emphasised the complex relationship between sport and the law, and the uncertainty around how sport might be captured by the regulatory framework currently in place for genetic testing. The obligation of sport to comply with the rule of law is part of a broader ongoing debate. The tendency of the law to treat discrimination in sport differently to other areas of society is leaving athletes in a vulnerable position.

Nevertheless, this investigation has raised critical issues around the use of genetic testing in sport. Understanding our genetic traits and their relationship with athletic performance is a powerful tool and any such research is encouraged. Yet going beyond this and using such information to select athletes on the basis of genetics is problematic and discouraged. Position statements reflecting this stance are useful, but they represent a mild approach to this issue. The potential of the law to assist in the framing of good governance in this area is demonstrated by the existing measures. Although they may be piecemeal, there are some useful legal principles that should be adopted by sport, particularly the need to ensure that the interests of sport are appropriately balanced against the rights of the athlete.

## Competing Interests

The authors have no competing interests to declare.

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