This is the post-peer review final accepted manuscript of an article published in the Alternative Law Journal in 2020. The citation for the article is Marie Hadley and Donna McNamara, 'Genetic Testing in Sport: Considerations for Young Athletes' (2020) Alternative Law Journal. Copyright ©2020 (Marie Hadley and Donna McNamara). DOI: 10.1177/1037969X20956260.

Genetic Testing in Sport: Considerations for Young Athletes

Abstract

This article uses the experiences of professional footballer Abdelhak "Appie" Nouri, who suffered a cardiac arrhythmia at the age of 20 years old during a pre-season friendly in 2017, as the stepping off point for examining the use and regulation of genetic testing in sport and the human rights implications of genetic testing child athletes for the purposes of talent identification and performance enhancement. The authors identify recent trends in the use of genetic testing in sport, outline the legal and policy framework that regulates genetic testing in Australia, and consider human rights issues that arise in relation to a child's decision to undertake or withhold consent for testing.

Keywords: Genetic testing, non-discrimination, children's rights, talent identification, sports law, human rights, privacy law

Introduction

In what is one of the most high-profile career-ending events in professional football around the world, on 8 July 2017 Eredivisie club Ajax midfielder Abdelhak "Appie" Nouri suffered a cardiac arrhythmia in the 72nd minute of a preseason friendly in Austria against Werder Bremen. His 'heart defect' was known to the club.[1] Despite being revived on the pitch, 'inadequate' on-field care resulted in serious and permanent brain injury.[2] For 2 years and 9 months following the injury, Nouri was in a state of low consciousness. He recovered a degree of consciousness in 2020, yet he remains highly dependent for his daily care. Nouri will not play professional football again.

Legal commentary to date on Nouri's career-ending injury has focused on whether the Ajax club doctor adhered to medical guidelines in their on-pitch medical treatment: there was a

[1] 'NRC: KNVB and Ajax knew of a heart defect Nouri' *NOS* (online 5 January 2018) <https://nos.nl/artikel/2210692-nrc-knvb-en-ajax-wisten-van-een-hartafwijking-nouri.html>.
[2] 'Ajax Statement of Abdelhak Nouri Treatment', *Ajax* (Media Release, 26 June 2018) <https://www.ajax.nl/streams/actueel/verklaring-ajax-over-behandeling-abdelhak-nouri.htm>.

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five-minute delay between Nouri losing consciousness and the administration of CPR/defibrillators. However, while Ajax initially contested the negligence action initiated against the club in the Royal Dutch Football Association's Arbitration Panel – although paying Nouri's contracted salary in full and agreeing to pay his medical care for life – they later admitted liability.[3] With Nouri's contract formally cancelled from the 1 July 2020, speculation abounds that a final financial settlement, estimated to amount to 4.5 million pounds, will be reached in the coming months.[4] Yet, regardless of the impending resolution of this matter, as a high profile professional athlete with a cardiac abnormality, Nouri's experiences provide a useful stepping off point to reflect upon the use and regulation of genetic testing in sport.

Genetic testing examines one's DNA to gain an understanding of individual traits and characteristics including athleticism, susceptibility to diseases such as heart disease and different types of cancers, and predisposition to disabilities and mental illness. This article will focus on the uses of genetic testing in sport to elicit information about predisposition to illness and disease, injury prevention, performance enhancement, and talent identification. It will discuss the perceived benefits of genetic testing in these areas before identifying the legal and policy framework that testing occurs within, and the distinct ethical considerations for child athletes who, like Nouri, rise up through the ranks of youth sport. The article concludes that the human rights implications of children consenting to (or refusing to consent to) genetic testing should be addressed in the regulatory framework.

Uses of Genetic Testing in Sport

In 2014, the year that Nouri was named as one of the best 40 youth players in the world, a routine ultrasound of the heart detected a cardiac abnormality. Nouri was 17 years old at the time, a youth exponent from the Ajax youth development academy. According to news reports, the Dutch Football Association informed Ajax and Nouri of this result but determined that the condition was 'harmless'.[5]

[3] Ibid.
[4] See, eg, Jake Bacon, 'Abdelhak Nouri's Ajax Contract to End After Former Player Wakes From Coma but Club in Talks with Family Over Settlement', *TalkSport* (online, 31 March 2020) <https://talksport.com/football/689481/ajax-abdelhak-nouri-coma-contract-settlement/>.
[5] Stuart James and Priya Ramesh, 'Abdelhak Nouri's family say they were not told of existing heart condition', *The Guardian* (online, 7 January 2018) <https://www.theguardian.com/football/2018/jan/06/abdelhak-nouri-family-existing-heart-condition-ajax>.

It is unclear whether a heart defect caused Nouri's collapse on the pitch during the Werder Bremen game. However, most sudden cardiac arrests that occur in younger athletes aged less than 35 years during physical exertion are attributed to inherited or congenital disorders of the heart that predispose the athlete to cardiac arrhythmias.[6] While the usefulness of genetic testing for Nouri's health back in 2014 is speculation, genetic testing can in some instances supplement medical examinations like echocardiograms to generate key insights into an individual's susceptibility to injury and disease. It can confirm certain conditions that affect the heart, such as Marfan's Syndrome that has been linked to an aortic aneurysm in tall athletes like basketball players and volleyball players.

Genetic testing of athletes is perceived to be particularly beneficial in high-impact sports that involve repetitive blows to the head such as boxing and rugby. Genetic variations like apolipoprotein-E-4 ('*APOE4*') make individuals more susceptible to brain damage from head injuries, and polymorphism in the *APOE4* gene may predict Alzheimer's disease, and there is evidence of testing for this gene in the Australian boxing community.[7] Genetic testing can also be useful for general injury prevention and recovery, high priority areas for athletes, performance staff, and medical personnel. Research into genetic variation and its impact on tendon and ligament injuries has proven particularly fruitful, with a genetic contribution identified in certain musculoskeletal soft tissue injuries involving, for example, the Achilles tendon in the heel, the rotator cuff tendons in the shoulder, and the cruciate ligaments in the knee.[8] The Athlome Project Consortium was established in 2015 to, amongst other things, aid the identification of reliable genetic tests for exercise prescription and injury prevention.[9] While genetic testing for injury prevention remains uncommon, a Premier League football club was reported to be analysing player's genetic profiles for markers for injury in 2011, and in 2016 Barcelona Football Club announced they would be analysing the genetic markers of its players to identify those who may be predisposed to injury or need a longer recovery

[6] See, eg, Sandeep Basavarajaiaj, Ajay Shah and Sanjay Sharma, 'Sudden Cardiac Death in Young Athletes' (2007) 93(3) *Heart* 287, 287–9.
[7] Michael John McNamee et al, 'Genetic Testing and Sports Medicine Ethics' (2009) 39(5) *Sports Medicine* 339, 399–44.
[8] See, eg, Macolm Collins and Stuart Raleigh, 'Genetic Risk Factors for Musculoskeletal Soft Tissue Injuries' (2009) 54 *Medicine and Sport Science* 136, 136–49; A Gibbon et al, 'The MMP3 Gene in Musculoskeletal Soft Tissue Injury Risk Profiling: A Study in Two Independent Sample Groups' (2017) 35(7) *Journal of Sports Science* 655, 655–62.
[9] 'The Athlome Project Consortium', *Athlome Consortium* (Web Page, 2016) <http://www.athlomeconsortium.org/about/>.

period.[10] The ability to predict injuries could prove significant as research into risk marker genes continues.

More controversially, genetic testing is also perceived to hold value for performance enhancement and talent identification. At the more innocuous end of the scale, testing can offer insights into the nutritional requirements of high performing athletes. In 2016, Ajax announced that they were using genetic testing to tailor individual nutrition programs for their athletes.[11] At the more extreme end of the scale, gene manipulation known as 'gene doping' may offer athletes a competitive edge by improving their athletic abilities and performance. This involves using artificial means to enhance an individual's genetic makeup by adding certain genes associated with athletic performance (or subtracting genes that are not so characterised) to the individual's genetic makeup. While gene therapy has proven effective in treating some specific diseases, gene doping is expressly prohibited by the World Anti-Doping Association, as discussed in the next section.

Gene doping is an extreme application of genotyping – the process of determining differences in the genetic make-up of an individual by examining their DNA sequence. For over 50 years, sports scientists have used genotyping to try and predict future sports stars by identifying exercise-related genes. Genes are estimated to control up to 50% of one's athletic ability, such as the alpha-actinin-3 ('*ACTN3*') gene that is prevalent in elite sprinters.[12] A recent study of sub-elite Australian Rules Football Players confirmed that a number of physiological mechanisms of skill and talent for sport-specific skills are explained by the expression of a specific number of genes.[13] However, despite growing knowledge of genes

[10] See Nick Collins, 'Premier League Team Reads Players' DNA', *The Telegraph* (online, 16 October 2011) <https://www.telegraph.co.uk/news/science/science-news/8829894/Premier-League-team-reads-players-DNA.html>; Nicholas Staropoli, 'Can DNA identify injury-prone athletes? Soccer giant Barcelona believes so. Should you?', *Genetic Literacy Project* (Web Page, 29 March 2016) <https://geneticliteracyproject.org/2016/03/29/can-dna-identify-injury-prone-athletes-soccer-giant-barcelona-believes/>.

[11] Will Chu, 'AFC Ajax looks to fine-tune personalised nutrition as club prepare for new season', *NutraIngredients.com* (Web Page, 11 July 2016) <nutraingredients.com/Article/2016/07/12/AFC-Ajax-look-to-fine-tune-personalised-nutrition-as-club-prepare-for-new-season>.

[12] See, eg, Nan Yang et al, 'ACTN3 Genotype Is Associated with Human Elite Athletic Performance' (2003) 73(3) *American Journal of Human Genetics* 627, 627–31.

[13] Ysabel Jacob, Paola Chivers and Ryan Anderton, 'Genetic predictors of match performance in sub-elite Australian football players: a pilot study' (2019) 17(2) *Journal of Exercise Science and Fitness* 41, 41–6.

linked to sporting performance, scientists warn that genetics offer only an estimation of future performance and are not an exact prediction.[14]

Nevertheless, the use of DNA and gene mapping as a predictive tool and recruitment strategy for athletes continues to develop. Uzbekistan indicated that they would use genetic testing as a means to identify future Olympians from 2015, with children as young as 10 taking part.[15] Similarly, China has confirmed that they would be using genome sequencing as a means to recruit athletes for the 2022 Winter Olympics.[16] These strategies are not currently used in Australia, with the Chief Medical Officer at the Australian Institute of Sport ('AIS'), David Hughes, confirming that AIS does not support the genetic profiling of its athletes, particularly child athletes.[17] However, other Australian officials have previously been supportive of the possibility of routine genetic testing as part of talent identification strategies in future.[18] Research on genetic testing in sports continues to develop at a rapid pace, and it is likely to continue in Australia with DNA biobanks being established containing biological specimens and genetic data from thousands of elite athletes around the world.[19]

Genetic testing in sport – whether for identification of disease, injury prevention and recovery, performance enhancement, or talent identification – might be uncommon at present but it does occur in pockets, and it appears to have the potential to secure benefits to athletes and sporting organisations. It is anticipated that such benefits will increase with scientific advancements in future. It is thus timely to consider the regulatory framework that such testing in sport occurs within.

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[14] See, eg, Ron Trent quoted in Australian Law Reform Commission, *Essentially Yours: The Protection of Human Genetic Information in Australia* (Report No 96, May 2003) [38.16] <https://www.alrc.gov.au/publication/essentially-yours-the-protection-of-human-genetic-information-in-australia-alrc-report-96/38-sport/talent-identification-and-performance-genes/>.

[15] Ron Synovitz and Zamira Eshanova, 'Uzbekistan Is Using Genetic Testing to Find Future Olympians', *The Atlantic* (online, 6 February 2014) <https://www.theatlantic.com/international/archive/2014/02/uzbekistan-is-using-genetic-testing-to-find-future-olympians/283001/>.

[16] Catherine Taylor, 'How genetics could soon become the new frontier for advantage in sport', *ABC News* (online, 25 August 2019) <https://www.abc.net.au/news/2019-08-25/is-there-a-gene-for-speed/11437930>. The testing is rumoured to be completed in 2020.

[17] See Nicole Vlahovich et al, 'Ethics of Genetic Testing and Research in Sport: A Position Statement from the Australian Institute of Sport' (2016) 51(1) *British Journal of Sports Medicine* 5, 9; 'AIS warns against genetic testing for talent ID in children', *SportAus* (Media Release, 2 December 2016) <https://www.sportaus.gov.au/media_centre/news/ais_warns_against_genetic_testing_for_talent_id_in_children>.

[18] See the comments of AIS Assistant Director Peter Fricker quoted in Australian Law Reform Commission (n 15) [38.10].

[19] See, eg, the biobank established by the AIS, Victoria University and the University of Sydney discussed in Nir Eynon and Lauren Banting, 'Athletic ability and genetics: can science spot a sure-fire winner?', *The Conversation* (online, 20 July 2012) <https://theconversation.com/athletic-ability-and-genetics-can-science-spot-a-sure-fire-winner-7991>.

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Regulatory Framework

Formal regulation of genetic testing in sport is minimal. To date, international regulations have primarily focused on gene doping. As discussed, the use of gene doping was officially prohibited World Anti-Doping Code in 2004, which defined such methods as involving 'the non-therapeutic use of genes, genetic elements and/or cells that have the capacity to enhance athletic performance.'[20] No violations of this prohibition have been proven. However, anecdotal evidence of gene doping exists: in 2006 German athletics coach Thomas Springstein was revealed to have attempted to purchase Repoxygen – a substance used in gene therapy to treat patients with anaemia that induces expression of the erythropoietin gene – during an investigation into his supply of banned substances to athletes in 2003, and in 2008, a Chinese genetics laboratory reportedly offered gene-based manipulations before the Beijing Olympic Games.[21] Nevertheless, the lack of Doping Code violations are perhaps unsurprising given that an effective test for gene doping was only reported to WADA in late 2018.[22] Prior to this test, speculation abounded that WADA would require all Olympic athletes to submit copies of their full genetic code so that they would be able to determine if gene doping or gene editing has taken place.[23] This intrusive requirement never eventuated, and it is unclear whether it will be adopted in future.

In Australia, genetic testing in sport is subject to a blanket prohibition against based on disability[24] and policy guidance from interested bodies such as the AIS and the Human Genetics Society of Australasia ('HGSA'). The AIS discourage genetic testing for athletic performance or improvement including gene doping, sport selection and talent identification. Where there is adequate informed consent, genetic testing for the purposes of injury

[20] World Anti-Doping Agency, *The World Anti-Doping Code: The 2004 Prohibited List* (26 March 2004) 6 <https://www.wada-ama.org/sites/default/files/resources/files/WADA_Prohibited_List_2004_EN.pdf>.
[21] See, eg, 'Shamed German Athletics Coach Convicted of Doping Minors', *Deutsche Welle* (online, 20 March 2006) <https://www.dw.com/en/shamed-german-athletics-coach-convicted-of-doping-minors/a-1939297>; Theodore Friedmann, Olivier Rabin and Mark Frankel, 'Gene Doping and Sport' (2010) 327 *Science* 647, 647.
[22] Andy Brown, 'Professor Develops Reliable Gene Doping Test', *The Sports Integrity Initiative* (online, 8 December 2018) <https://www.sportsintegrityinitiative.com/professor-develops-reliable-gene-doping-test/>. Note that the first reliable test reported in Australia was created by the National Measurement Institute in 2016.
[23] Eric Niiler, 'Olympics Could Require Athletes' Genetic Code to Test for Doping', *Wired* (online, 2 May 2018) <https://www.wired.com/story/olympics-could-require-athletes-genetic-code-to-test-for-doping/>.
[24] *Disability Discrimination Act 1992* (Cth) s 28(1).

prevention is acceptable.[25] Conversely, the HGSA's Position Statement indicates concern for direct-to-consumer genetic tests and their scientific accuracy, and cautions against using test results to limit the opportunities of individuals who possess the "wrong" genotypes. The HGSA does not object to using genetic testing for talent identification and training purposes, but state that a 'simplistic and overly-deterministic approach to genetic testing' should be avoided, 'particularly when applied to children.'[26]

Outside of Australia, some jurisdictions have laws that directly address permissible uses of genetic testing in sport. Article 12 of the Council of Europe Bioethics Convention[27] explicitly states that:

> Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling.

This is limited to testing for diseases, which suggests that the use of testing for predictive purposes or talent recruitment would not be permissible unless it also served a specific health purpose. In such instances, the individual would need to receive their test results in conjunction with appropriate genetic counselling to avoid a breach of Article 12. Counselling might cover issues such as the nature of the relevant genetic disorder or condition, the relationship between the genetic markers and the likelihood that the identified condition will develop, or the risks of the misuse of genetic information.

Other jurisdictions, such as Canada, prohibit employers (including sporting organisations) from requiring genetic testing or the results of such tests, and from refusing to provide services on the basis of genetic tests.[28] In addition, the United States prohibits the use of genetic information to discriminate against an individual in employment, including when making hiring or termination decisions.[29] While no sport case has arisen under the US law, it

[25] Vlahovich et al (n 18) 5–11.
[26] Human Genetics Society of Australasia, *Position Statement: Genetic Testing and Sports Performance* (Document no 2012PS03, September 2012) <https://www.hgsa.org.au/documents/item/19>.
[27] Council of Europe. *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*, opened for signature 4 April 1997, ETS 164 (entered into force 1 December 1999).
[28] See *Genetic Non-Discrimination Act*, SC 2017, c 3, ss 3–5; *Canadian Human Rights Act*, RDC 1985, c H-6, s 3(3).
[29] *Genetic Information Nondiscrimination Act of 2008*, HR 493, ss 201–3.

likely encompasses a prohibition against mandatory genetic testing for predictive purposes in an employment context.[30] As such, circumstances like that which occurred in case of NBA player Eddy Curry, who was required by the Chicago Bulls to take a DNA test after he had experienced some heart discomfort during the 2005 season (and before the introduction of the relevant US law) before they would enter into contract renegotiations, would not be permitted.[31]

While such laws go some way towards redressing genetic discrimination, the legal concerns that arise with genetic testing in sport go beyond the general permissibility or desirability of testing in different contexts and also encompass human rights issues, as will now be explored in the context of child athletes.

Human Rights Concerns and Child Athletes

While Australia does not have a national human rights framework, it has signed and ratified a number of international Conventions that seek to protect human rights, including the UN Convention on the Rights of the Child[32] ('CRC'). The CRC is particularly instructive in identifying the human rights implications of genetic testing on child athletes as it traverses participatory decision-making as a human right and the right of children to consent to, or refuse to consent to, medical treatment. While mandated genetic testing in youth sport is rare (or at least, rarely reported), the Uzbekistan experience of testing children as young as 10 for future Olympics suggests that a child might, at some stage in their blossoming career, be encouraged to undergo testing. To the extent that such a request was for the purpose of gauging or confirming their future sporting ability, it could amount to a violation of the child's rights under the CRC, regardless of whether a parent or guardian approved of such testing.

[30] Seema Patel and Ian Varley, 'Exploring the Regulation of Genetic Testing in Sport' (2019) 17(5) *Entertainment and Sports Law Journal* 1, 9.
[31] As discussed in Jesse Bland, 'There Will Be Blood … Testing: The Intersection of Professional Sports and the Genetic Information Nondiscrimination Act of 2008' (2010) 13(2) *Vanderbilt Journal of Entertainment and Technology Law* 357, 358–60. Curry refused to undertake the test and moved to the New York Knicks.
[32] *Convention on the Rights of the Child*, opened for signature 2 September 1990, 1577 UNTS 3 (entered into force 2 September 1990).

The CRC affords children under the age of 18 years a voice in the decisions that affect them, including those that might curtail their future opportunities.[33] Article 5 recognises the 'evolving capacities' of children, and Article 12 that outlines the child's right to participate in decision-making, states that their views should be given due weight in accordance with their age and maturity. Nouri was 17 years old when his cardiac abnormality was first detected. If he had been requested to undertake further tests by Ajax, he would have been entitled to make a decision to comply or refuse, and given his age it is likely that this decision would be legally enforceable, regardless of the views of his parents, agent, the club or others. However, younger children, such as those that are considered for youth academy programmes typically from the age of nine, might be given the opportunity to express their views but their views are unlikely to carry the same weight as older children.

Given the potential for non-selection on the basis of "unfavourable" genetic test results, all children should be given the opportunity to express their views freely once they are 'capable of forming their own views'.[34] Moreover, their views should carry due weight in line with the child's age and level of maturity. It has long been recognised in international law that minors have the capacity to consent to medical treatment provided their decision is valid, informed and voluntarily made. As the Committee on the Rights of the Child have stated, in healthcare, '[c]hildren, including young children, should be included in decision-making processes, in a manner consistent with their evolving capacities.'[35] Informed consent is emphasised as decision-making is often a three-way process between the child, their parents and the healthcare professional, and each party may have competing objectives.[36] A child could have 'little space' to freely articulate their views during the consultation, inhibiting them from understanding what is being said or recommended.[37] The decision-making processes for a child asked to undertake genetic testing is likely to be even more complex and crowded, with the views of individuals such as their agents, managers, sports selectors, coaches, or lawyers,

[33] Committee on the Rights of the Child, *The Right of the Child to be Heard*, General Comment No 12, UN Doc CRC/C/GC/12 (2009) para 81.

[34] See, eg, Donna M McNamara, 'The Right of the Child to Be Heard: The Case for Child Participation in Foster Care Proceedings' (2016) 19 *Trinity College Law Review* 151, 151–74.
[35] Committee on the Rights of the Child, *The Right of the Child to be Heard*, General Comment No 12, UN Doc CRC/C/GC/12 (2009) para 100.
[36] Ursula Kilkelly and Mary Donnelly, 'Participation in Healthcare: The Views and Experiences of Children and Young People' (2011) 19(1) *International Journal of Children's Rights* 107, 109.
[37] Ibid.

to be taken into consideration. The regulatory framework on genetic testing should support a child's right to express their views freely, and those views should carry due weight.

The right to consent to medical testing also includes the corollary right to withhold consent.[38] Exercising the right to refuse a genetic test is likely to be fraught, particularly in circumstances where a lucrative sporting contract lies in the balance. The ready availability of direct-to-consumer genetic tests which claim to be able to identify athletic ability means that a parent, guardian, coach, or selector could order a kit online and encourage the child to take a test at home (or coerce them to do so), without the child receiving genetic counselling as part of this process. The regulatory framework should explicitly address this possibility and provide guidance on when it may be appropriate to require direct-to-consumer genetic testing as part of, for example, contract negotiation. The position adopted in the Australian Medical Association's Position Statement of Genetic Testing that 'children should not normally undergo predictive genetic testing until they have reached the age of consent and so are able to request the test on their own behalf',[39] should also be endorsed.

Finally, even when a child's free and informed consent to genetic testing is secured, privacy concerns around the management of their genetic information remain. There might be uncertainty around how the genetic information can be used, how long it is stored for and who will have access to it (such as insurance bodies and possibly even law enforcement agencies). Concerns are heightened by the fact that it is common for athletes to sign a waiver of medical confidentiality when entering a professional sports program and privacy breaches can ruin an athlete's market value. In addition, while the AIS and many private sector sports organisations fall within the jurisdiction of the *Privacy Act 1988* (Cth) they are not health service providers and thus, the results of genetic tests of contracted athletes would likely be considered part of 'employee records' and not health information protected by the Act.[40] This means that sensitive information, including a player's entire medical history and potentially their family members' information, could be legally made available to third parties, such as

[38] See, eg. *Brightwater Care Group (Inc) v. Rossiter* [2009] WASC 239 and *Dept of Community Services (NT) v. JWB (Marion's case)* (1992) 175 CLR 218.
[39] Australian Medical Association, 'Genetic Testing-2012', *Australian Medical Association* (Web Page, 1 April 2012) <https://ama.com.au/position-statement/genetic-testing-2012>.
[40] *Privacy Act 1988* (Cth) s 7B(3).

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their employers or agents (or future employers).[41] This raises clear concerns for the child's right to privacy, as enshrined in Article 16(1) of the CRC, which states that:

> No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour and reputation.

The privacy implications of genetic testing should be explained to all children in clear and accessible language as appropriate to their age, so that it factors in their decision-making. When an athlete, including a child athlete, consents to genetic testing, confidentiality clauses should be used to protect their privacy and manage the risk of unauthorised dissemination of test results. Further elaboration on specific privacy protections and guarantees are also required to ensure compliance with the CRC.

Conclusion

Genetic testing in sport can arguably improve health and performance outcomes but it occurs with little regulatory oversight. In circumstances where testing is becomingly increasingly advanced and direct-to-consumer tests more widespread, the time is ripe for more detailed legal and policy guidance in this area.

We do not know the extent to which Abdelhak Nouri's pre-existing cardiac condition contributed to his collapse on the pitch on the 8 July 2017. It is also unclear whether genetic testing would have prevented his injury. However, respect for the health of promising athletes like Nouri who progress through the ranks of youth sport and may carry genetic abnormalities, requires attentiveness to the potential benefits of testing but also human rights concerns in the legal and policy framework.

[41] On the ethics of this see generally, Aisling de Paor, *Genetics, Disability and the Law: Towards an EU Legal Framework* (Cambridge University Press, 2017) 48–9.