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## Sickle Cell Screening of College Athletes: Legal Obligations Fulfilled, Moral Obligations Lacking

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### INTRODUCTION

In 2010, the National Collegiate Athletic Association (NCAA) implemented a policy requiring all NCAA Division I athletes to be screened for the genetic condition sickle cell trait, an inherited condition that has been linked in athletes to exertional heat illness and exertional collapse, which are potentially fatal medical emergencies.

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The screening policy was established as part of a legal settlement with the family of Dale Lloyd II, a nineteen-year-old football player at Rice University whose death after a football practice was attributed to sickle cell trait.<sup>1</sup> Screening expanded to encompass Division II athletes in 2012, and will include all Division III athletes beginning in the 2014-15 academic year, placing it among the largest mandatory genetic screening programs in the United States.<sup>2</sup> But the policy has spawned a heated debate, pitting the NCAA against professional and advocacy groups that criticize the sickle cell trait testing policy as illegitimate—due to the paucity of scientific evidence that such testing can save lives, or as unfair to players—due to the potential for the testing to result in racist consequences.

A person is considered to have sickle cell trait if they have one copy of the mutated gene that codes for sickle hemoglobin; two copies of the mutated gene would indicate sickle cell disease, a life-long, chronic medical condition. The condition of “carrier” or “trait” might not ever affect a person, besides the fact that that person could pass on the sickle cell gene to a child. An individual with sickle cell trait may, however, experience pain or life-threatening symptoms in certain unique situations such as skydiving, being at a high elevation, or participating in intense athletic exertion. Under current NCAA policy, a student-athlete must have a blood test to screen for the trait or provide results from a previous screening test before joining a team. Alternatively, the student-athlete may decline the test and sign a legal waiver, releasing the NCAA institution from liability in connection with the condition.

At best, testing for sickle cell trait can inform student-athletes about potential health issues. This could potentially save lives,<sup>3</sup> which is why Dale Lloyd’s family included it in their settlement.<sup>4</sup> But there is no empirical evidence that such screening tests will be lifesaving. The leading group of physicians specializing in sickle cell trait, the American Society of Hematology, characterizes the testing as “medically and ethically inappropriate” and is firmly opposed to

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<sup>1</sup> Beth A. Tarini et al., *A Policy Impact Analysis of the Mandatory NCAA Sickle Cell Trait Screening Program*, 47 HEALTH SERVS. RES. 446, 446–47 (2012).

<sup>2</sup> See Janis L. Abkowitz, *President’s Column—Sickle Cell Trait and Sports: Is the NCAA a Hematologist?*, AM. SOC’Y HEMATOLOGY (May 1, 2013), <http://www.hematology.org/Publications/Hematologist/2013/10463.aspx>.

<sup>3</sup> Tarini et al., *supra* note 1, at 446–61.

<sup>4</sup> Brett Zarda, *Lawsuit Prompts NCAA to Screen Athletes for Sickle Cell*, USA TODAY (July 2, 2010, 2:34 PM), [http://usatoday30.usatoday.com/sports/college/2010-06-30-sickle-cell-ncaa-cover\\_N.htm](http://usatoday30.usatoday.com/sports/college/2010-06-30-sickle-cell-ncaa-cover_N.htm).

sickle cell screening of college athletes.<sup>5</sup> Its position is supported by five other organizations including the Sickle Cell Disease Association of America and the American Public Health Association.<sup>6</sup> In addition, a federal-level committee advising the Secretary of Health and Human Services also opposes the testing policy.<sup>7</sup> Yet neither the policy nor the controversy it has generated is widely known to student-athletes, their families, or their college communities.

Instead, the screening requirement is one of “thousands of rules” in the four-hundred-page NCAA manual<sup>8</sup>: student-athletes are obliged to have the blood test for sickle cell—or to forego the possibility of legal action against the NCAA in the event of a medical catastrophe, just as they are prohibited from accepting remuneration connected to their status as athletes. Given the important debate surrounding genetic screening for sickle cell trait, the NCAA-mandated screening should not be buried in the mountain of rules; it should be on the table in discussions about the rights and status of student-athletes, and in debates over the fairness and legitimacy of NCAA policies.

This Article takes as its starting point that a focused inquiry into the NCAA’s screening policy is necessary. We explore the moral obligations of those administering such testing to provide information about the meaning and results of the test, including its perceived benefits and potential risks. Such obligations are part of the long-standing and well-described process of informed consent in medicine, and are fundamental to more recent discussions of shared decision making between doctors and patients. But it is not clear whether the obligations are upheld by the NCAA-mandated testing for sickle cell

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<sup>5</sup> See *ASH Policy Opposes Mandatory Sickle Cell Trait Screening for Athletic Participation, Recommends Universal Training Interventions & Additional Research*, AM. SOC’Y HEMATOLOGY (Jan. 26, 2012), <http://www.hematology.org/news/2012/7703.aspx>; see also Abkowitz, *supra* note 2.

<sup>6</sup> *Statement on Screening for Sickle Cell Trait and Athletic Participation*, AM. SOC’Y HEMATOLOGY (Jan. 26, 2012), <http://www.hematology.org/advocacy/policy-statements/7704.aspx>.

<sup>7</sup> See Letter from R. Rodney Howell, Chairperson, The Sec’y Advisory Comm. on Heritable Disorders in Newborns and Children, to The Honorable Kathleen Sebelius, Sec’y of Health and Human Servs. (June 14, 2010), *available at* <http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/recommendations/correspondence/sicklecell061410.pdf>.

<sup>8</sup> Marc Edelman, *The Future of Amateurism After Antitrust Scrutiny: Why a Win for the Plaintiffs in the NCAA Student-Athlete Name & Likeness Licensing Litigation Will Not Lead to the Demise of College Sports*, 92 OR. L. REV. 1019, 1022, 1053–54 (2014); see NCAA, 2013–14 NCAA DIVISION I MANUAL §§ 13.11.2.1(g), 13.11.3.7.3, 13.11.3.8.1, 13.11.3.9.1, 17.1.5.1 (2013).

trait as currently practiced. In addition, genetic testing is a special form of medical testing, with many arguing that those who conduct genetic testing are ethically required to provide genetic counseling.<sup>9</sup> Nevertheless, the NCAA has not made counseling obligatory. We focus on three aspects of the informed consent issue: (1) ensuring a process of informed consent or shared decision making and a process for genetic counseling, (2) preventing racist consequences of sickle cell screening, and (3) conducting research on the use of the sickle cell screening test to protect athletes.

This Article will show that, as currently practiced, the NCAA sickle cell trait testing policy does not consistently inform student-athletes about sickle cell trait or the health issues linked to it. Moving beyond arguments that the policy may be illegitimate and unfair, we will show that the policy as practiced places a substantial unmet burden on those involved with the testing who have the responsibility of informing and counseling student-athletes about the sickle cell screening test. More extensive training and education is needed for those working with student-athletes to carry out that responsibility, and student-athletes should have access to additional staff, including genetic counselors, to discuss the test. Open discussion should be offered to help student-athletes understand the genetic test, the possible implications of being a carrier for sickle cell trait, the reasons for the testing policy, the options to decline the test or have it done elsewhere, and the potential racist consequences that may be associated with this genetic test. This discussion would enable student-athletes to be active and fully-informed participants in the testing.

## I

### ENSURING THE PROCESS OF INFORMED CONSENT

One of the most unsettling aspects of the NCAA policy on sickle cell trait screening involves the lack of direction to member institutions for ensuring informed consent. The fact that the testing is mandatory in some situations does not negate an ethical obligation to involve the student-athlete in the screening process. Genetic tests, in particular, have unique consequences not commonly encountered in

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<sup>9</sup> Catherine Taylor et al., *Sickle Cell Trait—Neglected Opportunities in the Era of Genomic Medicine*, J. AM. MED. ASS'N (2014), available at <https://jama.jamanetwork.com/article.aspx?articleid=1841474>; *Quality & Safety in Genetic Testing: An Emerging Concern*, WORLD HEALTH ORG., [http://who.int/genomics/policy/quality\\_safety/en/](http://who.int/genomics/policy/quality_safety/en/) (last visited Apr. 3, 2014); Abkowitz, *supra* note 2.

traditional medical care.<sup>10</sup> Student-athletes, minimally, should be offered a discussion of alternatives to screening, potential consequences, and potential benefits in order to make an informed decision.<sup>11</sup> In addition to the issues involved with genetic testing, the student-athlete has a distinctive relationship with the team physician.

Physicians in other settings may involve genetic counselors to ensure patients are able to ask all questions about a genetic test. In addition, individuals who discover they have sickle cell trait may develop anxiety, and this can be alleviated through counseling and providing appropriate health related information.<sup>12</sup> Yet, NCAA member institutions apparently do not offer genetic counseling, so special attention must be given to ensure that the student-athlete is comfortable asking questions and participating in decision making with the team physician, an individual who has a certain amount of control over the student-athlete's opportunity to compete. All parties involved with the genetic testing of student-athletes should be made aware of the unique nature of these tests and the environment within which they are carried out so that they may ensure the student-athlete is able to participate in decision making with regards to his or her own care.

#### *A. A Process, Not a Form*

Decades ago, medicine followed an authoritarian model; informing was not emphasized<sup>13</sup> and consent was conceived of as a signature on a piece of paper with very small print. Since then, the world of physicians and patients has undergone dramatic changes.<sup>14</sup> The federal government has defined informed consent since 1993 as “a process, not just a form,” adding that “[i]nformation must be

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<sup>10</sup> Dale Halsey Lea, *Ethical Issues in Genetic Testing*, 50 J MIDWIFERY WOMEN'S HEALTH 234 (2005); see *Quality & Safety in Genetic Testing: An Emerging Concern*, supra note 9; see also Abkowitz, supra note 2.

<sup>11</sup> See Neil A. Holtzman, *Promoting Safe and Effective Genetic Tests in the United States: Work of the Task Force on Genetic Testing*, 45 CLINICAL CHEMISTRY 732 (1999).

<sup>12</sup> Eila K. Watson et al., *Psychological and Social Consequences of Community Carrier Screening Programme for Cystic Fibrosis*, 340 LANCET 217 (1992).

<sup>13</sup> See JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 142–47, 198–99 (1984).

<sup>14</sup> See generally TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 288–331 (6th ed. 2009); Yael Schenker & Alan Meisel, *Informed Consent in Clinical Care: Practical Considerations in the Effort to Achieve Ethical Goals*, 305 AM. MED. ASS'N 1130 (2011).

presented to enable persons to voluntarily decide.”<sup>15</sup> Today, without question, informed consent governs the practice of medicine. Under modern healthcare ethics, older notions of informed consent have evolved into a model of shared decision making: the doctor, a trusted expert with a duty to inform and act in ways that promote the patient’s best interests, engages the patient in a discussion such that doctor and patient come to a joint decision, “taking into account the best scientific evidence available, as well as the patient’s values and preferences.”<sup>16</sup> The shared decision-making model and its requisite moral duties are firmly established; informing patients adequately and involving them in medical decisions is considered a standard for high-quality medical care.<sup>17</sup> The shared decision-making model also plays an important role in clinical controversies, where views of risks and benefits diverge so that it is not possible to arrive at a single interpretation of what is in a patient’s best interests.<sup>18</sup> Further, shared decision making is key to the notion of patient-centered care, which is defined by the Institute of Medicine as “care that is respectful of and responsive to individual patient preferences, needs, and values.”<sup>19</sup>

However, the history of medicine has not always focused on a patient-centered approach and, even today, resistance to ensuring informed consent remains. Though it is a legal requirement of medical care,

Many physicians are skeptical about it or are even hostile to it. Some believe that it is impossible because patients can never understand medical situations as well as doctors. Other physicians regard informed consent as a meaningless legal ritual because they

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<sup>15</sup> *Office for Human Research Protections Tips on Informed Consent*, U.S. DEP’T OF HEALTH & HUM. SERVS. (Mar. 16, 1993), <http://www.hhs.gov/ohrp/policy/ictips.html>.

<sup>16</sup> *What is Shared Decision Making?*, INFORMED MED. DECISIONS FOUND., <http://www.informedmedicaldecisions.org/what-is-shared-decision-making/> (last visited Feb. 17, 2014, 1:04 PM).

<sup>17</sup> Clarence H. Braddock III et al., *Informed Decision Making in Outpatient Practice*, 282 J. AM. MED. ASS’N 2313 (1999); Cathy Charles et al., *Decision-Making in the Physician-Patient Encounter: Revisiting the Shared Treatment Decision-Making Model*, 49 SOC. SCI. & MED. 651 (1999); Floyd J. Fowler Jr. et al., *How Patient Centered Are Medical Decisions?: Results of a National Survey*, 173 J. AM. MED. ASS’N INTERNAL MED. 1215 (2013).

<sup>18</sup> Martine C. de Vries, *A Tango for Four: Deciding on Growth Hormone Therapy in Idiopathic Short Stature*, 79 HORMONE RES. PEDIATRICS 2, 3 (2013) (citing Naomi T. Laventhal et al., *Warning about Warnings: Weighing Risk and Benefit When Information is in a State of Flux*, 79 HORMONE RES. PEDIATRICS (2013)).

<sup>19</sup> INSTITUTE OF MEDICINE, *CROSSING THE QUALITY CHASM: A NEW HEALTH SYSTEM FOR THE 21ST CENTURY* 3 (2001), available at <http://www.iom.edu/Reports/2001/Crossing-the-Quality-Chasm-A-New-Health-System-for-the-21st-Century.aspx>.

can almost always persuade patients to follow their recommendations.<sup>20</sup>

And more than twenty years after the government's 1993 statement on consent as "not just a form,"<sup>21</sup> consent forms continue to be used in many settings—and continue to be criticized as failing to effectively inform patients.<sup>22</sup>

Even where there is the intent to inform and provide opportunities for discussion, physicians and patients may not succeed in sharing decisions. Studies of actual interactions in healthcare show that frequently decisions are not fully informed or involve poor communication, incomplete discussion of the pros and cons of a given treatment choice, or a failure to attend to patient preferences.<sup>23</sup> The federal Patient-Centered Outcomes Research Institute (PCORI), mandated to fund research that will provide the information needed for patients to reach "better and more personalized healthcare decisions,"<sup>24</sup> has called for improving "the systems in which patients and clinicians make decisions" and removing "barriers to acting on the new information."<sup>25</sup>

Informing is also a legal issue; states have standards that doctors must meet when informing patients, and doctors can be found liable for failing to properly inform patients about tests, test results, and treatments.<sup>26</sup> *Canterbury v. Spence* was the first decision to hold a physician liable for not adequately fulfilling the requirements of informed consent. More recent case law includes *Truman v. Thomas*

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<sup>20</sup> BERNARD LO, *RESOLVING ETHICAL DILEMMAS: A GUIDE FOR CLINICIANS* 18 (4th ed. 2009).

<sup>21</sup> See *Office for Human Research Protections Tips on Informed Consent*, *supra* note 15.

<sup>22</sup> See MARC A. RODWIN, *CONFLICTS OF INTEREST AND THE FUTURE OF MEDICINE* 214–19 (2011).

<sup>23</sup> See Clarence H. Braddock III et al., *Informed Decision Making in Outpatient Practice*, 282 J. AM. MED. ASS'N 2313 (1999); Karen Sepucha & Albert G. Mulley Jr., *A Perspective on the Patient's Role in Treatment Decisions*, 66 MED. CARE RES. REV. 54S, 55S (2009).

<sup>24</sup> Joe Selby, *Our Draft National Priorities and Research Agenda*, PATIENT-CENTERED OUTCOMES RES. INST. (Jan. 23, 2012), <http://www.pcori.org/blog/national-priorities-and-research-agenda/>.

<sup>25</sup> Joe V. Selby et al., *The Patient-Centered Outcomes Research Institute (PCORI) National Priorities for Research and Initial Research Agenda*, 307 J. AM. MED. ASS'N 1583, 1583 (2012).

<sup>26</sup> See *Canterbury v. Spence*, 464 F.2d 772, 786–88 (D.C. Cir. 1972).

and *Pate v. Threlkel*.<sup>27</sup> These legal decisions uphold the basic tenet of informed consent that, “[e]very human being of adult years and sound mind has the right to determine what shall be done with his own body.”<sup>28</sup> Typically, patients deserve to be told what a reasonable patient would expect to learn under the circumstances, the so-called “reasonable patient” standard, but this is a rapidly evolving area of law and one in which the standards of different states vary.<sup>29</sup>

Within the shared decision-making model, genetic tests are accorded special status; the information required is categorized differently than other medical information because of the permanent nature of the findings, and as mentioned, informing about the tests may be done by genetic counselors in addition to, or in place of, physicians. According to the World Health Organization, “[t]he results of a genetic test can have a considerable impact on the life of a patient and his or her family; it is therefore essential that the quality of the test be assured, which includes the provision of non-directive counseling and other support services.”<sup>30</sup> The President of the American Society of Hematology also acknowledged the role of genetic counselors: “[c]omprehensive and accurate counseling is especially important when screening for a genetic trait because having the trait is immutable.”<sup>31</sup>

The legal situation surrounding genetic tests also has special features. Shannon Stevens gives the example of a 2001 case, *EEOC v. Burlington Northern Santa Fe Railroad*, where railroad employees claiming work-related injuries said they were required to submit blood samples but were not informed that the blood would be used for genetic testing.<sup>32</sup> This situation led the EEOC to seek a preliminary injunction requiring the company to stop the testing.<sup>33</sup>

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<sup>27</sup> *Truman v. Thomas*, 611 P.2d 902 (Cal. 1980); *Pate v. Threlkel*, 661 So.2d 278 (Fla. 1995).

<sup>28</sup> *Schloendorff v. Society of The New York Hospital*, 211 N.Y. 125, 126 (1914).

<sup>29</sup> Krista J. Sterken & Michael B. Van Sicklen, *Reshaping the Boundaries of Informed Consent in Wisconsin*, 112 WISC. MED. J. (2013); see also Laurence B. McCullough & Frank A. Chervenak, *Informed Consent*, 34 CLINICS PERINATOLOGY 275 (2007).

<sup>30</sup> *Quality & Safety in Genetic Testing An Emerging Concern*, *supra* note 9.

<sup>31</sup> Abkowitz, *supra* note 2.

<sup>32</sup> Shannon K. Stevens, *Baseball's DNA Testing Policy Strikes Out: Genetic Discrimination in Major League Baseball*, 41 SETON HALL L. REV. 813, 826 (2011).

<sup>33</sup> *Id.*



*B. Applying Current Models of Informed Consent to the NCAA-Mandated Sickle Cell Trait Test*

How do the models of shared decision making and patient-centered care apply to the screening test for sickle cell trait? Controversies over the effectiveness of screening tests are not limited to the test for sickle cell trait. For more than a decade, a debate has raged over the value of the prostate-specific antigen (PSA) test for prostate cancer: while it may detect an early form of cancer, the test may not prevent deaths and may cause harm by triggering unnecessary, potentially harmful, interventions.<sup>34</sup> A doctor's role is to inform a person considering a screening test about the reason the test is being considered, and discuss the varying opinions about the risks and benefits of the test. By this standard, anecdotal evidence from media reports and interviews of a convenience sample of student-athletes suggests that student-athletes in some programs are unacceptably uninformed about the screening test for sickle cell trait.

To successfully promote informed consent regarding the sickle cell test, a team physician would discuss the nature of the test, information about sickle cell trait, the reason the test was mandated, and what effects a positive or negative result might have. Either the physician or a genetic counselor would be able to help the student-athlete understand how the results may affect current and future family members. For example, a student-athlete's discovery that he or she carries sickle cell trait suggests that if the student-athlete's partner carries it, their offspring are at risk for sickle cell disease. The positive test also can raise paternity issues; if neither the student-athlete's mother nor father carries the trait, then the student-athlete can deduce that they have at least one different parent. Paternity questions are a known risk of having this test, and the physician might want to mention this along with other potential risks and benefits, since paternity findings have implications for the student-athlete's family.<sup>35</sup> The test has further risks in the form of disclosure: as a

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<sup>34</sup> See Michael Wilkes & Jerome Hoffman, *PSA Tests Can Cause More Harm Than Good*, S.F. CHRON. (Oct. 1, 2010), <http://www.sfgate.com/opinion/openforum/article/PSA-tests-can-cause-more-harm-than-good-3172165.php>; Michael Wilkes & Gavin Yamey, *The PSA Storm: Questioning Cancer Screening Can Be a Risky Business in America*, 324 BRIT. MED. J. 431 (2002); H. Gilbert Welch & Peter C. Albertsen, *Prostate Cancer Diagnosis and Treatment After the Introduction of Prostate-Specific Antigen Screening: 1986–2005*, 101 J. NAT'L CANCER INST. 1325 (2009).

<sup>35</sup> See Anneke Lucassen & Michael Parker, *Revealing False Paternity: Some Ethical Considerations*, 357 LANCET 1033 (2001); see also Lyn Turney, *The Incidental Discovery*

student who is also an athlete, one's privacy may not be protected in the same way as a student who is a non-athlete, so a positive result could be publicly known. This can have far-reaching effects due to future risks of discrimination in employment and insurance.<sup>36</sup>

But knowing that one has sickle cell trait could be beneficial in several ways. The most obvious benefit is that an affected and informed student-athlete could take precautions to prevent illness and death associated with exertional collapse. Another benefit is that student-athletes who have sickle cell trait will be aware of the risk that their children could have sickle cell disease *before* they begin planning to have families. This awareness is not standard,<sup>37</sup> and it is a benefit others have wished for. In a study involving interviews with more than thirty parents of children with sickle cell disease, Patricia Kavanagh found the overwhelming majority did not learn they had sickle cell trait until they were pregnant or had a child with sickle cell disease.<sup>38</sup> Further, all of the parents interviewed wished they had had this information before becoming pregnant, as it would have allowed them to be fully educated on their risks of having a child with sickle cell disease.<sup>39</sup>

In addition to risks and benefits, the physician is able to discuss alternatives, such as providing previous test results, or agreeing to release the university and its employees from liability and playing a chosen sport without knowing if one is affected by sickle cell trait.<sup>40</sup> The possibility of waiving the test is essential to the notion of consent because a patient's decision should not be manipulated or coerced.<sup>41</sup> However, in the view of one commentator, the option of a waiver suggests "that the NCAA has implemented this [testing] program

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*of Nonpaternity Through Genetic Carrier Screening: An Exploration of Lay Attitudes*, 15 QUALITATIVE HEALTH RES. 620, 620–23 (2005).

<sup>36</sup> See *Statement on Screening for Sickle Cell Trait and Athletic Participation*, *supra* note 6; Rob Stein, *Sickle Cell Testing of Athletes Stirs Discrimination Fears*, WASH. POST (Sept. 20, 2010), <http://www.washingtonpost.com/wp-dyn/content/article/2010/09/19/AR2010091904417.html>.

<sup>37</sup> Taylor et al., *supra* note 9.

<sup>38</sup> E-mail from Patricia Kavanagh, Assistant Professor of Pediatrics, Bos. Univ. Sch. of Med. and Bos. Med. Cent., to Miriam Shuchman, Assoc. Professor of Psychiatry, Univ. of Toronto (Feb. 23, 2014) (on file with authors).

<sup>39</sup> *Id.*

<sup>40</sup> LO, *supra* note 20, at 20.

<sup>41</sup> JESSICA PIERCE & GEORGE RANDELS, CONTEMPORARY BIOETHICS: A READER WITH CASES 62–63 (2010).

simply to cover its ass.”<sup>42</sup> And others have said much the same thing. Quick quotes the chief medical officer of the Sickle Cell Association of America, who described the testing policy as “screening for protection of the universities, not protection of the athlete.”<sup>43</sup>

Some schools mandate that all student-athletes be screened; they do not present the waiver option as an alternative. Other schools, such as the University of California at San Diego (UCSD), strongly encourage student-athletes to be screened for sickle cell trait, rather than waive testing and release the institution from legal liability.<sup>44</sup> At Virginia Tech, screening is encouraged, though student-athletes are responsible for the cost of the test.<sup>45</sup> Quick reports that the NCAA has said schools should “promote testing as much as possible,” and should not encourage waivers, citing an NCAA “Question and Answer Document.”<sup>46</sup> A team administrator at one school that does not present a waiver option told us this was justified because the school considers it essential to know a student-athlete’s sickle cell status. Yet, media reports suggest that other teams “collectively waive” the screening for all student-athletes,<sup>47</sup> perhaps to avoid the costs of the screening test.

In these situations, a student-athlete is not free to make a decision to have or forgo screening. Even in those settings, though, if the test is offered, a physician is obligated to inform student-athletes about the test. An explicit acknowledgement of the test, and the reasons it is mandatory can contribute to the student-athlete’s knowledge of the

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<sup>42</sup> Matt McCarthy, *Did the NCAA Screw Up Another Player Health Decision?*, REGRESSING (Dec. 5, 2013, 11:02 AM), <http://regressing.deadspin.com/did-the-ncaa-screw-up-another-player-health-decision-1474781122>.

<sup>43</sup> Heather R. Quick, *Privacy for Safety: The NCAA Sickle Cell Trait Testing Policy and the Potential for Future Discrimination*, 97 IOWA L. REV. 665, 669 n.20 (2012) (citing Michelle Brutlag Hosick, *Protocol Decided for Sickle Cell Testing*, NCAA.ORG (Apr. 13, 2010), [http://fs.ncaa.org/Docs/NCAANewsArchive/2010/d1/protocol\\_decided\\_for\\_sickle\\_cell\\_testing.html](http://fs.ncaa.org/Docs/NCAANewsArchive/2010/d1/protocol_decided_for_sickle_cell_testing.html)).

<sup>44</sup> See *Student-Athlete Participation Information and Forums*, UCSD (June 10, 2010), <http://www.ucsdtritons.com/ViewArticle.dbml?ATCLID=204958637>.

<sup>45</sup> See *Sickle Cell Trait Testing*, HOKIESPORTS.COM, <http://www.hokiesports.com/sportsmed/policies/sickle-cell-trait-testing-policy.pdf> (last visited Apr. 3, 2014).

<sup>46</sup> Quick, *supra* note 43, at 668 (citing NAT’L COLLEGIATE ATHLETIC ASS’N, QUESTION AND ANSWER DOCUMENT, NCAA DIVISION I PROPOSAL NO. 2009-75-B 2 (June 2, 2010), available at [http://www.gohofstra.com/fls/22200/pdf/SCTFAQs\\_SCI2.pdf?DB\\_OEM\\_ID=22200](http://www.gohofstra.com/fls/22200/pdf/SCTFAQs_SCI2.pdf?DB_OEM_ID=22200)).

<sup>47</sup> Rose Eveleth, *Exercising Caution: Intensive Athletic Activity Could Be Fatal to Those with Sickle-Cell Trait*, SCI. AM. (Aug. 13, 2013), <http://www.scientificamerican.com/article/athletic-activity-could-be-fatal-to-those-with-sickle-cell-trait/>.

process and help him or her be a more involved and informed participant in the screening. In other words, the fact that the test is mandatory should not result in disregard for the notion of informed consent; student-athletes should be aware of the nature of the test and of the potential consequences of having sickle cell trait.

A similar issue arises with respect to mandatory newborn screening in the United States: in some states, parents are not told that the screening is occurring, thus leaving them out of the decision-making process.<sup>48</sup> This has been justified by a child welfare rationale: newborns are screened for inherited conditions such as phenylketonuria (PKU), requiring urgent, early treatment and therefore, public health officials have argued that the state may waive the parent's usual right of informed consent to ensure appropriate treatment of affected newborns, under the state's authority to promote child welfare.<sup>49</sup>

However, Tarini and Goldenberg report that attitudes have changed recently regarding the need to inform parents, even though newborn screening is mandatory:

Historically, the obstetrics community has resisted the responsibility to educate parents about newborn screening, contending that they are already tasked with discussing numerous prenatal tests with parents. This perspective seems to be changing, however; the American College of Obstetricians and Gynecologists recently recommended that prenatal providers give information about newborn screening to their patients through informational brochures, electronic sources, or discussion during prenatal visits.<sup>50</sup>

In the case of a student-athlete, the NCAA does not claim that affiliate programs may test athletes for sickle cell trait without informing them, but NCAA literature does not specify the details of informed consent for the test, nor does it provide for genetic counseling about the meaning of the test, nor psychological support if the results of the test are positive. Educational information is provided to student-athletes and coaches regarding the physical implications

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<sup>48</sup> See Ellen Wright Clayton, *State Run Newborn Screening in the Genomic Era, or How to Avoid Drowning When Drinking from a Garden Hose*, 38 J.L. MED. & ETHICS 697, 697–99 (2010).

<sup>49</sup> THE PRESIDENT'S COUNCIL ON BIOETHICS, *THE CHANGING MORAL FOCUS OF NEWBORN SCREENING: AN ETHICAL ANALYSIS* 1–3, 75–76 (2008), available at [https://bioethicsarchive.georgetown.edu/pcbe/reports/newborn\\_screening/introduction.html](https://bioethicsarchive.georgetown.edu/pcbe/reports/newborn_screening/introduction.html); Beth A. Tarini & Aaron J. Goldenberg, *Ethical Issues With Newborn Screening in the Genomics Era*, 13 ANN. REV. GENOMICS & HUM. GENETICS 381, 383–84 (2012).

<sup>50</sup> Tarini & Goldenberg, *supra* note 49, at 384–85 (citations omitted).

with respect to someone who carries the trait,<sup>51</sup> but nowhere in the 2013–14 NCAA Sports Medicine Handbook is any mention made of the special circumstances that genetic testing invokes, though much attention is given to the possible complications that might occur if a student-athlete has sickle cell trait.<sup>52</sup> The moral duty to ensure student-athletes are fully informed and adequately counseled falls to physicians ordering or administering the test. In light of this, it is disturbing that student-athletes in some programs are screened for sickle cell trait without knowing it. The student-athletes deserve to have all of the information necessary to make an informed decision regarding whether to proceed with the genetic screening and this information should be provided even where the test is deemed mandatory.

Scholars concerned about the NCAA requirement to screen student-athletes for sickle cell trait raised the issue of informed consent early on as one of several medical and ethical issues to be considered. In 2010, Bonham and colleagues asked the following questions:

Will the NCAA assist student athletes and their parents in making informed decisions regarding testing and in understanding the implications of the test results? Will the first line test, hemoglobin solubility, be followed by a second test to eliminate false positives? What role will primary care providers play in screening and counseling? How will knowledge of their carrier status affect student athletes and their families? How will the athletic program and the institution protect the privacy of athletes who test positive? Surveillance and research aimed at understanding the program's effects on universities, athletes, and families will need to be conducted if inadvertent harm is to be avoided.<sup>53</sup>

Three years later, the president of the American Society of Hematology worried that the NCAA testing program would give student-athletes who test negative a false sense of security, leading them to ignore signs of health problems such as asthma, or the heart disorder known as long Q-T syndrome, both of which can also be a cause of athlete deaths.<sup>54</sup>

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<sup>51</sup> *Sickle Cell Trait: A Fact Sheet for Coaches*, NCAA.ORG, <http://www.ncaa.org/sites/default/files/NCAASickleCellTraitforCoaches.pdf> (last visited Apr. 3, 2014).

<sup>52</sup> NCAA, 2013–2014 NCAA SPORTS MEDICINE HANDBOOK (2013), available at <http://www.ncaapublications.com/productdownloads/MD13.pdf>.

<sup>53</sup> Vence L. Bonham et al., *Screening Student Athletes for Sickle Cell Trait—A Social and Clinical Experiment*, 363 NEW ENG. J. MED. 997, 998 (2010).

<sup>54</sup> Abkowitz, *supra* note 2.

Informal conversations with a small number of student-athletes and anecdotal media reports indicate that the application of the sickle cell screening policy varies widely. Some schools provide excellent information, while others provide limited information, if any at all. The result is that some student-athletes are aware of the issue yet others are unaware of the sickle cell screening policy and even unaware that they have been screened for their carrier status.

A few examples illustrate the large differences in how the policy is applied in practice. Media reports about Anya Covington, a three-time captain of the women's basketball team at the University of Wisconsin, suggest that she and her coaches and trainers were well aware of her need as an individual with sickle cell trait to occasionally "pull herself out of a line drill in practice and take an extra water break now and then."<sup>55</sup> Covington told a reporter that her team trainer had helped her realize when she needed to sit out; her coach told the reporter, "[s]he's going to go and go and go, so you have to manage her."<sup>56</sup>

Reports of Chris Carter's basketball career at the Air Force Academy during 2011–12 suggest that Carter and his coaches were also well informed about his status as a sickle cell carrier.<sup>57</sup> The Air Force Academy is in Colorado Springs, where altitude adds greater physical stress for athletes with sickle cell trait and places them at increased risk of dangers to their health.<sup>58</sup> Carter and his coach may have been forced to grapple with his condition because he experienced an episode of dizziness early on that led to a few weeks off the court.<sup>59</sup> Subsequently, Air Force staff monitored his workouts and in the fall of 2011 a team trainer told reporters, "[s]ickle cell trait is something that can be managed."<sup>60</sup>

A conversation with a rower at another university, by contrast, revealed she underwent the required physical exam and blood test at

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<sup>55</sup> Dennis Punzel, *UW Women's Basketball: Sickle Cell Trait Hasn't Kept Covington from Becoming Go-To Player for Badgers*, MADISON.COM (Jan. 30, 2012), [http://host.madison.com/sports/college/basketball/women/uw-women-s-basketball-sickle-cell-trait-hasn-t-kept/article\\_12874a9a-4af9-11e1-be75-001871e3ce6c.html](http://host.madison.com/sports/college/basketball/women/uw-women-s-basketball-sickle-cell-trait-hasn-t-kept/article_12874a9a-4af9-11e1-be75-001871e3ce6c.html).

<sup>56</sup> *Id.*

<sup>57</sup> See Frank Schwab, *Carter Fights Through Sickle Cell Trait to Make Immediate Impact for Air Force Basketball*, GAZETTE (Nov. 17, 2011), <http://gazette.com/carter-fights-through-sickle-cell-trait-to-make-immediate-impact-for-air-force-basketball/article/128708>.

<sup>58</sup> *Id.*

<sup>59</sup> *Id.*

<sup>60</sup> *Id.*

the start of her freshman year but did not know what the test was for.<sup>61</sup> When she told her mother that there was a blood draw during the routine physical, her mother thought it was for a random drug test. The rower told us later that she did not feel comfortable asking questions about the nature of the blood test; she only learned what the test was accidentally when she took a class where it was discussed.

Another conversation between one of the authors and two student-athletes from a football team at one school showed a similar degree of misinformation. As part of a discussion of newborn genetic screening in a class the football players attended, information on the NCAA screening policy was given to the class. The student-athletes first said they had not been screened, but returned to class the following week saying that they found out they had been screened. When the student-athletes brought up the class discussion at practice, a teammate told them the screening test had been part of their incoming physical. Anecdotes like these indicate that informed consent is not successfully attained with all athletes.

Clearly, the practice of testing without explicitly informing student-athletes is outmoded. Recently, the Department of Health and Human Services (HHS) has ensured that patients in all fifty states can access the results of a blood test or other lab test without going through their doctor's office.<sup>62</sup> At the time of this HHS ruling, in 2014, HHS Secretary Kathleen Sebelius said in a press release, "[i]nformation like lab results can empower patients to track their health progress, make decisions with their healthcare professionals, and adhere to important treatment plans."<sup>63</sup> Yet, student-athletes on some college campuses are commonly unaware that there is a lab result for them to check.

These divergent practices on different campuses raise a critical issue for athletic programs and team physicians in light of the authority that programs wield over student-athletes. Institutional officials, such as coaches, control student-athletes' playing time, eligibility for competition, and access to training resources, which are

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<sup>61</sup> The authors have chosen to withhold the identity of the athletes in this section. Revealing any information regarding the schools they attended would compromise their anonymity.

<sup>62</sup> See *HHS Strengthens Patients' Right to Access Lab Test Reports*, U.S. DEP'T HEALTH & HUM. SERVS. (Feb. 3, 2014), <http://www.hhs.gov/news/press/2014pres/02/20140203a.html>.

<sup>63</sup> *Id.*

among the most important aspects of the college sports experience. After devoting years of training to be selected for competition at this elite level, many student-athletes have finally reached the pinnacle of their aspirations and they want to compete. Any individual who controls their access to competition has power over the student-athlete, and this unavoidable imbalance in power puts the student-athlete in a unique and vulnerable situation. Quick describes the power differential this way:

Student-athletes not only face the pressures of attempting to perform at a higher level of competition but also attempting to achieve a higher level of education. Also, student-athletes hope to create strong relationships with their coaches. In an attempt to create these relationships, student-athletes are more likely to follow the recommendations of these people without thinking of the consequences.<sup>64</sup>

An awareness of the nature of these relationships is essential in ensuring informed consent about recommended medical tests and treatments.

One might argue that a student-athlete might never be able to freely consent to a procedure due to the influences noted above. Some have raised this argument regarding a class-action lawsuit by football players against the National Football League (NFL) over the consequences of repeated head trauma.<sup>65</sup> A major question in the litigation was whether the NFL failed to fully disclose information about the risks of the trauma, and in that context, one of the discussion points was “the imbalances of financial power between the NFL and most players.”<sup>66</sup> However, others writing about sports medicine note that “all decisions are made within a context of some external influences.”<sup>67</sup> In other words, while the context of the athlete may be different than that of a non-athlete, we are just trading some external influences for others—but this argument does not account for the vulnerable situation of student-athletes.

In ensuring that athletes are fully informed, it may be valuable to consider the suggested protocols for screening for other genetic conditions. For example, counseling an individual undergoing a

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<sup>64</sup> Quick, *supra* note 43, at 691 (citations omitted).

<sup>65</sup> Caleb Korngold et al., *The National Football League and Chronic Traumatic Encephalopathy: Legal Implications*, 41 J. AM. ACAD. PSYCHIATRY L. 430, 433 (2013).

<sup>66</sup> *Id.*

<sup>67</sup> Pam R. Sailors et al., *Prescription for “Sports Medicine and Ethics,”* 13 AM. J. BIOETHICS 22, 22 (2013).



genetic test for Huntington's Disease, an inherited, fatal condition for which no treatment is available, may involve several meetings with a genetic counselor both before and after having the test.<sup>68</sup> These discussions typically include at least one meeting after the test, where the counselor communicates the result of the test and educates the individual about it.<sup>69</sup> Even for nonfatal conditions, discovering that one carries a genetic trait linked to certain health issues can cause anxiety and in many models of genetic testing, this is addressed via counseling and appropriate health education.<sup>70</sup> Taylor et al. suggest that the appropriate route for counseling individuals about sickle cell trait is via primary care clinicians.<sup>71</sup> As the anecdotal evidence suggests, at present no such process exists within the NCAA model and student-athletes in some programs are not informed of the results of their screening tests, foregoing any chance for counseling or greater education.

There may be written or web-based materials that are intended to provide information. For example, at UCSD, student-athletes are provided with sickle cell fact sheets and instructed to watch an NCAA educational video.<sup>72</sup> At one school, staff told us that a three-page handout is given to all student-athletes at an information session. Student-athletes are given the opportunity to ask questions and be involved in a discussion about sickle cell trait. The handout provides information about sickle cell trait: what it is, who may have it, how to get tested, information about training and competing, and the availability of options such as waiving the test. If the student-athlete voluntarily waives the testing, he or she is given another document that outlines the risks of waiving the test and his or her inability to pursue legal action against the NCAA or the institution if he or she has an injury because of sickle cell trait. Additionally, this waiver form requires the student-athlete to affirm that he or she has had time to ask any questions he or she may have. This appears to be an admirable model, especially considering the student-athletes are involved in face-to-face discussions about the information. Obtaining

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<sup>68</sup> *Guidelines for Genetic Testing for Huntington's Disease, The Importance of a Team Approach*, HEREDITY DISEASE FOUND. (Jan. 27, 2014, 1:05 PM), <http://www.hdfoundation.org/html/hdsatest.php>.

<sup>69</sup> *Id.*

<sup>70</sup> Watson, *supra* note 12.

<sup>71</sup> Taylor et al., *supra* note 9.

<sup>72</sup> See DVD: The Student-Athlete with the Sickle Cell Trait (NCAA 2010), available at [http://s3.amazonaws.com/ncaa/web\\_video/health\\_and\\_safety/sickle\\_cell/sickleCell.html](http://s3.amazonaws.com/ncaa/web_video/health_and_safety/sickle_cell/sickleCell.html).

a student-athlete's signature on a form without discussing it does not constitute informed consent because there is no certainty that the student-athlete has been properly informed if a form is handed to him or her without discussion.

*C. Applying Current Models of Informed Consent to the Special Role of Team Physicians*

There is a pressing obligation to meet recognized standards set for informed consent for college athletes, but who bears the obligation? Team doctors are in a unique role in that they are interested in the health of the team as a whole as opposed to a personal physician concerned solely with the best interests of the patient. Much has been written about the potential for team physicians to face conflicts of interest and experience “divided loyalties” because they care for athletes but answer to the institution.<sup>73</sup> The rules of informed consent still apply, but with caveats.

An analogy might be made to physicians in the military or to company doctors, also known as industry employed physicians.<sup>74</sup> The analogy to the military seems applicable to team doctors, because, as discussed earlier, coaches and trainers wield substantial authority over athletes. Annas writes of medical ethics in the military:

There is no special medical ethics for active-duty military physicians any more than there is for Veterans Affairs physicians, National Guard physicians, public health physicians, prison physicians, or managed care physicians. The only question is whether there are “extreme contingencies” that justify physicians’ suspension of their medical–ethical obligations.<sup>75</sup>

He also refers to the need for military doctors to treat only with the “voluntary and informed consent of the soldier-patient,” and quotes military authors as stating that physicians in the military are “[p]hysician first, [o]fficer second.”<sup>76</sup>

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<sup>73</sup> See, e.g., Daniela Testoni et al., *Sports Medicine and Ethics*, 13 AM. J. BIOETHICS 4, 4–6 (2013).

<sup>74</sup> B. Sonny Bal & Lawrence H. Brenner, *Care of the Professional Athlete: What Standard of Care?*, 471 CLINICAL ORTHOPAEDICS & RELATED RES. 2060, 2060–61 (2013); Nancy M.P. King & Richard Robeson, *Athletes Are Guinea Pigs*, 13 AM. J. BIOETHICS 13 (2013); Charles Marsan, *Professional Codes of Ethics as Leading Benchmarks*, 13 AM. J. BIOETHICS 24 (2013).

<sup>75</sup> George J. Annas, *Military Medical Ethics—Physician First, Last, Always*, 359 NEW ENG. J. MED. 1087, 1087 (2008).

<sup>76</sup> *Id.* at 1088–89.

Industry employed physicians are described as having “ties to a third party” but with responsibilities “very similar to those of other physicians,” apart from the fact that they are not obliged to follow patients over time or provide continuity of care.<sup>77</sup> Bal and Brenner view the obligations of the team doctor as an open question, asking what the norms are, “if there is a different standard of care for orthopaedic surgeons treating professional athletes.”<sup>78</sup> They also wonder if such different norms, applied to an athlete suffering an in-play injury, “include an abbreviated but meaningful process of informed consent.”<sup>79</sup> Yet the notion of different norms seems inapplicable in the realm of college team doctors treating non-professional, student-athletes.

However, team doctors may view certain aspects of informed consent differently from a typical primary care physician. Typically, it is acceptable and appropriate for physicians to offer their opinions and recommendations regarding a diagnostic test or treatment, but this may be different in the case of team physicians acting on behalf of their teams and obliged to provide the test for sickle cell trait unless the athlete waives it.

### *1. Preventing Racist Consequences*

Sickle cell trait, like sickle cell disease, disproportionately affects blacks with ancestry in certain parts of Africa and others with ancestry from Mediterranean or equatorial regions such as Greece or Central and South America.<sup>80</sup> According to one estimate, perhaps four million people in the United States carry the trait, including eight percent of African Americans.<sup>81</sup> A policy analysis concluded that if sickle cell trait screening of student-athletes were carried out effectively, 2147 athletes would be identified as carriers over a ten-year period.<sup>82</sup> Of these 2147 athletes, 1918 would be black, 25 would be Hispanic, and 204 would be of other races.<sup>83</sup> To be clear, anyone of any race may carry the gene for sickle cell. However, in the United

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<sup>77</sup> Marsan, *supra* note 74, at 25.

<sup>78</sup> Bal & Brenner, *supra* note 74, at 2062.

<sup>79</sup> *Id.*

<sup>80</sup> *Sickle Cell Anemia*, AM. SOC’Y HEMATOLOGY, <http://www.hematology.org/Patients/Blood-Disorders/Anemia/5228.aspx> (last visited Feb. 16, 2014).

<sup>81</sup> Abkowitz, *supra* note 2.

<sup>82</sup> Tarini et al., *supra* note 1, at 451–52.

<sup>83</sup> *Id.*

States, the majority of those who are carriers of the trait or are affected by the disease are African American. In light of this knowledge, it is important to understand the impact that race may have on informed consent, especially when it involves those with African American heritage.

In a letter criticizing the NCAA testing requirement, the chair of a federal advisory committee expressed concern “because of the risk of stigmatization and discrimination against athletes with sickle cell trait and because the . . . request for screening does not provide . . . protection from the potential discriminatory use of such information.”<sup>84</sup> The Sickle Cell Disease Association of America also believes the test carries a risk of stigmatization and discrimination,<sup>85</sup> and Quick describes how this might happen: a student-athlete could face discrimination by a potential employer “if the employer believes carrying the trait makes a candidate less qualified.”<sup>86</sup>

These concerns are in line with current legal thinking: Stevens points out that in the context of employment, acquiring genetic information has led to concerns about discrimination because of “fears that an applicant’s genetic profile can be discriminatorily used to deny or terminate employment.”<sup>87</sup> Quick describes current legislative efforts to protect employees against such discrimination, but concludes that the Genetic Information Nondiscrimination Act (GINA) does not fully cover the situation of student-athletes.<sup>88</sup> Discrimination is wrong for many reasons and it is also contrary to an NCAA core value of “fairness of opportunity to compete.”<sup>89</sup>

Clearly the possibility of racist consequences is a risk that student-athletes may be informed about, but there may be other, additional ways to consider the issue of race in informed consent. In the creation of laws regarding informed consent, there has been no consideration given to religious, ethnic, or racial perspectives.<sup>90</sup> However, there is a documented trend of mistrust in the medical establishment by the

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<sup>84</sup> Howell, *supra* note 7.

<sup>85</sup> *Sickle Cell Trait and Athletics*, SICKLE CELL DISEASE ASS’N AM., <http://www.sicklecelldisease.org/index.cfm?page=sickle-cell-trait-athletics> (last visited Feb. 17, 2014).

<sup>86</sup> Quick, *supra* note 43, at 683.

<sup>87</sup> Stevens, *supra* note 32, at 836.

<sup>88</sup> Quick, *supra* note 43, at 670.

<sup>89</sup> Timothy Davis & Christopher T. Hairston, *Majoring in Infractions: The Evolution of the National Collegiate Athletic Association’s Enforcement Structure*, 92 OR. L. REV. 979, 980 (2014).

<sup>90</sup> See Dayna Bowen Matthew, *Race, Religion, and Informed Consent—Lessons from Social Science*, 36 J.L. MED. & ETHICS 150 (2008).

African American community.<sup>91</sup> This distrust has translated into lower participation rates in research by African Americans, and has also carried over into alarming differential trends in healthcare for African Americans. For example, African Americans “generally receive less health care than whites, and often it is received later in an illness, when it is not as likely to be effective.”<sup>92</sup> Racial differences permeate our healthcare system, and whatever the reason, we would be naïve if we assumed they did not also affect the process of informed consent for a genetic condition that occurs disproportionately in African Americans.

Sickle cell trait is also a test with a troubled racial history in the United States.<sup>93</sup> Knowledge of this complicated past involving race and medicine can help to better inform patients. It may result in an extended amount of time dedicated to asking and answering questions, or an effort to introduce the subject of race and sickle cell testing as a means of taking cultural and racial differences into account when informing student-athletes about sickle cell trait screening.

## 2. *Conducting Research on the Screening Test*

In 2014, it is inappropriate to embark on a major medical initiative without evidence to justify it. More recently, some have advocated for an evidence-based approach to healthcare policy decisions.<sup>94</sup> In addition, informed consent and shared decision making requires sharing evidence with patients. But there is limited evidence regarding the NCAA screening policy and gathering such evidence requires an active research program. Others have called on the National Institutes of Health and the Centers for Disease Control to study the issue of whether student-athletes with sickle cell trait are at increased risk of exercise-related sudden death,<sup>95</sup> and further research

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<sup>91</sup> See GREGORY E. PENCE, CLASSIC CASES IN MEDICAL ETHICS 241–50 (2nd ed. 1995) (discussing the Tuskegee study of syphilis and the use of deception on the African American subjects).

<sup>92</sup> RONALD MUNSON, INTERVENTION AND REFLECTION: BASIC ISSUES IN BIOETHICS 788 (9th ed. 2nd prtg. 2011).

<sup>93</sup> See KEITH WAILOO & STEPHEN PEMBERTON, THE TROUBLED DREAM OF GENETIC MEDICINE: ETHNICITY AND INNOVATION IN TAY-SACHS, CYSTIC FIBROSIS, AND SICKLE CELL DISEASE 116–22 (2006).

<sup>94</sup> See, e.g., David Atkins et al., *Making Policy When the Evidence is in Dispute*, 24 HEALTH AFF. 102 (2005).

<sup>95</sup> Howell, *supra* note 7.

is also required on the real-world use of the screening test, including studies of health outcomes, evaluations of other methods for preventing deaths related to sickle cell trait, and studies of whether the screening can be practiced in a fair and nondiscriminatory way.<sup>96</sup> The need for empirical research on sickle cell trait and the NCAA policy is underscored when one considers the intense debate over whether the screening is necessary or valuable. Several groups have called for the policy of mandatory screening for sickle cell trait to be reversed.<sup>97</sup> Other experts have suggested the policy be viewed as experimental until there is data to show that it is effective.<sup>98</sup>

To take just one example of the need for research, there is limited evidence that a student-athlete who knows he or she has sickle cell trait could be protected by that knowledge. The policy analysis referenced earlier concludes that under the NCAA screening policy, screening could prevent the deaths of seven student-athletes over the course of a decade, but only if one assumes that every athletic program involved is using a “100 percent effective intervention” for students found to be carriers of sickle cell trait.<sup>99</sup> Informal reports suggest that the current levels of intervention by a student’s coach, trainers, or fellow athletes are less than one hundred percent effective, so the hoped-for goal of saving lives by preventing athletes from experiencing physical crises that could be secondary to sickle cell trait rests on assumptions that may not be met at many college athletic programs.

Other areas where research is needed become apparent from reviewing the NCAA handbook. After a positive result is recorded on a sickle cell solubility test, the result should then be confirmed with a second test due to the inadequacies of the solubility test. The NCAA handbook states, “screening positives must be confirmed with additional diagnostic testing such as hemoglobin electrophoresis or high performance liquid chromatography (HPLC).”<sup>100</sup> Yet in one published report on athletes with sickle cell trait who had died

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<sup>96</sup> See Bonham et al., *supra* note 53; see also Abkowitz, *supra* note 2; Jonathan C. Goldsmith et al., *Framing the Research Agenda for Sickle Cell Trait: Building on the Current Understanding of Clinical Events and Their Potential Implications*, 87 AM. J. HEMATOLOGY 340 (2012).

<sup>97</sup> See, e.g., Howell, *supra* note 7; see also Abkowitz, *supra* note 2.

<sup>98</sup> Bonham et al., *supra* note 53, at 999; *Statement on Screening for Sickle Cell Trait and Athletic Participation*, *supra* note 6.

<sup>99</sup> Tarini et al., *supra* note 1, at 451.

<sup>100</sup> 2013–2014 NCAA SPORTS MEDICINE HANDBOOK, *supra* note 52, at 94.

suddenly, several had no hemoglobin electrophoresis recorded.<sup>101</sup> Research on the process for requesting and checking the confirmatory test, and quality assessment or “implementation” research on the implementation of the screening test policy, could undergird the screening test policy with information about best practices.

The NCAA handbook also notes that if the confirmatory test is positive, athletes “should be offered counseling on the implications of sickle cell trait, including health, athletics and family planning,”<sup>102</sup> but it is not known if any of the NCAA member schools provide such counseling, and it is not clear if student-athletes would be receptive to it. Given the importance of genetic counseling for such testing, and the potential for athletes who test positive for sickle cell trait to experience anxiety over the result, the actual availability of counseling and the attention to the mental health needs of those athletes who discover they are carrying sickle cell trait could be additional foci of research.

Perhaps the most significant research deficiency is the lack of evidence that the screening test could save lives.<sup>103</sup> The NCAA handbook alerts athletes and programs to the intended use of the test results: “[s]creening can be used as a gateway to targeted precautions. Precautions can enable student-athletes with sickle cell trait to thrive in their sport.”<sup>104</sup> The NCAA handbook also recommends several steps that athletes and programs should take in the instance of an athlete who is positive for sickle cell trait to prevent bad outcomes. For example, deaths related to sickle cell trait are linked to heat and the student-athlete’s hydration; they typically occur early in training, such as the first day or the first week; and they are associated with the sorts of high-effort drills known as “gassers,” or the intense station or “mat” drills used in football practices.<sup>105</sup> The NCAA recommends that student-athletes with sickle cell trait take “precautions” such as setting their own pace and using adequate rest and recovery between repetitions, especially during “gassers” and “mat” drills.<sup>106</sup> But there

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<sup>101</sup> Stephen C. Nelson, *Scaring Athletes with Sickle Cell Trait*, 111 AM. J. CARDIOLOGY 149 (2013).

<sup>102</sup> 2013–2014 NCAA SPORTS MEDICINE HANDBOOK, *supra* note 52.

<sup>103</sup> See Goldsmith et al., *supra* note 96.

<sup>104</sup> *Id.*

<sup>105</sup> *Id.*

<sup>106</sup> *Id.* at 95.

is no data attesting to the feasibility and actual use of these recommended preventive steps.

In an analysis of twenty-three athletes whose deaths were linked to sickle cell trait, none died suddenly; all experienced gradual deterioration over several minutes and, for all but one, that deterioration happened during a conditioning drill.<sup>107</sup> The analysis concludes, “[u]nderstanding the risks, mechanisms, and event triggers of [sickle cell trait] may allow lifesaving alterations in training methods to be implemented,”<sup>108</sup> and in a subsequent publication, the same authors describe deaths linked to sickle cell trait as “potentially preventable with vigilance, a high index of suspicion, and effective treatment strategies.”<sup>109</sup> The authors of a 2010 case report on a nineteen-year-old college football player who died following a training run in Texas also conclude that following simple precautions for athletes who test positive for sickle cell trait may prevent such tragedies.<sup>110</sup> But these opinions are not yet backed by evidence from scientific studies.

The NCAA advises institutions to provide an environment in which the student-athlete can “activate” the recommended precautions,<sup>111</sup> and it endorses the list of ten preventive steps developed by the Inter-Association Task Force for Preventing Sudden Death in Collegiate Conditioning Session, which includes as item three, “[d]o not use exercise and conditioning activities as punishment,” and as item four, “[e]nsure proper education, experience and credentialing of strength training and conditioning coaches.”<sup>112</sup> However, it is not clear how student-athletes, trainers, coaches, or athletic directors learn to be vigilant about sickle cell trait and its effects on athletes, nor is there research assessing whether NCAA-recommended policies are feasible at athletic programs. Informal data and anecdotal media reports underscore the need for this sort of research by suggesting that the culture of a typical college athletic practice varies widely.

At Oklahoma University, according to media reports, basketball player Danielle Robinson tested positive for sickle cell trait during the

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<sup>107</sup> Kevin M. Harris et al., *Sickle Cell Trait Associated with Sudden Death in Competitive Athletes*, 110 AM. J. CARDIOLOGY 1185, 1185 (2012).

<sup>108</sup> *Id.*

<sup>109</sup> Barry J. Maron et al., *Reply*, 111 AM. J. CARDIOLOGY 149, 149 (2013).

<sup>110</sup> Mary L. Anzalone et al., *Sickle Cell Trait and Fatal Rhabdomyolysis in Football Training: A Case Study*, 42 MED. & SCI. SPORTS & EXERCISE 3, 3 (2010).

<sup>111</sup> 2013–2014 NCAA SPORTS MEDICINE HANDBOOK, *supra* note 52, at 94–95.

<sup>112</sup> *Id.* at 30-31.



athletic program's "routine" blood work.<sup>113</sup> Danielle is monitored during times of exertion and is monitored especially closely during preseason training.<sup>114</sup> Her preseason training is gradual; she also sits out occasional sprints and avoids all-out exertion lasting longer than two to three minutes. At the University of Tulsa, a football player with sickle cell trait had what his family's lawyer later referred to as "these sickle cell attacks" more than once and the Tulsa trainers knew how to treat it, according to the lawyer.<sup>115</sup> Years later the former player died after a boxing match.<sup>116</sup>

But at other schools, the athletic culture is not one in which trainers and student-athletes are accustomed to taking such steps as having students "set their own pace." Moreover, there are suggestions that in college sports programs, physical suffering is expected as part of a difficult workout. A 2011 report in the *Los Angeles Times* described a series of incidents, including one at the University of Iowa, in which vigorous football training situations led to the condition known as rhabdomyolysis among multiple team members.<sup>117</sup> A similar incident after an "immersion camp" for the McMinnville, Oregon, high school football team garnered national headlines in 2010, when about thirty players suffering from symptoms of rhabdomyolysis were referred to the hospital, with three requiring emergency surgery.<sup>118</sup>

At Slippery Rock University, according to a lawsuit filed after the death of a twenty-one-year-old basketball player, the basketball team was asked to do a third practice one day that was described as an "insanity workout . . . intended to serve as punishment for the entire

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<sup>113</sup> Berry Tramel, *Sooners' Danielle Robinson Doesn't Let Sickle Cell Trait Slow Her Down*, NEWSOK (Mar. 25, 2011), <http://newsok.com/sooners-danielle-robinson-doesnt-let-sickle-cell-trait-slow-her-down/article/3551922>.

<sup>114</sup> *Id.*

<sup>115</sup> Jarrel Wade, *Guts Church Boxer Died of Complications of Sickle Cell Trait, Medical Examiner Says*, TULSA WORLD (Jan. 4, 2012, 12:00 AM), [http://www.tulsaworld.com/news/crimewatch/guts-church-boxer-died-of-complications-of-sickle-cell-trait/article\\_30fadd2c-f25d-5d65-87e5-622eec8f3861.html](http://www.tulsaworld.com/news/crimewatch/guts-church-boxer-died-of-complications-of-sickle-cell-trait/article_30fadd2c-f25d-5d65-87e5-622eec8f3861.html).

<sup>116</sup> *Id.*

<sup>117</sup> Shari Roan, *A Potentially Deadly Danger for Athletes; Overexertion can Cause the Serious Muscle Condition Rhabdomyolysis*, L.A. TIMES, Feb. 6, 2011, at A20.

<sup>118</sup> Michael Russell, *Combination of Intense Drill, Heat, Dehydration, May Have Sent McMinnville Players to Hospital*, OREGONIAN (Aug. 22, 2010, 10:30 PM), [http://www.oregonlive.com/news/index.ssf/2010/08/combination\\_of\\_intense\\_drill\\_h.html](http://www.oregonlive.com/news/index.ssf/2010/08/combination_of_intense_drill_h.html); Katie Thomas, *Muscle Injuries Rattle an Oregon High School*, N.Y. TIMES (Aug. 23, 2010), <http://www.nytimes.com/2010/08/24/sports/24tissue.html>.

team.”<sup>119</sup> At the University of Central Florida, in 2008, a quarterback who transferred to a different school said that he and his teammates requested water from the athletic trainers “at your own risk” because the coach would swear if an athlete interrupted a workout.<sup>120</sup>

A reporter with a Florida paper interviewed a number of players about the issue of overly strenuous off-season workouts. “Some blame a culture that pushes for toughness, one where players run for punishment and athletic trainers might be intimidated by millionaire head coaches who aren’t educated on the risks associated with sickle cell trait,” she wrote.<sup>121</sup> Media reports also discuss the role of athletic trainers, who often have the responsibility of deciding whether to pull a player out of a drill session or a workout: “some veteran athletic trainers admitted it can be intimidating saying no to a coach who wants a player to finish a drill.”<sup>122</sup> The National Strength and Conditioning Association and the National Athletic Trainers’ Association convened a task force in January 2012 that recommended enacting educational requirements and minimum standards to ensure that appropriately-trained coaches are hired,<sup>123</sup> and an op-ed commenting on the task force notes that the absence of such standards “is thought to be a major contributor to the abusive behavior and inappropriate training programs resulting in unnecessary deaths.”<sup>124</sup> Researchers could study the culture of college athletic practices via qualitative methods or by testing experimental interventions, but as

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<sup>119</sup> Paula Reed Ward, *Lawsuit Targets Slippery Rock: Deceased Athlete was not Tested for Sickle Cell Trait*, PITT. POST-GAZETTE (Sept. 7, 2013, 12:15 AM), <http://www.post-gazette.com/news/education/2013/09/07/Lawsuit-targets-Slippery-Rock/stories/201309070229>.

<sup>120</sup> Iliana Limón, *Former UCF Players Saw No Water, No Trainer Intervention During Ereck Plancher’s Last Workout*, ORLANDO SENTINEL (May 29, 2011), [http://articles.orlandosentinel.com/2011-05-29/sports/os-ereck-plancher-trial-depositions-020110528\\_1\\_ucf-attorneys-plancher-attorneys-plancher-family](http://articles.orlandosentinel.com/2011-05-29/sports/os-ereck-plancher-trial-depositions-020110528_1_ucf-attorneys-plancher-attorneys-plancher-family).

<sup>121</sup> Rachel George, *Danger Zone: College Football Culture, Sickle Cell Trait are Lethal Combination*, ORLANDO SENTINEL (July 25, 2011), [http://articles.orlandosentinel.com/2011-07-25/sports/os-college-football-culture-sickle-ce20110722\\_1\\_sickle-cell-trait-dale-loyd-ii-devaughn-darling](http://articles.orlandosentinel.com/2011-07-25/sports/os-college-football-culture-sickle-ce20110722_1_sickle-cell-trait-dale-loyd-ii-devaughn-darling).

<sup>122</sup> *Id.*

<sup>123</sup> Douglas J. Casa et al., *The Inter-Association Task Force for Preventing Sudden Death in Collegiate Conditioning Sessions: Best Practice Recommendations*, 47 J. ATHLETIC TRAINING 477 (2012), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3396308/pdf/i1062-6050-47-4-477.pdf>.

<sup>124</sup> Jay Hoffman, *My Word: Protect Kids with Standards for Coaches*, ORLANDO SENTINEL (Dec. 1, 2013), [http://articles.orlandosentinel.com/2013-12-01/news/os-ed-youth-safety-sports-myword-120113-20131129\\_1\\_hiring-practices-coaches-standards](http://articles.orlandosentinel.com/2013-12-01/news/os-ed-youth-safety-sports-myword-120113-20131129_1_hiring-practices-coaches-standards).

yet, there is very little scientific data on the culture of practice and therefore the evidence of a problem is anecdotal.

Balancing evidence, values, and resources “can seem particularly difficult when decision makers are asked to set policy concerning a clinical intervention where there is no consensus about the evidence.”<sup>125</sup> But it is difficult, if not impossible, to achieve a consensus when the evidence is lacking. The dearth of evidence on exertional heat illness was underscored in 2008, when the American College of Sports Medicine convened a roundtable aimed at achieving consensus regarding “the best guidance to return athletes and soldiers to activity” following an episode of exertional heat illness.<sup>126</sup> Due to the deficiencies in available evidence, evidence-based recommendations were not feasible.<sup>127</sup> Though the United States Army later issued recommendations for soldiers who suffered exertional heat illness, a subsequent report on the Roundtable concluded: “[t]he currently available science cannot support a high-level, evidence-based, consensus return-to-play document, and much work has yet to be accomplished. The panel strongly believes this document provides a strong foundation for future clinical and bench research in this vitally important area.”<sup>128</sup>

In the case of the sickle cell test, the lack of evidence for its value in promoting athletes’ health and welfare has prompted calls to implement universal precautions instead of screening.<sup>129</sup> Universal precautions refer to minimal conditions for all student-athletes that include reducing dehydration, monitoring for heat related illness, and monitoring for exercise-related illness<sup>130</sup>: ideally, such conditions could eliminate the need for knowledge of a student-athlete’s sickle cell status because no student-athlete would be put in a situation that would induce exercise-related collapse. The United States Army has instituted universal precautions to protect all soldiers from exposure to extreme training environments, and the Army’s heat illness

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<sup>125</sup> Atkins et al., *supra* note 94, at 102.

<sup>126</sup> Francis G. O’Connor et al., *American College of Sports Medicine Roundtable on Exertional Heat Stroke—Return to Duty/Return to Play: Conference Proceedings*, 9 CURRENT SPORTS MED. REP. 314, 319 (2010).

<sup>127</sup> *Id.* at 320.

<sup>128</sup> *Id.*

<sup>129</sup> See *Sickle Cell Trait and Athletics*, SICKLE CELL DISEASE ASS’N AM., <http://www.sicklecelldisease.org/index.cfm?page=sickle-cell-trait-athletics> (last visited Feb. 17, 2014).

<sup>130</sup> *Id.*

prevention programs are credited with leading to a marked drop in the rate of hospitalization for heat illness in soldiers.<sup>131</sup> However, exertional heat illness remains a common cause of hospitalization during intensive military training<sup>132</sup> and heat exposure still occasionally and tragically claims soldiers' lives.<sup>133</sup> Further research is required to discover the effects of military policies in this area.

Research is also required on specific sports that place student-athletes at greater risk. In an analysis of case reports, the American College of Sports Medicine found that exercise collapse associated with sickle cell trait in NCAA student-athletes occurred primarily in American football training.<sup>134</sup> Further, the typical scenario for an exercise collapse event involved characteristics such as, "day 1 of conditioning, newly arrived at altitude, just returning from a vacation, or a sudden increase in the intensity of a conditioning drill."<sup>135</sup> Experimental research could test the effect of eliminating the "gassers," "insanity workouts," and punishment drills mentioned previously from athletes' training.

There are signs that the NCAA is interested in encouraging research. In 2013, the organization appointed a chief medical officer for the first time;<sup>136</sup> in 2014, they put out a call for research proposals;<sup>137</sup> and at some point in the future, the NCAA's Concussion Task Force will analyze data from leagues that restrict full-contact football practices to twice a week.<sup>138</sup> To date, the NCAA's medical focus seems to be restricted to the issue of concussions—a response to multiple pressures, including suggestions from elected officials that Congress needs to investigate the NCAA due to its failure to protect student-athletes from the short- and long-term effects of sustaining

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<sup>131</sup> Robert Carter III et al., *Epidemiology of Hospitalizations and Deaths from Heat Illness in Soldiers*, 37 MED. SCI. SPORT EXERCISE 1338, 1338, 1340 (2005).

<sup>132</sup> Shilpa Hakre et al., *Predictors of Hospitalization in Male Marine Corps Recruits with Exertional Heat Illness*, 169 MIL. MED. 169, 169 (2004).

<sup>133</sup> Carter III et al., *supra* note 131, at 1341.

<sup>134</sup> Francis G. O'Connor et al., *ACSM and CHAMP Summit on Sickle Cell Trait: Mitigating Risks for Warfighters and Athletes*, 44 MED. SCI. SPORT EXERCISE 2045, 2047 (2012).

<sup>135</sup> *Id.* at 2048.

<sup>136</sup> Associated Press, *NCAA Hires First Chief Medical Officer*, AP BIG STORY (Oct. 8, 2012, 3:46 PM), <http://bigstory.ap.org/article/ncaa-hires-first-chief-medical-officer>.

<sup>137</sup> See *Call for Proposals: NCAA Innovations in Research and Practice Research Program*, NAT'L COLLEGIATE ATHLETIC ASS'N (Jan. 15, 2014), [www.ncaa.org/sites/default/files/Research%20Grant%20RFP\\_final.pdf](http://www.ncaa.org/sites/default/files/Research%20Grant%20RFP_final.pdf).

<sup>138</sup> Jon Solomon, *College Football and Concussions*, AL.COM (Mar. 3, 2014, 8:21 PM), [http://www.al.com/sports/index.ssf/2013/10/ncaa\\_and\\_concussions\\_a\\_talk\\_wi.html](http://www.al.com/sports/index.ssf/2013/10/ncaa_and_concussions_a_talk_wi.html).

multiple concussions.<sup>139</sup> But practices surrounding the NCAA blood test program for sickle cell trait warrant similar scrutiny. No doubt, the NCAA intends to prevent athlete deaths, but making college athletics safer requires evidence to inform policy.

CONCLUSION: NCAA OBLIGATIONS REGARDING THE TEST FOR  
SICKLE CELL TRAIT

The NCAA policy of mandatory sickle cell trait testing, as currently written and practiced, is not achieving the NCAA's objectives for the rule or the objectives of the Lloyd family. While other NCAA policies also have deficiencies,<sup>140</sup> the implications of the NCAA's sickle cell trait testing policy and the duties it foists on team physicians and other athletic staff warrant attention from all who are concerned about the health and well-being of student-athletes. Testing for sickle cell trait could be beneficial to student-athletes if they are aware, informed, and able to take action to prevent a sickle cell trait related condition, and the test could also be valuable to student-athletes in the future, when they may start a family, if they are aware of the result and its implications. But it is unclear that student-athletes are receiving such information or are given the tools to make use of it.

At present, the clinical practices surrounding the screening of student-athletes for sickle cell trait appear unacceptable in several ways: student-athletes undergoing the test know far too little about it because the NCAA and its member institutions are not always meeting the obligations of informed consent; and student-athletes who learn that they are carriers of sickle cell trait may not understand the implications of that result or may be anxious without a chance to ask questions, because the NCAA and its member institutions do not routinely offer counseling. Yet the test is not benign. It could have substantial negative outcomes on and off the field, including a false sense of security that leads athletes to overlook symptoms of health problems in training or playing situations, and racist consequences for individual student-athletes when they seek employment or insurance. Further, while the test is intended to be beneficial, the testing policy is

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<sup>139</sup> Brad Wolverton, *Bill in Congress Aims to Give NCAA Athletes Greater Protections*, CHRON. HIGHER EDUC. (Aug. 1, 2013), <http://chronicle.com/blogs/players/bill-in-congress-aims-to-give-ncaa-athletes-greater-protections/33327>.

<sup>140</sup> See, e.g., Matthew Mitten & Stephen F. Ross, *A Regulatory Solution to Better Promote the Educational Values and Economic Sustainability of Intercollegiate Athletics*, 92 OR. L. REV. 837 (2014).

not based on evidence and it is unclear whether student-athletes are benefitting from it.

The NCAA's mandated sickle cell trait test, one of the largest genetic screening programs in the country, is not merely one more rule in the NCAA handbook. Much more open and transparent discussion of the policy and the surrounding issues is needed in order for the testing to become legitimate, and for the testing policy to be implemented in a way that is fair to student-athletes.