

**UNIVERSITY OF PITTSBURGH STUDENT-ATHLETE PERCEPTIONS AND  
ETHICAL EVALUATION OF THE NCAA SICKLE CELL TRAIT  
SCREENING PROGRAM**

by

**Rosalie Ferrari**

BS, Niagara University, 2010

Submitted to the Graduate Faculty of  
the Graduate School of Public Health in partial fulfillment  
of the requirements for the degree of  
Master of Science

University of Pittsburgh

2014

UNIVERSITY OF PITTSBURGH  
GRADUATE SCHOOL OF PUBLIC HEALTH

This thesis was presented

by

**Rosalie Ferrari**

It was defended on

**June 13, 2014**

and approved by

**Thesis Advisor:**

Lisa S. Parker, Ph.D  
Associate Professor of Human Genetics  
Graduate School of Public Health  
University of Pittsburgh

**Committee Members:**

Robin E. Grubs, Ph.D, CGC  
Assistant Professor of Human Genetics  
Co-Director, Genetic Counseling Program  
Graduate School of Public Health  
University of Pittsburgh

Lakshmanan Krishnamurti, MD  
Professor of Pediatric Medicine, Department of Pediatric Medicine  
Program Director, Hemoglobinopathy Program  
Children's Hospital of Pittsburgh, University of Pittsburgh Medical Center

Jeremy Martinson, Ph.D  
Assistant Professor of Infectious Diseases and Microbiology  
Assistant Professor of Human Genetics  
Graduate School of Public Health  
University of Pittsburgh

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Rosalie Ferrari, M.S.

University of Pittsburgh, 2014

## ABSTRACT

**Background:** Individuals with sickle cell trait (SCT) typically do not suffer any health complications; however, adverse effects associated with SCT can occur, especially under extremely physical conditions. The National Collegiate Athletic Association (NCAA) mandates SCT testing for all incoming freshmen or transfer students-athletes. The NCAA SCT screening program has been controversial; organizations, such as the American Society of Hematology (ASH), instead recommend implementing universal interventions (e.g. monitored work-rest cycles) to protect all student-athletes, regardless of SCT status, from exercise-related injuries. Concerns about the program stems from its mandatory nature and how the program can impact student-athletes, with potential harm through stigmatization and discrimination.

Screening programs can often be effective and important public health interventions; however, when any program is mandatory in nature, their appropriateness should be investigated. Despite the direct impact of the program on them, student-athletes' perceptions of the program have not been thoroughly assessed. The purpose of this study was to elicit student-athletes' thoughts and feelings toward the NCAA program to learn about their perceptions and to evaluate the ethical concerns about the program.

**Methods:** Qualitative interviews were conducted with freshmen or transfer student-athletes at the University of Pittsburgh. The interviews were transcribed and coded using qualitative thematic analysis and analyzed.

**Results:** Sixteen student-athletes were interviewed. Participants were supportive of the NCAA policy, due to their perception of SCT as a significant health concern. Furthermore, participants were in favor of genetic counseling which provided understanding of screening rationale. Participants did not readily raise concerns the ASH had identified, such as stigmatization or discrimination; moreover, student-athletes were hesitant to endorse implementation of universal interventions, worrying such measures may hinder athletic performance.

**Conclusion:** This study reflects the attitudes of a small number of student-athletes at the University of Pittsburgh. Future studies are needed in order to evaluate the perceptions of student-athletes at other institutions. Despite the lack of student-athletes expressing ethical concerns, a non-mandatory “opt-in” screening program that includes genetic counseling, combined with the implementation of universal precautions, could achieve the health-promoting goals of the NCAA with regard to SCT and would be more ethically sound.

## TABLE OF CONTENTS

<b>PREFACE.....</b>	<b>X</b>
<b>1.0 INTRODUCTION.....</b>	<b>1</b>
<b>1.1 BACKGROUND AND SIGNIFICANCE.....</b>	<b>3</b>
<b>1.1.1 Sickle Cell Disease .....</b>	<b>3</b>
<b>1.1.2 Sickle Cell Trait .....</b>	<b>6</b>
<b>1.1.3 Sickle Cell Trait Testing Methodology .....</b>	<b>8</b>
<b>1.1.4 History of Sickle Cell Testing .....</b>	<b>10</b>
<b>1.1.5 Public Health and Ethical Considerations for Establishing a Screening Program .....</b>	<b>14</b>
<b>1.1.6 NCAA Sickle Cell Trait Student-Athlete Screening Program .....</b>	<b>19</b>
<b>1.1.7 Broader Implications of the NCAA Mandatory SCT Program .....</b>	<b>22</b>
<b>1.1.8 University of Pittsburgh SCT Screening Program.....</b>	<b>23</b>
<b>1.2 SPECIFIC AIMS .....</b>	<b>25</b>
<b>2.0 METHODS .....</b>	<b>26</b>
<b>2.1 INTERVIEW PROCESS .....</b>	<b>27</b>
<b>2.1.1 Participant Recruitment .....</b>	<b>27</b>
<b>2.1.2 Interview Process.....</b>	<b>27</b>
<b>2.2 DATA ANALYSIS.....</b>	<b>28</b>

2.2.1	Generating data codes .....	28
2.2.2	Identifying and categorizing themes .....	29
3.0	RESULTS .....	31
3.1	SPECIFIC AIM 1 .....	31
3.2	SPECIFIC AIM 2 .....	33
3.3	SPECIFIC AIM 3 .....	42
4.0	DISCUSSION .....	43
4.1	INTERVIEWS AND THEMES.....	43
4.2	IMPLICATIONS FOR SCREENING AND THE NCAA PROGRAM .....	44
4.2.1	Assessment of Mandatory SCT Screening from the Perspective of a Public Health Intervention.....	44
4.2.2	Assessment of Genetic Counseling in the SCT Screening Process .....	55
4.3	STUDY LIMITATIONS .....	58
4.4	FUTURE CONSIDERATIONS .....	59
5.0	CONCLUSION.....	61
	APPENDIX A : RESEARCH PROJECT APPROVAL AND RELEVANT FORMS .....	62
	APPENDIX B : OFFICIAL INSTITUTIONAL SCT DOCUMENTS .....	68
	BIBLIOGRAPHY .....	78

## **LIST OF TABLES**

Table 1 Complications of SCT .....	7
Table 2 Recommendations for SCT screening programs .....	19
Table 3 NCAA recommended precautions for student-athletes with SCT .....	20
Table 4 List of concepts coded for in interview transcripts .....	29



## **LIST OF FIGURES**

Figure 1 Comparison of normal red blood cells and sickled red blood cells.....	4
Figure 2 Stepwise measures involved in establishing a public health intervention.....	16
Figure 3 Participant Demographics .....	31
Figure 4 Participant Ethnicities.....	32
Figure 5 Participant Athletics Involvement .....	33

## **PREFACE**

I would like to express my thanks to the following individuals who have contributed to this research project. I have much gratitude for Dr. Lisa Parker, my thesis advisor; her willingness to support the research and constant guidance have been invaluable throughout this process. I would also like to thank the remaining members of my thesis committee, Dr. Robin Grubs, Dr. Lakshmanan Krishnamurti, and Dr. Jeremy Martinson, for their assistance and encouragement with this research project. Thank you to the faculty and staff of the Graduate School of Public Health, especially those in the Human Genetics Department, who have provided me an enriching educational environment these past two years. A special thanks is needed for the University of Pittsburgh Athletics Department, who have supported this research project and whose efforts were an integral part of this project's success. Finally, I would like to thank all the student-athletes who participated in this research study.

“Appreciation is a wonderful thing. It makes what is excellent in others belong to us as well.”

--Voltaire

## **1.0 INTRODUCTION**

Sickle cell trait (SCT) is a genetic condition present in approximately 1 in 12 African-Americans in the United States. Individuals with SCT have one copy of the functioning hemoglobin gene (Hb A) and one copy of the sickling hemoglobin gene (Hb S), and are said to be sickle cell carriers. Although SCT is typically considered a benign condition, research has shown that under intense, physical conditions various adverse health consequences can occur. Known as exertional sickling, the process is characterized by the accumulation of sickled red blood cells in the bloodstream, which can cause rapid muscle break down, rhabdomyolysis, and potentially sudden death. Previous cases involving the sudden death of young athletes with SCT have been reported. In the last three decades there have been 23 sudden deaths of athletes associated with SCT in middle school, high school, and college (Harris, 2012).

In 2010, the National Collegiate Athletic Association (NCAA) legislative council approved mandatory testing for SCT for all athletes participating at the Division I level; the mandatory screening program was extended to the Division II level in 2012 and to the Division III level in 2013 (Bonham, 2010; Thompson, 2011). The policy has been met with controversy. Organizations, such as the American Society of Hematology (ASH) and the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) among other physician and sickle cell advocate groups, oppose the ruling and recommend that universal interventions instead be implemented to protect all athletes from exercise-related injuries and

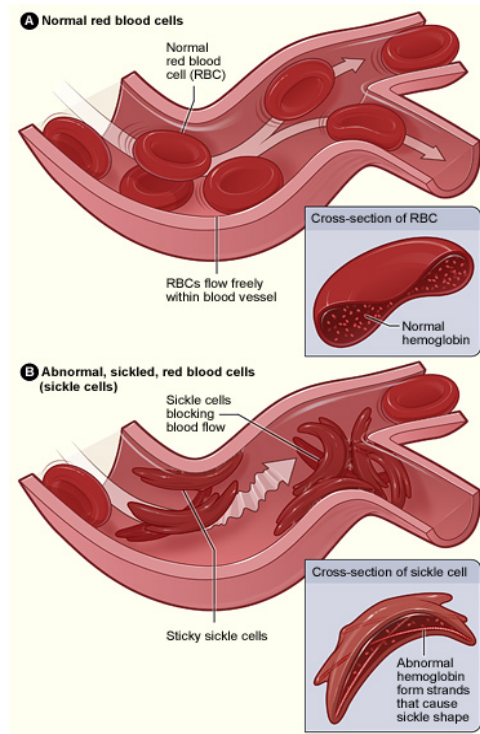
sudden death regardless of their SCT status (Nelson, 2013). Concerns about the NCAA SCT screening program focus in large part on the mandatory nature of the program. Mandatory testing is considered to undermine autonomy, circumvent informed consent, and threaten privacy. The NCAA program is especially problematic because it initially failed to mandate that individual education or genetic counseling occur prior to testing (Aloe, 2011). In order to address this latter concern, the University of Pittsburgh, with the help of the Hematology/Oncology department of Children's Hospital of Pittsburgh, developed, and in 2009 implemented, a process for mandatory SCT screening which includes genetic counseling for the incoming freshmen and transfer student-athletes who must be tested under the NCAA policy.

This project aimed to learn University of Pittsburgh student-athletes' perceptions of the NCAA SCT screening program and to evaluate both their perceptions and the program in light of ethical concerns raised in the literature with regard to the NCAA's mandatory screening policy. Sixteen semi-structured interviews were conducted to elicit student-athletes' thoughts and feelings about the SCT policy, the testing process, and the relevance of learning their SCT status. The interviews were voluntary, and verbal informed consent was obtained; all interviews were audio recorded, transcribed, and analyzed using qualitative thematic analysis. The ultimate goal of this project is to evaluate the ethical merit of the NCAA mandatory SCT screening program and to help ensure that the benefits of genetic counseling are afforded to student-athletes subjected to this screening program.

## 1.1 BACKGROUND AND SIGNIFICANCE

### 1.1.1 Sickle Cell Disease

Sickle cell disease is a genetic condition characterized by the presence of Hemoglobin S (Hb S) which produces red blood cells with a sickle-shape. The condition typically manifests during infancy or early childhood, and major phenotypic features include anemia, infarction, and asplenia (Nussbaum, 2007). Hemoglobin is composed of four heme chains, two  $\alpha$  chains and two  $\beta$  chains, and functions by carrying oxygen throughout the body. The  $\alpha$ -hemoglobin chains are encoded by *HBA* on chromosome 16 and the  $\beta$ -hemoglobin chains are encoded by *HBB* on chromosome 11. Sickle cell disease is associated with mutations in *HBB* and comprises a variety of symptomatic disorders, the most common being sickle cell anemia in which both copies of the *HBB* gene are mutated (Bender & Hobbs, 2012). The hallmark sickle cell shape of Hb S is caused by a single point mutation in *HBB* at amino acid six from glutamic acid to valine. The  $\beta$ -hemoglobin mutation Hb S has decreased solubility when deoxygenated compared to the standard adult hemoglobin, Hb A, and results in the production of stiff fibrous polymers which distort the red blood cell from its normally smooth, circular shape (Costanzo, 2011; Nussbaum 2007). The sickled cells can become affixed to each other and cause blockages in capillaries, illustrated in Figure 1.



*(National Heart, Lung, and Blood Institute, NIH, 2012)*

**Figure 1** Comparison of normal red blood cells and sickled red blood cells

Sickle cell disease presents in a variable, multisystem fashion; the sickled cells can cause vasoocclusive infarctions in many tissues contributing to pain crises, acute chest syndrome, cerebrovascular complications, as well as splenic and renal dysfunction (Ashley-Koch, 2000; Chelcun, 2014; Nussbaum, 2007). The most common reason for hospitalization for individuals with sickle cell disease is vasoocclusive pain crises (Thompson, 2011). Individuals with sickle cell disease also have an increased susceptibility to bacterial infections including pneumonia, meningitis, osteomyelitis, and sepsis due to functional asplenia; throughout their lives these infections increase the risk of death, while pulmonary and renal failure typically are attributed with deaths occurring in the fourth and fifth decades (Chelcun, 2014; Nussbaum, 2007).

Sickle cell disease results in chronic hemolytic anemia with varying severities of anemia, jaundice, cholelithiasis, and vasculopathy (Chelcun, 2014). The average red blood cell has a lifespan of approximately 120 days; a sickle red blood cell has a lifespan of approximately 20 days, which accounts for the anemia manifestation of the disease (Lawrence, 2010). Individuals with the highest rates of hemolysis are more likely to develop vasculopathy compared to individuals with lower rates of hemolysis, who are more prone to episodes of acute pain (Bender & Hobbs, 2012; Rees, 2010).

Sickle cell disease is the most common inherited blood disorder in the United States and affects millions of individuals worldwide. The disease affects an estimated 70,000 to 80,000 Americans, and the incidence is one in every 500 African Americans (Aloe, 2011; Thompson, 2011). Although the heterozygous state is present in approximately 8% of the African-American population, the disease can be seen in a number of different ethnicities including individuals of Mediterranean, Caribbean, Middle Eastern, and Indian descent (Ashley-Koch, 2000; Costanzo, 2011; Nussbaum, 2007). Sickle cell disease is an autosomal recessive disorder; thus the disease manifests when two abnormal hemoglobin genes are inherited. Although, the homozygous Hb S mutations account for the majority and most severe presentation of sickle cell disease cases, compound heterozygote cases of the disease can occur with Hb S and other  $\beta$ -hemoglobin chain mutations, commonly with hemoglobin C (Hb C), hemoglobin D (Hb D), and  $\beta$ -thalassemia (Ashley-Koch, 2000; Bender & Hobbs, 2012; Aloe, 2010). If both parents are carriers of a sickle cell disease mutation, each of their pregnancies would have a 25% chance of a child with sickle cell disease, a 50% chance of being unaffected and a carrier, and a 25% chance of being unaffected and not a carrier.

In the United States, universal screening programs for sickle cell disease are conducted at birth, which can facilitate early access to prophylaxis with penicillin, comprehensive care, and education about the detection of disease-related complications (Key, 2010; Rees, 2010). Management of sickle cell disease involves routine medical management (e.g., CBC count, pulmonary function tests, echocardiogram), prevention and treatment of pain crises, and management of specific problems. Continued monitoring of individuals with sickle cell disease is recommended to ensure preventive interventions, such as maintaining hydration and avoiding extreme conditions, are being utilized (Bender & Hobbs, 2012). Other therapies used or currently being investigated for the treatment of sickle cell disease include blood transfusions, stem cell transplantation, and administration of hydroxyurea which helps by increasing the synthesis of fetal hemoglobin and reducing the number of sickled cells, thus decreasing the frequency of pain crises (Charache, 1995; Rees, 2010).

### **1.1.2 Sickle Cell Trait**

Sickle cell trait affects approximately 3 million Americans and is characterized by the presence of both Hb S and Hb A (Bender & Hobbs, 2012; Costanzo, 2011; Lawrence, 2010). Also known as sickle cell carriers, individuals with SCT have a heterozygous genotype of Hb AS and have variable hemoglobin compositions of less than 50% Hb S, generally ranging between 20-45% (Aloe, 2010; Key, 2010; Tsaras, 2009). Not considered a form of sickle cell disease, SCT is considered an asymptomatic condition. SCT has no impact on life expectancy and actually may afford an evolutionary benefit since carriers have lower rates of mortality from malaria infection compared to noncarriers, Hb AA (Ashley-Koch, 2000; Goldsmith 2011). Worldwide, an estimated 300 million have SCT. The prevalence of SCT in newborns in the United States is



~1.3% (Goldsmith, 2011; Grant, 2011; Key, 2010). However, reports of specific adverse health effects associated with SCT have been described and are outlined in Table 1.

**Table 1** Complications of SCT

<u>Definite Associations</u>	<u>Probable Associations</u>	<u>Possible Associations</u>
<ul style="list-style-type: none"> <li>• Decreased malaria deaths</li> <li>• Exercise-related deaths</li> <li>• Exertional rhabdomyolysis</li> <li>• Hematuria and renal papillary necrosis</li> <li>• Hyposthenuria</li> <li>• Renal medullary carcinoma</li> <li>• Splenic infarctions</li> </ul>	<ul style="list-style-type: none"> <li>• Complicated hyphema</li> <li>• Pregnancy-related complications</li> <li>• Venous thromboembolic events</li> </ul>	<ul style="list-style-type: none"> <li>• Acute Chest Syndrome</li> <li>• Asymptomatic Bacteriuria</li> <li>• Retinopathy</li> </ul>

*(Adapted from Goldsmith, 2011; Key, 2010; Tsaras, 2009)*

The amount of sickling that occurs in individuals with SCT varies and is dependent on a number of factors, such as amount of Hb S present, the degree of hypoxia, and other factors contributory to exertional sickling events (Costanzo, 2011; Nussbaum, 2007). During intense exercise, SCT appears to be a risk factor for sudden death and/or rhabdomyolysis potentially due to exertional sickling. Conditions that appear to increase these risks include extreme physical activity or exertion at high altitude, especially when an individual is dehydrated or hyperthermic (Key, 2010; Lawrence, 2010). The most conclusive data of the association between SCT and sudden death comes from studies of the members of the US military. In 1987, an approximately 28-fold increased risk of exercise-related sudden death in US Army recruits with SCT, compared to those recruits without SCT, was reported in a cohort study of 2 million enlisted recruits (Kark, 1987).

Although exercise-related sudden deaths are generally rare, there is growing concern over the number of deaths among athletes with SCT. Within the last decade, out of 136 non-traumatic

sports deaths in high school and collegiate athletes, seven (5%) were considered to be due to exertional sickling (Thompson, 2011). Experts do not agree about the underlying pathophysiological means leading to sudden death in those with SCT, reports of sudden death for student-athletes with SCT have prompted the NCAA to enact mandated SCT screening for all student-athletes. This mandated screening program has been criticized, with those opposed to mandatory screening instead recommending effective prevention of exertional sickling events through universal interventions– i.e. interventions applied to all athletes regardless of their SCT status– including gradual buildup of performance levels, adequate hydration during exercise, ingestion of salt and potassium as required due to excessive sweating, and cessation of activity with onset of muscle cramping, fatigue, and shortness of breath (SACHDNC, 2010). Advocates of universal interventions disagree with the implementation of the SCT screening policy without clear supporting medical evidence that SCT is the underlying cause of sudden death. The primary concern is that student-athletes with SCT could be distinguished from other student-athletes based on the precautions required for SCT positive student-athletes after the NCAA determines their status (e.g., setting their own pace during practices) may lead to those individuals with SCT to suffer possible social and ethical harms, including loss of privacy, stigmatization, and discrimination (Thompson, 2013).

### **1.1.3 Sick Cell Trait Testing Methodology**

The laboratory detection for hemoglobinopathies, including SCT, has relied on three main observations (Benson, 2010):

1. The appearance of sickled red blood cells
2. Solubility of Hb S

### 3. Diagnostic hemoglobin profiles

Testing for SCT involves a blood draw. One method requires a sample of blood to be placed on a microscope slide and sealed with a cover slip, depleting the sample of oxygen and consequently causing Hb S to sickle and thus be visible using a microscope (Thompson, 2011). A second method is a solubility test (e.g. Sickledex) the test utilizes buffers, lysing agents, and reducing agents in combination with the sample of blood. Samples containing Hb S become cloudy in the solution, due to its insoluble nature in high molarity solutions (Costanzo, 2011; Hara, 1973). The limitation of both methods, however, is their inability to identify other sickle cell disease disorders, such as Hb C, since the methods are used solely to detect the presence of sickled cells (Aloe, 2010). Results can also be misleading since an individual with a high hemoglobin level may present with a false positive result, while an individual with a low hemoglobin level may have a false negative result. Nevertheless, the advent of these technologies allowed for an increase capability of high analytical throughput, and population-wide screening became feasible (Benson, 2010).

In order to confirm SCT status, as well as to differentiate the hemoglobin genotypes, samples can be run using electrophoresis or high-performance liquid chromatography (HPLC). Both methods can be effective to diagnose SCT. Hemoglobin variants, like Hb S, have particular charges based on the respective amino acid substitution (e.g. Hb A, has the negatively charged glutamic acid substitution compared to Hb S, which has the neutral valine amino acid) (Lawrence, 2010). The charge of the hemoglobin variant will dictate the movement during testing; however, if the hemoglobin variants have the same or similar charges (e.g. Hb S and Hb C), DNA analysis with gene sequencing may be necessary (Thompson, 2011). Therefore, there

is a possibility that individuals have incidental findings revealed (e.g. Hb C status) when verifying SCT status.

#### **1.1.4 History of Sickle Cell Testing**

Sickle cell disease was first described in the early 20<sup>th</sup> century when James B. Herrick discovered sickled cells in the blood of one of his interns, an anemic graduate student (Aloe, 2010; Rees, 2010). In 1949, Linus Pauling and his colleagues were the first to use electrophoresis to distinguish normal and abnormal hemoglobin and to demonstrate that sickle cell disease was a molecular disease (Benson, 2010; Costanzo, 2011; Rees, 2010). Advances in technology led to progressive understanding of sickle cell disease throughout the 1950s and 1960s. The public health significance of sickle cell disease was acknowledged in 1972 when the National Sickle Cell Anemia Control Act (Public Law 92-294) was passed by the U.S. Congress and became the first federal program aimed at screening for a specific genetic disease and carrier status (Ashley-Koch, 2000; Benson, 2010; Rutkow, 1974). The act pledged federal funding to expand sickle cell screening programs for individual states; in 1974, 10 states had implemented mandatory testing of African-Americans for sickle cell (Rutkow, 1974, Thompson, 2011). The Act met with criticism centered on its lack of sensitivity to issues of race, concerns about the accuracy and validity of the screening method, and furthermore, inadequate protection of individuals' rights. Some researchers denounced the programs and claimed that individuals found to have any abnormality were being discriminated against in addition to not receiving adequate counseling or education regarding the result (Lawrence, 2011; Rutkow, 1974).

Even though expansions of screening programs for sickle cell disease were controversial, governmental grant support allowed screening programs to be implemented. In 1975, the first

newborn screening (NBS) program for sickle cell disease began in New York, and by 2006 all 50 states had instituted universal mandatory testing for all newborns (Ashley-Koch, 2000; Thompson, 2011). The mortality and morbidity associated with sickle cell disease has decreased since NBS programs have been utilized. Early diagnosis, effective medical care, and education provided to family members has allowed individuals with sickle cell disease to live into adulthood and have an improved quality of life by managing sickle-cell related symptoms.

In addition to mandatory screening programs for sickle cell disease, screening programs for SCT were established in the U.S. military. In 1970 screening for SCT was recommended for incoming African-American military recruits due to concern over presumed complications associated with SCT, including the occurrence of sudden death (Binder, 1970). Once the Control Act passed in 1972, certain branches of the military, such as the U.S. Air Force, began screening all recruits for SCT and restricted individuals with SCT from flight duties (Brodine, 1977; Costanzo, 2011). However, by 1985 the U.S. Department of Defense removed all recommended restrictive measures for all sickle cell carriers in the military (Thompson, 2011). The U.S. Air Force adjusted its SCT screening practices slightly; all recruits are screened for SCT but those who test positive are offered the option to decline service (Grant, 2013; Mitchell, 2007). Other branches of the military have similar policies. Both the U.S. Marines and the U.S. Navy screen recruits for SCT. The Marines do not alter routine duties for those identified with SCT, while the Navy identifies those with SCT through a neck tag and a red belt during intense drills (Mitchell, 2007). Only the U.S. Army terminated its SCT screening program for recruits as of 1996 (Aloe, 2010; Grant, 2013; Thompson, 2011).

The NCAA mandated SCT screening program at the Division I level began in 2010. The screening program is expected to identify 2,000 Division I student-athletes with SCT and prevent

approximately 7 deaths of individuals with SCT over a decade (Tarini, 2012). The major apparent cause of sudden death associated with SCT and exercise is exertional heat illness (EHI) (Kark, 1994). A number of precautions have been recommended in an effort to avoid these potentially grave consequences. The U.S. Army mitigates the risk of EHI by employing universal preventive measures which include heat acclimatization, monitored work out and rest cycles, guidelines for nutrition and hydration, and staff preparedness for the early detection of possible symptoms (ASH Statement on Screening for Sickle Cell Trait and Athletic Participation, 2012). The NCAA also developed preventive measures for athletes with SCT; although the committee selected to do so, established rules only for football and not all sports programs. Both the U.S. Army and NCAA programs strive to reduce the effect of exercise-related sudden death, the main distinguishing feature between the two programs lies in the role of SCT testing: the NCAA mandates SCT testing while the U.S. Army program eliminated its SCT screening program while still seeking to protect recruits.

The controversy surrounding SCT screening programs has been evident since the 1970s. Programs have been scrutinized due to lack of sensitivity to race, poor design or implementation, and concerns about lack of informed consent, risks of discrimination, breaches of privacy, and potential stigmatization. From the inception, screening programs were focused on targeted screening of the African American population since SCT has a higher frequency among individuals of African descent, even though SCT is also commonly seen in individuals of Mediterranean, Caribbean, Middle Eastern, and Indian descent (Ashley-Koch, 2000; SACHDNC, 2010). Moreover, there is a tension in SCT screening programs between giving priority to prevention of adverse health consequences and providing adequate information about testing (Atkin, 1998). Although the NCAA is motivated to protect the health of student-athletes,

including those with SCT, the rationale behind its program may not be evident to the student-athletes targeted for the mandated SCT testing (Costanzo, 2011).

The U.S. military's initial SCT screening programs illustrate how the targeted nature of the policy resulted in discrimination and stigmatization, with the restriction of duties of those testing positive (e.g. barring them from flight duty or diving), which were typically the most prestigious, desirable, and remunerative duties, as well as being the less menial jobs in the military. African-American men who tested positive were frequently relegated to more menial or supportive roles, mirroring the type of employment discrimination and "ghettoizing" experienced in the broader American society of the time. In addition to concentrating on identifying individuals with a single condition rather than developing effective universal interventions for all individuals (Grant, 2013), the military's approach reflects an approach taken in numerous employment contexts where the attitude is to eliminate "risky or at-risk workers" rather than reducing the risk to them and their fellow employees (Draper, 1991). Finally, it is now recognized that current SCT screening programs should address issues relating to the privacy of individuals' health information (Thompson, 2011), which military programs that marked SCT positive recruits with tags and red belts fail to do. Individuals have a right to maintain the privacy of their health information, including their genetic information. This ethical right is the foundation for legal rights to privacy protection, for example, afforded by the Health Insurance Portability and Accountability Act (HIPAA). HIPAA protects the privacy of individuals, in regard to their identifiable health information, by setting national standards securing electronic health information, as well as regulating the sharing of non-electronic information (U.S. Department of Health & Human Services, 2013). Individuals' genetic information is included under HIPAA and remains private unless an individual authorizes a

release (Francis, 2010). It must be noted, however, that HIPAA only applies to specific covered entities that typically have access to individuals' health information in the course of their operation (e.g. clinics, hospitals, or insurance companies).

### **1.1.5 Public Health and Ethical Considerations for Establishing a Screening Program**

Public health interventions are designed and implemented to promote and protect the health of those composing the community; however, such interventions have the potential to infringe on individual's rights or interests for the sake of promoting the public or collective good. Criteria have been established in the public health ethics community to minimize the effect on individuals' rights and welfare of public health measures (Gostin, 2000). Like any mandatory public health policy, to be ethically justified, a mandatory SCT screening program should meet these criteria. As described by Gostin, public health interventions are more acceptable when criteria used to justify these programs demonstrate that:

1. The intervention addresses a *significant risk*
2. The intervention is *effective*
3. It may be implemented at *reasonable cost*
4. It *justly distributes* benefits, burdens, and costs

A stepwise approach in evaluating a public health intervention is discussed below and can be found in Figure 2.

A fundamental objective of public health is to reduce harm to the public's health by identifying potential risks. Therefore, conducting a thorough risk analysis is an imperative step to justify development and implementation of a public health intervention. Risk analysis should be done objectively with emphasis placed on scientific support. The process should involve a

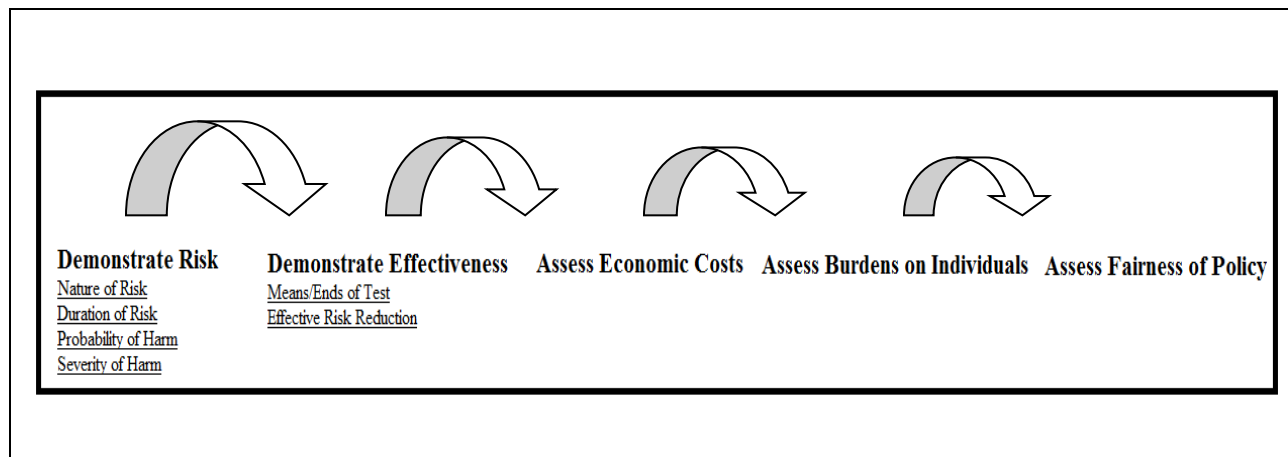


multidisciplinary effort in order to assure reasonable actions are undertaken without the emergence of conflicts such as motivation of actions due to irrational fears (Gostin, 2000). By evaluating four factors concerning any given risk, a more comprehensive risk assessment can be completed. These factors include determining the *nature of the risk* (various sources can present distinct risks), the *duration of the risk* (risks can be static or dynamic), the *probability of harm* (the chance the harm will occur), and the *severity of harm* (the effect and extent of the harm) (Gostin, 2000).

Public health interventions should also consider whether the means of their implementation actually are effective and produce the desired outcome (i.e. reduce the risk or amend the harm). It is important to note, the process of demonstrating an intervention's effectiveness should be a recurrent act and not merely a one-time occurrence (Gostin, 2000). Inherently tied to a public health intervention's effectiveness is the associated economic cost. Given limited resources, "cost-effective" interventions, i.e. those that provide considerable health benefit with the least cost are desirable. In addition to weighing the cost of an intervention, the effect an intervention has on individuals' rights (e.g. autonomy and privacy) should also be evaluated. Gostin describes certain questions that should be addressed in order to assess the personal burden an intervention may produce; these include "1- invasiveness: to what degree does the public health intervention intrude on the right in question? 2- frequency and scope: does the infringement of rights apply to one person, a group, or an entire population? 3- duration: how long a period is the person or group subject to the infringement?" (Gostin, 2000). When developing and implementing an intervention, it is preferable to develop one which is "least intrusive" while still having the potential to achieve the objective. This means that the intervention seeking social benefit or collective good should intrude as minimally as possible on

the other important values and rights. Therefore, to justify mandatory screening in the public health context, the above criteria and considerations should be addressed, because in virtue of being mandated, such programs have the potential to violate an individual's autonomy (Hodge, 2004).

Finally, the fairness of a public health intervention should be assessed. Assessment of fairness requires a combined analysis of the benefits, burdens, and costs to ensure their proper or fair allocation. Since interventions often target a population, it is important to consider who will bear the intervention's burdens and who will benefit; ideally, it is those who stand to benefit who bear the burdens of the intervention. Moreover, care must be taken to avoid either underinclusiveness or overinclusiveness (Gostin, 2000). In the public health context, overinclusiveness can be ineffective since people receive services they do not need or bear burdens unnecessarily, while being under-inclusive would fail to provide service to those who need them, or would fail to spread sufficiently the burdens of an intervention.



*A dapted from Gostin, 2000*

**Figure 2** Stepwise measures involved in establishing a public health intervention

It is important to note that the inclusion of informed consent, and the implied possibility to refuse as an integral part of voluntary consent, is not consistent with the mandatory nature of

screening programs. Often times, certain provisions are made for individuals who refuse to participate in mandatory programs, for example for deeply held religious beliefs. Such refusal is documented by signing a waiver indicating that they opt out. An ideal screening program should provide sufficient information to an individual, through education and counseling, so that the individual can decide whether to participate. In the case of mandatory genetic screening programs, though providing adequate education and effective genetic counseling cannot address the lack of informed consent entailed by the program's mandatory nature, can make those tested more aware of the risks involved so that they can take steps to mitigate them.

One of the most recognized mandatory screening programs is NBS. Today, nearly every individual born undergoes NBS, which began in the 1960s. NBS strives to identify individuals with genetic conditions in order to provide early interventions or treatment which can decrease the associated morbidity and mortality (Tarini, 2012). Each state's public health department is responsible for and has authority over its respective NBS programs; therefore conditions included on screening panels vary from state to state (Harwood, 2013). Initial criteria used to justify NBS and many of its' subsequent expansions were developed by Wilson and Jungner in 1968 (Arnold, 2013). These criteria include that:

1. The condition is an important health problem
2. An accepted treatment exists
3. Facilities for diagnosis and treatment are available
4. There is a recognizable latent or early symptomatic period
5. A suitable test or examination exists
6. The test is acceptable to the population
7. The natural history of the condition is adequately understood

8. There is policy agreement on whom to treat as patients
9. The cost of case-finding (including diagnosis and treatment) is balanced with regard to the possible expense of medical care.

Although NBS has, in general, benefitted from public acceptance, certain ethical issues have been raised concerning the programs, including matters pertaining to adequate parental consent/education, retaining and use of blood samples after screening, and communications of results (Tarini, 2012). Furthermore, public health policies are often driven by scientific advancement and related potential to protect health. Therefore, as technology has evolved additional conditions are being advocated for inclusion on NBS panels even when they do not meet the Wilson and Jungner criteria (Kraszewski, 2006), prompting criticism that NBS programs are susceptible to the “technological imperative” (Hofmann, 2002).

Points of analogy and dis-analogy can be drawn between NBS programs and SCT screening programs. Both seek to gather information about an individual in order to directly benefit that individual and both present ethical challenges. In 2009, the CDC hosted a meeting on SCT, discussed the public health implications and issued recommendations in order to organize a screening program, which can be found in Table 2.

**Table 2** Recommendations for SCT screening programs

<u>Programs should attempt to minimize discrimination, exclusion, and stigma based on SCT status</u>	<u>Policies should protect an individual's privacy and reduce redundant screening procedures</u>	<u>Research that monitors ethical, legal, and psychosocial results of screening programs</u>
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*(Adapted from Grant, 2011)*

### **1.1.6 NCAA Sickle Cell Trait Student-Athlete Screening Program**

The NCAA approved mandatory testing for all student-athletes for SCT at the Division I level on April 13<sup>th</sup>, 2010 (Bonham, 2010). The screening program has since been extended to include mandatory testing at the Division II and Division III levels. The impetus for the implementation of a genetic-based population-wide screening program for SCT was the 2006 death of Dale Lloyd II, a Rice University football player. The freshman student-athlete's death was caused by acute exertional rhabdomyolysis and was associated with his unknown SCT (Aloe, 2010; SACHDNC, 2010). Lloyd's family filed a lawsuit against both the NCAA and Rice University in order to raise awareness of the potential adverse health consequences associated with SCT for student-athletes (Costanzo, 2011). Over the last decade, a number of sudden deaths occurred in student-athletes at the college level who were unaware of their SCT status (Bonham, 2010). Although SCT screening is typically performed as part of NBS for sickle cell disease, the results are often not disclosed to parents or the newborns' clinicians. Thus, the NCAA now requires SCT testing, through a sickle cell solubility test, as part of the medical examination for all freshmen and transfer student-athletes unless the student-athlete chooses to decline testing by

providing documented results of a prior test or signing a written waiver release (NCAA Sports Medicine Handbook, 2013-2014). The adoption of a waiver was not designed to discourage student-athletes from participating in the screening program but rather to give student-athletes an opportunity to decline participation (Thompson, 2011). The document shields the given institution and the NCAA from liability for harms that could result due to athletic participation without determining SCT status (Appendix B.2). The NCAA also requires that student-athletes who sign a waiver be provided “additional education regarding the risks, impact, and precautions associated with sickle cell trait” beyond the general educational material provided to all student-athletes concerning SCT (NCAA Sports Medicine Handbook, 2013-2014).

The NCAA developed precautions for student-athletes with SCT as well as their trainers and institutions in order to prevent the adverse health outcomes associated with SCT (Table 3).

**Table 3** NCAA recommended precautions for student-athletes with SCT

Manage their individual pace
Engage in a measured preseason conditioning to be prepared for sports-specific performance testing and the rigors of competitive collegiate athletics
Build up gradually while training (e.g. paced progressions)
Use adequate rest and recovery between repetitions
Not be persuaded to perform all-out exertion of any kind beyond two to three minutes without a rest
Be excused from certain performance tests (e.g. serial sprints)
Stop activity immediately upon difficulty or experiencing symptoms such as muscle pain
Stay well hydrated at all times
Maintain proper asthma management
Refrain from extreme exercise during illnesses (e.g. experiencing a fever)
Access to supplemental oxygen at altitude if needed
Seek medical care when experiencing unusual distress

*(Adapted from NCAA Sports Medicine Handbook, 2013-2014)*

Although, the NCAA cites “growing support for the practical benefits of screening,” the NCAA SCT screening program has been criticized due in large part to the contentious evidence regarding the connection between sudden death occurrences and exertional sickling, and the mandatory nature of the program given the potential social, behavioral, and psychological implications for those with SCT (Bonham, 2010; Lawrence, 2010; NCAA Sports Medicine Handbook, 2013-2014; SACHDNC, 2010). Like other mandatory screening programs, the NCAA SCT screening program raises a number of ethical considerations surrounding the balancing of individuals’ rights, including the right of informed consent for healthcare interventions, and the health-related value of identifying those at risk. The NCAA program also must contend with the reality that more African American student-athletes will be identified with SCT than other racial groups. Due to the past history of racial issues associated with governmental and military SCT screening programs, there is a possibility the NCAA screening program will provoke similar problems with an exacerbation of stigma when racial identities intersect. Furthermore, the NCAA has yet to develop any policy seeking to protect student-athletes with SCT against discrimination (SACHDNC, 2010). For these reasons, the American Society of Hematology and the Sickle Cell Disease Association of America do not support the NCAA’s mandated SCT screening program and instead recommend implementing universal interventions for all athletes (SACHDNC, 2010). This approach would require the NCAA to consider whether altering the underlying culture of college athletics by instituting universal interventions would be more beneficial than population-wide testing followed by targeted interventions (Bonham, 2010).

The NCAA policy’s emphasis on education is heralded by both those opposed to and those supportive of the NCAA program. All endorse SCT awareness and ensuring that athletes,

coaches and trainers understand the condition and recognize the symptoms associated with heat related illness. Such understanding may facilitate prompt and appropriate health care for an individual if needed (NCAA Sports Medicine Handbook, 2013-2014; SACHDNC, 2010). However, the NCAA mandate itself initially lacked any recommendation that student-athletes receive education regarding SCT during the screening process (Thompson, 2011). Since extending the SCT screening program to other division levels, the NCAA has required that each student-athlete be provided with education regarding SCT through NCAA bylaw 17.1.6.4.1.1 (NCAA Sports Medicine Handbook, 2013-2014). However, the bylaw does not state what constitutes “education”; therefore each institution can have differing standards of SCT education.

#### **1.1.7 Broader Implications of the NCAA Mandatory SCT Program**

Among the broader implications of the NCAA program is concern that the emergence of one mandatory genetic screening program may generate additional, potentially mandatory, genetic screening programs by making them more socially acceptable and perhaps establishing their cost effectiveness and efficacy with regard to a desired health outcome. The most common non-traumatic cause of NCAA student-athletes deaths is inherited cardiac arrhythmia and cardiomyopathy syndrome (Bonham, 2010; Harmon, 2011). The high public profile of these sudden cardiac death cases has increased support for cardiovascular screening directed at student-athletes even at the high school level (Glover, 2007).

The NCAA mandates a pre-participation cardiovascular evaluation for all Division I, II, and III level student-athletes prior to their first athletic involvement (e.g. practice) which includes assessment of family history and physical examination (Aloe, 2010). Currently, the requirement is less invasive since it does not require an individual submit a sample of blood for



genetic testing as the SCT screening program does; however that may not always remain the case. Cardiovascular genetics is an evolving and complex discipline; as more genes are being identified that are associated with cardiovascular disorder most notably with susceptibility to hypertrophic cardiomyopathy (Thompson, 2011). Given the potential apparent attractiveness of perhaps instituting screening for these cardiovascular-related genetic mutations, it is important to scrutinize the justification proffered for the mandatory NCAA SCT screening program due to its potential precedent-setting role.

### **1.1.8 University of Pittsburgh SCT Screening Program**

The University of Pittsburgh, with the help of the Hematology/Oncology department of Children's Hospital of Pittsburgh, developed a SCT screening program for student-athletes that includes genetic counseling. SCT counseling and testing is organized through the athletic training coordinator and often held concomitantly with student-athlete physicals. If needed, additional testing dates are arranged during which student-athletes receive genetic counseling. The University of Pittsburgh has participated in the NCAA SCT screening program since 2009, and before it became mandatory, offered testing on a voluntary basis (Costanzo, 2011). Testing is billed through each student-athlete's personal insurance plan or in the absence of such insurance through the insurance provided by the athletics department. In 2009, initial education of athletic personal regarding SCT genetic testing was presented through a PowerPoint lecture by former University of Pittsburgh genetic counseling student, Amy Aloe. It included information concerning sickle cell disease, SCT, and the NCAA's recommendations regarding SCT. Annual genetic counseling of student-athletes includes succinct summaries of the screening rationale, types of possible test results, implications of results, symptoms of and precautions for SCT, and

information about the testing procedure, as well as information about the reproductive significance of SCT. Student-athletes are each provided with literature explaining the health related significance of SCT (See Appendix B.3). Each student-athlete participates in an informed consent process and signs a consent form prior to undergoing testing [See Appendix B.1]. If a student-athlete declines testing, a waiver must be signed releasing the university from liability for harm associated with the student-athlete not confirming his/her SCT status [See Appendix B.2]. The University of Pittsburgh athletic department is provided with each student-athlete's result for its records. If a student-athlete is found to be SCT positive, the student-athlete is informed. A more formal, private-individual genetic counseling session is arranged to discuss the implications for the student-athlete. In addition, review of SCT education is provided for the athletic trainers involved in the student-athlete's training and care.

The University of Pittsburgh has a distinctive SCT program insofar as genetic counseling is provided. Past research has shown that college student-athletes at other institutions as well as at the University of Pittsburgh may not have an adequate understanding of the mandated NCAA SCT screening program or SCT (Costanzo, 2011; Lawrence, 2010). The purpose of the research project reported here is to understand in greater detail student-athletes' thoughts, feelings, opinions, and concerns with regard to the SCT screening program. Student-athletes' responses suggest ways to improve not only the University of Pittsburgh SCT screening program but also the NCAA SCT screening program. This research is significant because, first, it informs both an ethical analysis of the NCAA SCT program. Second, it provides the basis for recommendations to improve for the University of Pittsburgh SCT program to make the process more responsive to the opinions and concerns of the population undergoing genetic testing, as well as ethical concerns reported in the literature. Because the NCAA mandatory SCT screening program is a

rare exception to the usual practice of voluntary genetic testing, this ethical analysis of the program and of the student-athletes' concerns is especially important.

## **1.2 SPECIFIC AIMS**

This study has three aims for which both qualitative empirical and ethical analysis was undertaken. The first aim of this study was to elicit student-athletes' thoughts and feelings toward the SCT screening program. The second aim of this study was to conduct a qualitative thematic analysis to assess student-athletes' attitudes toward the SCT screening program and to identify concerns they may have. The third aim of this study was to evaluate the ethical concerns expressed in the literature regarding the NCAA SCT screening program, both by comparing student-athlete responses to the ethical issues which have been reported and further by analyzing the possible ethical implications of such a screening program.

## **2.0 METHODS**

The study was reviewed and approved by the University of Pittsburgh Institutional Review Board on September 19<sup>th</sup> 2013 identified as IRB #PRO13070107 (See Appendix A.1). The study was categorized as an exempt study. Notification was given to the University of Pittsburgh Department of Athletics concerning the study. Since 2009, the Athletic Department has worked jointly with the Department of Hematology/Oncology at Children's Hospital of Pittsburgh in order to provide SCT testing services, including genetic counseling. The Graduate Assistant Athletic Training coordinator, who arranges student-athlete screening days, was informed of the study and assisted in organizing interviews.

A descriptive, guided interview approach was utilized. This approach ensures the same general areas of information are collected; the uniformity maintains a level of focus and consistency with the data while still providing freedom and adaptability during each interview (Turner, 2010). All interviews were audio recorded, transcribed, and coded with relevant themes and concepts during analysis. The data analysis method selected was thematic analysis. The use of thematic analysis allows for the identification, analysis and reporting of themes within the data.

## **2.1 INTERVIEW PROCESS**

All interviews were scheduled between September and November 2013.

### **2.1.1 Participant Recruitment**

Student-athletes were emailed a request to participate in a study interview (See Appendix A.2). Graduate assistant athletic trainers helped coordinate scheduling interviews with interested student-athletes. A total of 15 interviews with student-athletes, either freshmen or transfer students, during the 2013 fall semester, were sought with the goal of including student-athletes involved in a number of different sports in order to obtain various responses of student-athletes from different sports teams. The rationale behind the number of interviews sought was to allow for sufficient data from at least ten individuals in order to reach data saturation. Furthermore, responses at that point were believed to represent a general opinion in which the same themes are repeated.

### **2.1.2 Interview Process**

The study's aims and methods were explained to all participants and their verbal (oral) consent was obtained prior to beginning the interview (See Appendix A.3). Student-athlete participation was voluntary. Interviews were not expected to exceed 30 minutes. An interview guide was developed and included questions directed at eliciting student-athletes' thoughts about the SCT screening process and results (See Appendix A.4). All interviews were audio recorded. At the

end of each interview, student-athletes were offered a small token of appreciation (e.g. a sports-themed beverage and pack of gum) for their participation.

## **2.2 DATA ANALYSIS**

Thematic analysis is a commonly used qualitative analytic method. The goal of thematic analysis is to describe a data set in rich detail as themes which are consistent among research participants (Turner, 2010). Thematic analysis was chosen due to its flexible approach to analyze data qualitatively (Braun, 2006). Unlike grounded theory, which has as its goal the development of a theory which can serve as an explanation for the topic of interest, thematic analysis is used to identify patterns which can serve as a description surrounding a concern. Since the purpose of this research was to better understand student-athlete thoughts concerning the screening program, thematic analysis was appropriate. It was also chosen due its accessibility as a form of analysis, especially for novice qualitative researchers (Braun, 2006).

Analysis involved involves a series steps, done in sequential fashion in order to complete a thematic analysis of the responsive interviews (Rubin, 2011). The following is a narrative of the main steps performed during the thematic analysis of this research.

### **2.2.1 Generating data codes**

After interviews were transcribed verbatim, all transcripts were read to gain a general sense of how participants responded to the interview questions. Each interview was then assessed, in sequential order. It was believed interviews which were earlier in the study process may be more

rigid, and as more interviews were conducted there would be a level of comfort obtained. Thus, if responses emerging in beginning interviews were consistent with responses emerging in later interviews, then it could be concluded a specific concept, or code, was present. Coding attempts to understand what participants' meanings were with a particular statement and is a way to mark such incidents in the text (Rubin, 2011). Coding allows for participants' responses to be compared in a relatively easy fashion by summarizing the overall content and connecting the data to a concept (Rubin, 2011). Each interview was read carefully and when a response implied a particular code(s), it was noted in the text. A list of codes for this study can be found in Table 4, below.

**Table 4** List of themes coded for in interview transcripts

• <b>Attitudes toward University of Pittsburgh screening program</b>
• <b>Attitudes toward NCAA screening program</b>
• <b>Attitudes toward mandatory nature of testing</b>
• <b>Awareness of testing and its purpose</b>
• <b>Awareness of potential impact of SCT status</b>
• <b>Confidence that trainer* intentions are in the best interest of the student-athlete (*trainer defined as any coach or support training staff (e.g. strength coach))</b>
• <b>Importance accorded with sports participation</b>
• <b>Informed consent to testing</b>
• <b>Perceived risk associated with screening program</b>
• <b>Reasons for involvement in sports</b>
• <b>Understanding of SCT status</b>

### 2.2.2 Identifying and categorizing themes

After transcripts were coded completely, the process of identifying and categorizing themes was conducted. A theme describes an important aspect about the data in relation to the broader research question(s) and furthermore represents a pattern from the responses (Braun, 2006). Interviews were compiled into a master file, containing all transcripts with codes. Every code,

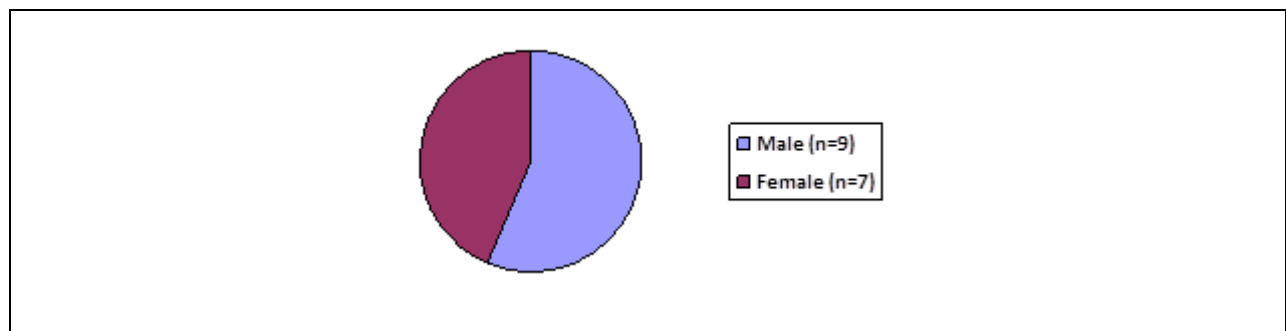
previously described above, acted as a category for which themes were explored. Participant responses for a given category were compared and summarized; themes were generated based on the integration of the descriptions provided by the participants. A list of quotes, demonstrating the soundness of a given theme, was also noted during the analysis.



### 3.0 RESULTS

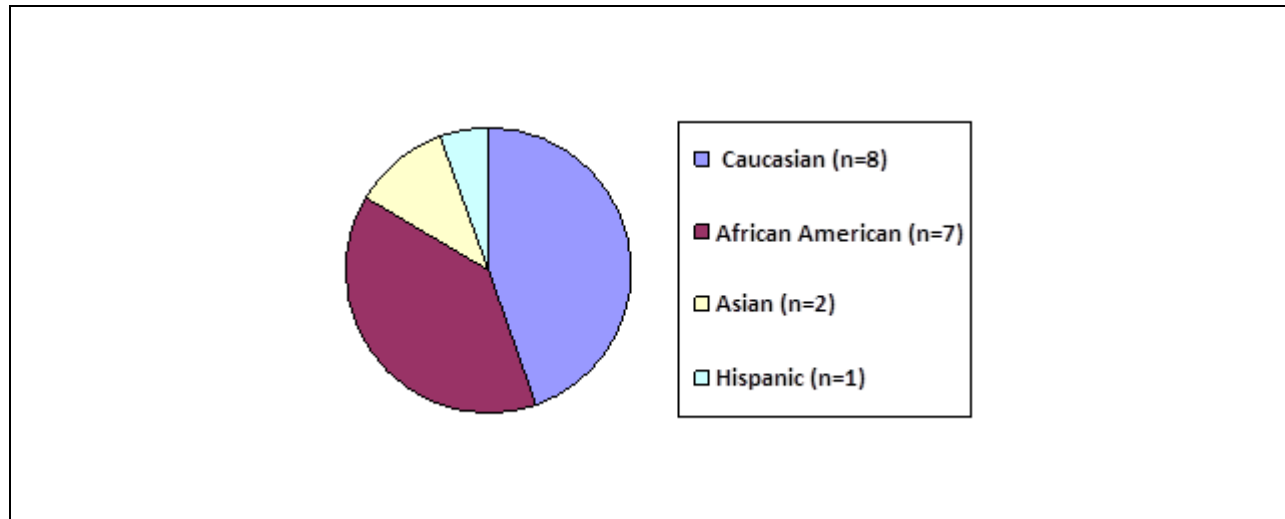
#### 3.1 SPECIFIC AIM 1

Sixteen interviews were conducted with student-athletes from the University of Pittsburgh. Slightly more males participated in the study than females; a total of nine males and seven females were participants (see Figure 3). Furthermore, three student-athletes revealed they were positive for SCT during the interviews.



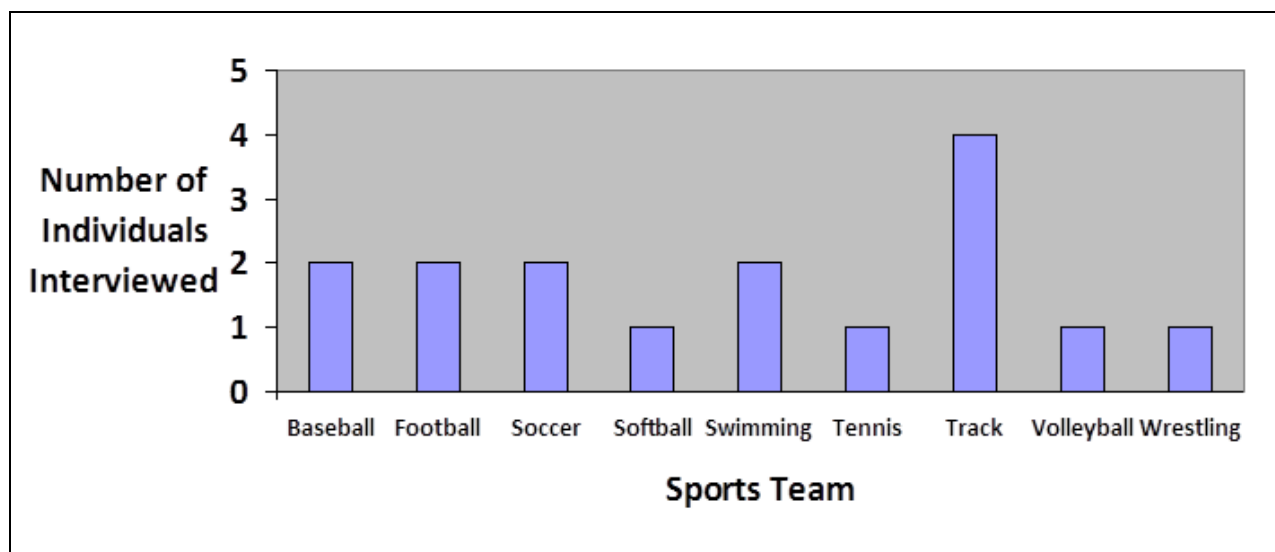
**Figure 3** Participant Demographics

Participant's ethnicities were also obtained, eight individuals identified themselves as Caucasian, seven individuals identified themselves as African American, two individuals identified themselves as Asian, and one individual identified as Hispanic (see Figure 4).



**Figure 4** Participant Ethnicities

Interview days and locations were coordinated with each student-athlete as well as their respective athletic trainer, in order to avoid potential conflicts with academic or athletic schedules. Student-athletes interviewed were members of various sports teams including baseball, football, soccer, softball, swimming, tennis, track, volleyball, and wrestling (see Figure 5). Interview times ranged from 10 – 30 minutes. During the course of interviews it was discovered that not every student-athlete received genetic counseling as part of their SCT screening participation, although most received SCT literature regarding why student-athletes are being tested. Three student-athletes (19%) did not receive formal genetic counseling; moreover one of those student-athletes did not receive SCT literature.



**Figure 5** Participant Athletic Involvement

### 3.2 SPECIFIC AIM 2

Themes emerging from the interviews were organized based on the coded transcripts, including: attitudes toward the University of Pittsburgh screening program, attitudes toward the NCAA screening program, attitudes toward the mandatory nature of testing, awareness of testing and its purpose, awareness of potential impact of SCT status, and perceived risks associated with the screening program. Responses to most of the questions were similar across interviews. Further analysis was completed to discover themes raised by student-athletes who received genetic counseling compared to those who did not receive counseling and also to evaluate the themes presented by student-athletes participants with SCT. Select quotes from interviews are provided to help explicate each theme. It is important to note, reference to a *majority* of student-athlete responses, is intended to represent a general consensus from the thematic analysis and does not suggest any level of statistical significance.

### Attitudes toward the University of Pittsburgh screening program

The majority of student-athlete participants were appreciative of the transparency of the University of Pittsburgh SCT screening program, which provided genetic counseling as part of the process. Student-athletes were supportive of the counseling which included education about sickle cell and explanation of the rationale for screening.

Student-athletes commented on how the counseling provided a comfortable level of understanding, stating: “...*the counseling really helped me understand what was going on, why we were doing this...*” They offered other comments like “...*they handed us a sheet explaining everything on the sheet so we didn’t have to sit there and read for twenty minutes...it was pretty informative and [re]assuring that what’s going on.*”

Student-athletes also appreciated the advantages of the coordinated nature of the University of Pittsburgh program that removed responsibility from the student-athlete to arrange for testing and concomitantly ensured compliance. Student-athletes commented on the convenience of the process, for example, stating “...*someone was explaining to me why I was getting it done and...I didn’t have to worry about doing it on my own, it was provided for me, which was nice. And the fact that I actually knew what was happening was nice too.*” Student-athletes emphasized the benefits of keeping the process organized and uniform, rather than relying on individuals to seek the testing independently:

*...if you just tell some athletes to go get their blood tested, some of them will forget or just won’t do it and with making the test part of your physical, that you have to get done in order to participate, I feel like it puts less responsibility on the athletes to remember to do it and everyone knows they did it cause they’re with them.*

A few student-athletes expressed concern over not being formally informed of a result (i.e., a negative result). They were also concerned over screening programs where education was not provided. Student-athletes wanted to have awareness of what was being asked of them. As one participant commented, *“I would definitely want to know why my blood’s getting drawn and I would be concerned if somebody just told me to go get my blood drawn and no reason why. I would ask why? For what?”*

### **Attitudes toward NCAA screening program**

The majority of student-athlete participants were supportive of the NCAA program and of continuing screenings in the future for all student-athletes. One student-athlete made comments of support because of the realization that SCT is not exclusive to a specific racial group:

*...I think we should...test everybody, yeah we know it’s more dominant in African Americans but there are, in every genetic disorder, there’s also the select minorities that can also be affected...it’s good to branch out [and test every student-athlete for SCT]...*

Many student-athletes believed the screening program was the most effective way to establish individuals’ SCT status and commented on the importance of screening in order to avoid overlooking an individual who potentially could be positive for SCT:

*...we all get tested, so then we know and our coaches know, our trainers know; so I think that’s a good way of protecting us.”* And one student-athlete added, *“...genetically testing everybody is just more direct; you have it or you don’t and you go from there rather than taking the steps to caution yourself...”*

Some student-athletes commented that the NCAA is responsible for ensuring the detection of SCT for this population. One remarked on the role of the institution:

*If an athlete had that [SCT], putting themselves in danger, working hard and exercising, you know it's kind of on the college if you know one of their athletes has a health problem that could have been avoided.*

Student-athletes also acknowledged the importance of determining SCT status, for example:

*I think that at this level an athlete should know if they have that issue or not, and I think it's right of the NCAA, yes it's a lot of students, it's a big process to go through for probably just a couple people, but at the same time [for] those couple people, I think that that's worth it.*

Student-athlete participants were not in favor of universal interventions due their perception that they could hinder athletic performance. Most student-athletes supported the benefit of identifying those with SCT, so those student-athletes could have specialized routines.

Student-athletes commented, for example, that “...if you take more breaks, it may affect someone's performance or something, like for those who really don't have it [SCT positive]. But if you do have it then it can be more directed toward that athlete.” Student-athletes saw a distinct value afforded by detection through a screening program, stating, “I think everyone should just get tested... We should be able to push through work outs if we have the physical capacity to do so.” Another participant, commented, “...knowing that you have sickle cell trait or not, I think, would be better; you would know for sure if you should build up slowly.”

### **Attitudes toward mandatory nature of testing**

The majority of student-athletes commented that SCT is a sufficient reason as a health concern to mandate testing and discussed the benefit of learning one's SCT status. One student-athlete stated, *"And with testing, I do think it's a good thing to test for certain things that could affect how you are as a player and as a person, since certain conditions can [impact your health]."* Student-athletes commented on their perception of the significance of SCT, for example, saying, *"...a big reason why everyone should be tested, because it's better to know what everyone has, especially something as serious as sickle cell trait that could affect a student-athlete that strongly."* And another student-athlete stated, *"...knowing the line between this isn't good for me and oh, I'm just working hard; I think that's important, especially if you did test positive, being aware of that would probably be important."*

Many student-athletes seemed to recognize that they had the right to sign a waiver to decline testing, although none chose that option. Some comments acknowledged directly the option to decline, for example: *"...it was optional; it is good to check...I had all the tests, so might as well [complete all tests offered by the institution prior to participation]..."*

### **Awareness of testing and its purpose**

A majority of student-athletes were aware SCT testing was a part of the medical/physical examination prior to sports participation, but did not express substantial understanding of SCT.

One student-athlete commented:

*...we showed up for our physicals and they just told us what tests we would be doing.*

Another said:

*When we had to get our physical done, they told us all the tests that would be done.*

Still another said:

*...we had a physical coming up and they were going to do sickle cell.*

Participants' comments reflected a lack of concern regarding the SCT testing; for example, one student-athlete stated, *"I didn't really think about it too much."*

Some student-athletes expressed concern regarding the blood draw itself, but did not express concern about the testing objective (i.e. determining SCT status), for example, saying:

*...I had practice and I knew I was having blood taken, but they didn't take much blood at all, so I wasn't worried much once I saw it. I was just worried I would be drained.*

Another admitted:

*I've always been squeamish around needles; that was my biggest concern...*

### **Awareness of potential impact of SCT status**

Student-athletes generally thought testing positive for SCT was not likely, in part because their health or other family members had not been affected thus far; however, some expressed the realization that they might test positive. Student-athlete made comments like,

*...I'm pretty sure I would know if I had sickle cell by now, so I'm not too worried about it.*

*Or this:*

*...I'm sure if I had had sickle cell then I probably would have noticed some fatigue or something like that.*

Some student-athletes stated their sense of reassurance based on apparent statuses of family members, for example, stating, *"...I wasn't concerned; my brothers didn't have it. I haven't heard of it running in my family; since it's genetic I would have known."* However, some



student-athletes recognized the possibility and anxiety associated with testing positive, saying, for example: “...*there’s always that paranoia, oh my gosh, what if I actually have it?*”

Although student-athletes appeared to have a lack of understanding of SCT, they were aware of, and commented on, the influence a positive SCT result would have in their lives. SCT would be an additional health condition to contend with or be cautious about. They expressed concern that SCT would alter athleticism and potentially athletic ability. SCT could make training more difficult especially when an individual already may another health issue to cope with (e.g. asthma). Furthermore, student-athletes’ commented that the onus is on the individual to advocate for him/herself, if SCT positive. One student-athlete commented on the challenges of keeping people aware of one’s positive SCT status:

*...trying to remind my coaches, my strength coaches, my athletic trainer, sometime they don’t remember because they’re taking care of so many people and so it really would have to be on me to make sure that I was properly being taken care of.*

Another student-athlete stated, “*I would talk to coaches and staff and make sure that they were aware that I had this condition and that it needed to be closely monitored.*”

Student-athletes understood the basic reproductive implications of SCT (e.g., the possibility of passing SCT to children: *...it would have affected my kids possibly, cause I could pass on the trait to them.*” Another stated: “*I’d want to see if my partner had it [SCT] because you gotta look out for your children.*” Although student-athletes’ lacked concern for other family members in relation to their test result, some did acknowledge the familial implications that exist, for example, commenting, “*If I did test positive, I would probably tell my family that they might need to be tested because it runs in the family. I would definitely inform family*

members.” Another acknowledged, *“It could affect my family, it’s passed down genetically so maybe someone else has it and they don’t know...”*

### **Perceived risks associated with the screening program**

Student-athlete participants did not raise concerns regarding discrimination based on SCT status or recognize any potential for future or long-term discrimination. One student-athlete stated, *“...I wasn’t worried that I would be kicked off the team or anything like that.”* Most had no concerns regarding negative consequences related to SCT screening, making statements like *“...why not check everyone?”* However, one student-athlete did comment on how a positive SCT result may lead to adverse implications for a student-athlete, commenting, *“...if someone did test positive, [they] might not want that on the record because athletes may be treated differently, or their scholarship might be reduced...”*

### **Responses of those who did not receive genetic counseling**

Three participants reported that they did not receive genetic counseling. They expressed uncertainty concerning the testing process, and a lack of understanding regarding the rationale for screening. Moreover, they unaware of the waiver option and viewed the screening program as compulsory. They made comments regarding the process such as, *“I was wondering how they would do it or what would be involved in the testing.”* And, *“...if it’s required by all student-athletes, then I guess it’s a big deal.”* They also stated their apparent lack of choice to participate in testing, saying, *“It was just something that I had to do, didn’t think much of it,”* and, *“...I’m not a big fan of blood work but I guess I had no choice.”*

Participants who reported not receiving counseling also had a lack of understanding of the significance of SCT and conveyed a desire for more education, as well as the institution of a structure to ensure student-athletes are informed. They commented, “...*I want to know why it [SCT testing] is so important.*” They also wanted to know, “...*just what it [SCT] is or how it could affect you, if you had it, cause I didn’t know much about sickle cell.*”

### **Responses of those who are SCT positive**

Participants who were SCT positive knew their SCT status prior to the NCAA screening. They viewed the testing as confirmatory, stating, “...*I knew I had the sickle cell trait, so I wanted to see if I actually did have it.*” These participants with SCT were aware that they must be cautious of their health and stated, for example: “...*if you have any, feel any type of lightheadedness or something like that, you should not just try to fight it out and keep practicing. Just stop and get some help.*” Those who were SCT positive also had an understanding of the reproductive consequences of SCT, commenting, “...*if you get married and your wife has sickle cell trait too, you could have a kid that will probably have disease. If your wife doesn’t have sickle cell trait or disease, your kid will probably have the trait.*”

Finally, student-athletes with SCT did express initial concern that trainers would treat an individual differently based on their SCT status, for example, commenting, “*I kind of thought that the trainers [would]...try to keep me from doing certain stuff.*” Another observed: “*I thought they would baby me, like on the field or something, with the sickle cell trait...but it hasn’t been like that.*”

### **3.3 SPECIFIC AIM 3**

Although student-athlete responses were supportive of the NCAA program, ethical analysis suggests that the NCAA SCT screening program has particular ethical shortcomings which the NCAA should address. Because it is possible that a non-mandatory “opt-in” program, combined additionally with the implementation of universal precautions, could achieve the health-promoting goals of the NCAA with regard to SCT, without incurring the ethical liabilities that are presented by the mandatory program, for the good of the student-athlete population and overall benefit for the collegiate environment. A more thorough assessment can be found in the Discussion.

## **4.0 DISCUSSION**

### **4.1 INTERVIEWS AND THEMES**

Both aims of the research study were achieved and, as a whole, provide additional insight into the controversial nature of mandatory SCT screening. The objective of conducting at least fifteen interviews was exceeded, with sixteen student-athlete interviews completed. Student-athletes offered sufficiently similar responses as to represent a general consensus, among those interviewed, regarding most points. The interview process revealed that not every student-athlete at the University of Pittsburgh received genetic counseling or educational literature prior to undergoing the SCT testing. Analysis revealed that those without genetic counseling had less understanding regarding SCT, the screening process, and the rationale for screening.

Student-athlete' perceptions were effectively assessed through thematic analysis based on their interview responses. Certain themes, such as student-athlete support of the NCAA SCT screening program and their lack of understanding of SCT are supported by past research and were shared by the participants. Other themes, such as student-athletes not being in favor of universal implementations, have not been reported elsewhere in the literature and might be explored further in future research.

## **4.2 IMPLICATIONS FOR SCT SCREENING AND THE NCAA PROGRAM**

### **4.2.1 Assessment of Mandatory SCT Screening from the Perspective of a Public Health Intervention**

Before analyzing the justifiability of the mandatory nature of the NCAA SCT screening program, it is important to clarify what and who is being mandated. Collegiate institutions are mandated to *confirm* SCT status of their student-athletes; and student-athletes' mandatory medical examinations prior to participation *include* sickle cell solubility testing. Student-athletes can “opt out” and decline testing if they sign a waiver and assume the health-related risks associated with being at risk of having SCT. Nevertheless, student-athletes are embedded in a doubly or triply hierarchical structure. They are students within an educational institution and thus subject to the authority of professors and administrators; they are athletes and subject to the authority of their coaches and trainers; and they may be beholden to the athletic department and their ability to continue to be eligible in order to receive a college education. The structural position of student-athletes within these hierarchies suggests that there is good reason to question whether they feel empowered to refuse that which is offered to them as being for their own good, the good of their teammates, or the good of the school and its athletic program. Therefore, their ability to give a truly informed consent or refusal may be undermined. This is true even in the context that includes genetic counseling and an informed consent process for testing as is provided at the University of Pittsburgh.

Mandatory screening programs can be effective as public health interventions; however, any mandatory intervention limits certain rights and liberties of an individual. While a public health intervention like mandatory quarantine during an epidemic limits individuals' freedom of

movement, and mandating participation in screening limits individuals' rights to determine control of their bodies (e.g., whether or not to have blood drawn) and their right to refuse consent to such intervention. Mandating an intervention limits an individual's freedom or right to make an autonomous choice. Autonomy refers to the capacity of competent individuals to be self-determining, i.e., to determine what they do and what they allow to happen to them. The right to exercise autonomy refers to this the right of self-governance. The doctrine of informed consent—a key feature of ethical healthcare and research—seeks to respect this right of individuals to be self-determining. However, truly mandatory interventions, like a fully mandatory screening program, do not permit an informed consent process. Despite this infringement of autonomy, these programs may be justified by different ethical principles that are deemed to outweigh respect for autonomy in certain limited contexts.

In some public health interventions, for example, concern to avoid serious risk to others' health may outweigh an individual's right to autonomy or freedom of action. The harm principle maintains that individuals have freedom of action unless they place others at risk of harm (Gostin, 2000). By virtue of the harm principle, substantial risk to others may be invoked to override and to justify an individual's autonomous choice that presents that risk. Although the harm principle may be used to justify situations such as mandatory quarantine to prevent the spread of an infectious disease or mandatory vaccination to promote herd immunity, it cannot be invoked to justify the mandatory nature of the NCAA SCT screening program. SCT testing is performed for the potential health benefit of the person tested, not for the sake of other individuals or public's health. Because it is not the risk to other individuals, but a risk to the individual who is to be tested that is at the issue with the NCAA program, the harm principle cannot be used to justify the NCAA's making its screening program mandatory. Indeed, because

individual student-athletes are allowed to refuse testing, sign a waiver, and thereby assume the potential health risk associated with SCT, the NCAA's program is not truly or fully mandatory at the level of the individual student-athlete. Nevertheless, because of the strength of the presumption that all athletes should be, and will be, tested, it effectively functions as a quasi-mandatory program.

The justification for the NCAA's SCT screening program resides in the goal of protecting each individual athlete from the risk to self that is posed by SCT. A paternalistic intervention is one that interferes with a person's freedom of action or autonomous choice with the intent of benefitting that person (Gostin, 2000). The NCAA therefore acts paternalistically in overriding the student-athletes' autonomous choice to be tested or not for their own sake. The NCAA attempts to mitigate the risks of SCT by interfering with individual student-athletes' self-regarding behaviors and mandating that they be tested. Although individuals do have the option to opt out of the NCAA program, this option may not present a true choice of which student-athletes may voluntarily avail themselves. The choice is presented by their coach, trainer, or other authority figure within their university and/or athletic department. Student-athletes are not only in the habit of following the direction of their coaches, trainers, and teachers, but also may be completely dependent for their current education and future athletic career on pleasing their coaches and trainers, complying with their direction, being given sufficient playing time to demonstrate their skill, and so on. These are not the conditions under which a student-athlete may be comfortable issuing an informed refusal of a recommended intervention that is supposed to be in his/her own interest.

This situation is a primary reason that the mandatory nature of the NCAA SCT screening program is called into ethical question, particularly given the risks—and historical record—of



stigma and discrimination associated with SCT. Therefore, it is appropriate to consider whether it is necessary and justifiable to mandate SCT screening. Criteria developed by Gostin to evaluate the justifiability of mandatory interventions seeking the public's health, may be used to evaluate the justifiability of this mandatory intervention that has the paternalistic goal of protecting student-athletes with SCT.

To justify being mandatory, a public health intervention should demonstrate that it addresses a significant risk, is an effective intervention, presents a reasonable cost, and justly distributes benefits, burdens, and costs (Gostin, 2000). Moreover, any public health intervention that overrides individuals' autonomous choice or infringes their liberty must do so as minimally as possible; that is, it must be the "least restrictive" alternative available (Gostin, 2000). Similarly, a paternalistic intervention must meet similar conditions in order to be justified. These criteria then can be applied to mandatory SCT screening for student-athletes.

To be justified, an intervention should be demonstrated to be an effective intervention with a reasonable cost (Gostin, 2000). The NCAA screening program is estimated to prevent seven student-athlete deaths over a decade, and screening can be accomplished through a sickle cell solubility test which is considered relatively inexpensive (Harris, 2012; Tarini, 2012). The targeted population for this screening program is, of course, the student-athletes; however, in order to comply with the NCAA mandate, the cost of screening is placed on the institutions at the Division I, II and III levels. This financial cost can be substantial. At the University of Pittsburgh each student-athletes receives Rapid Hemoglobin S, a test used to effectively quantify Hb S but is less expensive than hemoglobin electrophoresis (Edwards, 2009). Since screening is coordinated, most student-athletes have their testing billed through the athletic department. Whether the costs are justified requires a normative judgment. Whether they are distributed

fairly is a second question. Both must be considered to justify mandating SCT screening and implementing the program as the NCAA does. Consideration of these value-laden cost-focused questions is, however, beyond the scope of this project. The question of the significance of the risk to be mitigated by SCT screening can be addressed to some degree, and indeed was an issue raised by student-athletes in interviews as part of this project.

The SCT has been shown to be associated with a significant risk of sudden death in exercise-related conditions (Tsaras, 2009; Harris, 2012). The NCAA views screening as necessary and as a way to provide targeted precautions for individual student-athletes (NCAA Sports Medicine Handbook, 2013-2014). Student-athletes interviewed stated their belief that SCT was a significant risk that should be assessed in the athletic community. Student-athletes also agreed with the NCAA and supported the mandatory SCT screening program based on the importance of identifying those with SCT. Some of the student-athletes went further, suggesting it was the NCAA's responsibility to ensure detection of SCT. In contrast, the ASH and other organizations do not believe that the requisite connection between SCT and a significant health risk has been adequately established to warrant mandatory screening; they instead believe that more research is needed to understand the etiology of the increased risk of sudden death for individuals with SCT (Lawrence, 2010; O'Connor, 2012). Although substantiating the risk is an essential component of establishing interventions, the effectiveness of the intervention should also concomitantly be evaluated.

Student-athletes agreed the risk of student-athlete deaths and of SCT as a sufficient potential health concern to warrant an intervention. Sick cell solubility testing, however, can be unreliable and misleading. The testing relies on the relative insolubility of deoxygenated hemoglobin S, which would occur if an individual had SCT or any other form of SCD

(O'Connor, 2012). Moreover, solubility testing can provide false results and cannot accurately identify other common hemoglobin traits (e.g. Hb C), issues that contribute to its questionable status as a requirement (Aloe, 2011). Student-athletes could have a false sense of security following a negative solubility test, as they may still be at risk for adverse health complications.

The NCAA does require confirmatory testing of those with positive screening results through diagnostic testing such as hemoglobin electrophoresis or high performance liquid chromatography (HPLC) (Tarini, 2012; NCAA Sports Medicine Handbook, 2013-2014). However, when diagnostic testing is performed, there is the possibility to identify incidental findings beyond an individual's SCT status (e.g. Hb C status). The NCAA has not developed a policy to address these incidental findings, whereas the University of Pittsburgh not only reports the atypical hemoglobin present but also provides counseling regarding the implications. Since student-athletes, in general, lack knowledge of SCT, it is reasonable to assume that they do not comprehend this aspect of screening (i.e., the possibility of discovering incidental findings) either.

Student-athletes did not have comments concerning the scientific method of testing; rather their concerns focused on the discomfort or perceived loss of physical stamina associated with the blood draw, which is unavoidable if SCT status is being determined. Student-athletes also commented on the advantage of the organized screening program's removing responsibility from the student-athlete to arrange for testing. Since student-athletes are required to have screening for SCT as part of the medical process (or sign a waiver and assume the risk of having undetected SCT), and nearly every student-athlete complies with this mandate, the program extends to a large collegiate community. The ASH suggests this population could be protected through the implementation of universal interventions rather than genetically screening all

student-athletes for SCT (Lawrence, 2010). It may be argued that implementing universal interventions—despite being applied to all student-athletes in a way that limits their training activity—would actually be the least restrictive means of addressing the risk of SCT, because it would be implemented as a part of normal training protocols. It would not single out any individual to limit his/her actions or choices. This universal intervention approach would also eliminate the risk of stigmatization those with SCT may experience, including the risk of internalized stigma, especially if effective education is not provided (Thompson, 2013). Student-athlete participants were not in favor of such measures, however; they connected the implementation of universal interventions with possible hindrance of athletic performance. They did not appreciate that “leveling the playing field” for all student-athletes to the level that could be tolerated by those with SCT could benefit all student-athletes while avoiding the risk the identifying those with SCT may lead to individuals being treated differently both within and outside of their sport. Moreover, the NCAA has not yet established any form of protection of individuals who test positive for SCT. Although the NCAA has stated SCT is not a barrier for athletic participation, they have not made a formal regulation in the NCAA Sports Medicine Handbook to ensure individuals with SCT are not in jeopardy of adverse effects (e.g. loss of playing time) resulting from their SCT status. Rather, the NCAA has merely suggested that institutions provide an environment where precautions can be activated.

The mandatory nature of SCT screening is a major concern raised by opponents of the NCAA program. Organizations, like the ASH, assert that the NCAA program is not justified and could further undermine an individual’s autonomy through breaching the confidentiality of the SCT test result and thus the individual’s privacy regarding his/her health status. For example, an individual’s welfare would be undermined if institutions participating in the NCAA program

tolerated an environment that allows for discriminatory practices (SACHDNC, 2010; Grant, 2013). Confidentiality is related to how an individual's information may be distributed, which can, in turn, protect an individual's privacy (Francis, 2008). Student-athletes waive, to some degree, their confidentiality when allowing educational institutions access to at least the part of their medical records that includes their SCT status. But such student-athletes have a reasonable expectation that the confidentiality of that information will, in turn, be protected by the athletic departments that access it.

Student-athletes interviewed appeared cognizant of this collegiate atmosphere, where at the University of Pittsburgh student-athletes release their complete medical records to the athletic department. They did not, however, express any awareness of measures that would be taken to protect the confidentiality of that information in possession of the athletic department, aside of being a part of their file record. Keeping such information confidential (i.e. protecting the informational privacy of the student-athletes) is important for both instrumental and intrinsic reasons. Respecting individuals; privacy is an intrinsic part of respecting them as persons. Moreover, protecting the privacy of individuals' health information has instrumental value in safeguarding them from stigma and discrimination. Student-athletes are already mandated to partake in the screening program, which is an infringement on their autonomy; to subsequently present an environment in which their right to privacy can be violated would exacerbate this intrusion of their autonomy and risk their welfare. Individuals with SCT risk their privacy being breached by the measures used by the NCAA to protect them—namely, the recommended precautions—since these allow individuals with SCT to be easily distinguished from because other teammates who would not be allowed the same accommodations (Thompson, 2013). Student-athletes interviewed with SCT responded differently regarding the importance of

keeping their status private. One individual felt it was better to have teammates aware of the trait and possible complications. Another individual did not want to reveal the trait status to teammates, although the student-athlete stated it was not due to concerns of discrimination but did not elaborate further.

Student-athletes with SCT can be accomplished athletes. There is no reason that individuals with SCT should be marginalized, a view both the NCAA and the ASH accept (Nelson, 2013; NCAA Sports Medicine Handbook, 2013-2014). Nevertheless, concern about the marginalization and stigmatization of those with SCT, and the potential for discrimination against them, have been raised. Past SCT screening programs, specifically in the military and governmental population-wide screening programs, have a history of discrimination or stigmatization (SACHDNC, 2010; Grant, 2013). The NCAA mandatory SCT screening program will raise much awareness of SCT with the potential for misinformation that may lead to undue alarm and create an atmosphere of stigmatization and discrimination for those with SCT (Bonham, 2010; SACHDNC, 2010). Moreover, as discussed above, there is a history of discrimination against those with sickle cell disease and SCT, particularly by those who failed to distinguish the two conditions. Student-athlete participants did not volunteer information indicating awareness of this history or reveal concerns about stigmatization or discrimination. Further, they did not anticipate being dissuaded from continuing athletics if they were found to have SCT.

Since most student-athletes are unaware of the history of prejudice pertaining to SCT this may explain their collective lack of concerns (Lawrence, 2014). However, the NCAA program will inevitably reveal a health issue disproportionately affecting African Americans, due to the greater incidence in that population. Therefore, there is the potential for complications of racial

discrimination to develop. It is important to note, that University of Pittsburgh student-athletes with SCT did express initial concern over being treated differently based on their SCT status; the student-athletes stated this was not found to be well-founded, and they were not concerned about stigmatization or discrimination in the athletic setting. This amelioration of initial concern may be attributed to the strong educational approach taken at the University of Pittsburgh, which provides detailed SCT counseling for an individual positive for SCT and also for their trainers. The method attempts to ensure all parties are well-informed regarding the significance of SCT. Of course, such education can only reach those involved in the athletic department; other entities that might stigmatize or discriminate on the basis of SCT or race, would not receive such education. To some degree, education and genetic counseling provides resources for individuals to protect themselves against stigmatization and discrimination (O'Connor, 2012), which would allow for potential burdens associated with the screening program to be partly offset. Educating the potential victims of stigma and discrimination, however, does not address the misinformation itself or ill-intent of those who perpetrate stigmatizing or discriminatory practices.

The NCAA SCT screening program is unethical as currently conducted due to the implied mandatory nature of testing at the individual level. Recognizing the possibility of harms such as discrimination, controversy surrounding scientific significance associated with SCT, the limitations surrounding the effectiveness of the interventions, and the reality that the program is not the least restrictive option which the NCAA could implement; it is difficult to justify even implicitly mandating that student-athletes be tested. The NCAA needs to address these concerns. Similar to previously implemented mandatory screening programs, like NBS, the relevance in determining whether it is necessary or appropriate to mandate screening should be considered. Past research regarding NBS have revealed a debate between whether programs should be

elective and voluntary or whether screening can be appropriately mandatory. Since most, if not all, student-athletes, it is assumed, would freely comply with SCT testing if genetic counseling was provided, the implied NCAA mandate of testing is not necessary. Steps need to be taken to ensure that student-athletes realize that they have the choice of refusing the offer of testing. With adequate genetic counseling, it is unlikely that many would refuse testing that affords them benefit. Especially if universal precautions are implemented so that fellow teammates cannot identify those who test positive, because everyone is subject to the same level of rigor and safety during training, student-athletes would rarely have reason to reject the offer of learning their SCT status.

Although genetic counseling cannot eliminate the possibility of discrimination, it can provide a compromise between the NCAA and the ASH and enable student-athletes to be treated in the most ethical, least infringing manner. Mandating genetic counseling and allowing for SCT screening to be voluntary is the best method for screening available. The benefit of counseling is applied to everyone and the NCAA can still identify student-athletes' SCT statuses.



#### **4.2.2 Assessment of Genetic Counseling in the SCT Screening Process**

Genetic counseling is a principle-based ethical process which strives to ensure beneficence, nonmaleficence, and autonomy (Uhlmann, 2009). Informed consent is particularly relevant during the genetic counseling process. Informed consent in the genetic screening context, implies that prior to genetic testing, individuals are allowed (Hodge, 2004):

- explanations of the nature and scope of information being gathered
- meaning of possible results
- meaning of the underlying condition
- any risks that may be associated through testing

The NCAA cannot be considered to implement these measures due to the mandatory nature of its SCT screening program and the integral incompatibility between ensuring the opportunity to give informed consent—which includes a right to informed refusal—and mandating participation. However, the University of Pittsburgh SCT screening program attempts to provide an informed consent process which respects student-athletes' autonomy within the genetic counseling provided as part of the University's SCT screening program (Uhlmann, 2009). Genetic counseling prior to undergoing SCT testing includes review of the screening rationale, the types of possible results, the implications of results, symptoms and precautions for SCT, information about testing procedure, and the reproductive significance of SCT. Furthermore, each student-athlete is asked to sign a consent form that documents what is explained about the accuracy and confidentiality of testing, the implications of results, and the potential for incidental findings. Individuals with positive SCT results are given post-test counseling which reviews similar information as the pre-test counseling in a private setting with a licensed genetic counselor.

Maintaining a true process of informed consent within screening programs is beneficial but can be challenging depending on by how much emphasis is placed on student-athletes' comprehension and knowledge of a subject, such as SCT (Dunn, 2007). Research, including this study, has highlighted the lack of understanding of SCT among student-athletes (Lawrence, 2014; Costanzo, 2011; Thompson, 2011). Interestingly, most student-athletes interviewed considered themselves informed prior to undergoing SCT screening, and they attributed this to the genetic counseling. However, they did not volunteer substantial evidence of understanding SCT or the implications of testing positive. Student-athletes were concerned about screening programs at other institutions not providing a similar genetic counseling process.

The University of Pittsburgh SCT screening program is believed to be the only institution that includes genetic counseling. Genetic counseling goes beyond merely educating an individual. Education involves attempting to teach information, whereas genetic counseling seeks to enable an individual can make an autonomous decision while considering the meaning of the information (Kessler, 1997). As discussed above, it is difficult to imagine that student-athletes make an autonomous decision within the contexts of their athletic departments and the mandatory nature of the NCAA screening program. On the other hand, at the University of Pittsburgh, both the education and the pre-test genetic counseling afforded student-athletes include the fact that they may opt out of testing.

Although the NCAA has recently required mandatory SCT education [See Appendix B.4], which should include information on the risks, impact, and precautions associated with SCT, they have not issued guidelines to ensure student-athletes are receiving a consistent level of education or recommended how institutions should carry out this education. The University of Pittsburgh program exceeds the base level of education and counsels student-athletes on the

types of results and their implications, including implications for reproduction. Counseling allows for understanding; in regard to SCT screening, it provides student-athletes awareness of the testing and its risks and benefits. The possibility of anxiety associated with genetic testing has been shown to be allayed by genetic counseling (Atkin, 1998). Significantly, however, it is the University of Pittsburgh, not the NCAA that mandates genetic counseling.

Student-athlete participants were supportive of the University's genetic counseling program. However, this study revealed that even at the University of Pittsburgh, some student-athletes did not receive genetic counseling prior to screening. These student-athletes had uncertainty regarding screening and expressed a desire for more education. Some student-athletes' comments reflected other areas for improvement as well. The psychological and social implications involved in genetic screening where individuals may be identified as carriers is often complicated by the process of providing results (Atkin, 1998). Student-athletes with SCT did not express concern about how results were revealed to them, although these student-athletes were aware of their status prior to screening. Some student-athletes were concerned about not being told a negative result. While, the athletic department receives documentation of each student-athletes' SCT status, a negative result is not formally given to student-athletes. This relatively simple issue can be corrected by providing student-athletes who screen negative for SCT with a letter stating their status and explaining both the significance of that result and its limitations, given the mode of testing employed. Other student-athletes suggested improving the ease by which student-athletes have avenues to disclose prior testing results. However, for student-athletes to avoid confirmatory SCT testing, the NCAA requires that they provide official documentation of a prior test result, such as NBS results which are difficult to obtain (Lawrence, 2010; NCAA Sports Medicine Handbook 2013-2014).

The ASH continues to argue the NCAA screening policy is not the least burdensome policy option available and calls for universal interventions (Thompson, 2013). Nonetheless, past research and this research has shown student-athlete acceptance of mandatory screening and preference to either incorporate or continue genetic counseling as part of screenings into the future (Thompson, 2011). Genetic counseling allows for the least restriction of individual liberties, by protecting and promoting an individual's autonomy as much as possible within a setting in which screening is quasi-mandatory. Therefore, the NCAA should consider mandating that genetic counseling be included in SCT screening programs, to afford all student-athletes the benefit experienced by student-athletes at the University of Pittsburgh.

### **4.3 STUDY LIMITATIONS**

Although the findings of this study have afforded a greater understanding of student-athlete perceptions on the NCAA screening program, as well as provide data to ground some recommendations for the program to improve its attention to potential ethical concerns and ensure genetic counseling for all those tested, the study has some limitations. First, participants were recruited with an emailed invitation; however, student-athlete trainers were essential in scheduling interviews with the student-athletes. This situation may not have provided student-athletes with the most minimal possibility of inappropriate or undue influence to participate. This potential for inappropriate influence during the recruitment process was alleviated in part by each student-athlete partaking in a verbal informed consent, stating their participation was voluntary, prior to beginning the interview.

The sample size of sixteen participants was relatively small as well. While responses were similar within the study population, these findings cannot be interpreted to express collective beliefs held by all student-athletes. Finally, throughout the interview process, participants were asked at times to elaborate on their responses. However, ethical issues, specifically privacy, stigmatization, or discrimination, were not probed unless a participant brought forward those concerns. In general, interviewing more student-athletes from the University of Pittsburgh and other universities– and interviewing them more in-depth with more probing of longer-term implications and possible ethical concerns– could provide additional understanding and also substantiate this project’s findings.

#### **4.4 FUTURE CONSIDERATIONS**

The NCAA has shown no indication of discontinuing the SCT screening program, and instead expanded the program as mandatory for Division I, II, and III student-athletes in the past four years. Organizations such as the ASH and the SACHDNC continue to oppose the mandatory program, cautioning the potential harm allotted to the student-athlete community and specifically those with SCT. These concerns are significant and should be addressed by the NCAA. However, student-athletes participants found SCT testing to be a positive program of the NCAA and information they valued as athletes. Their lack of understanding of some of the long-term implications of testing positive should be improved by the NCAA making measure to ensure adequate education is provided and possibly though mandating a universal genetic counseling process for the screening process.

The potential for other mandatory screening programs to be implemented is not an unlikely prospect. Therefore, the ethical status of the SCT screening program is essential to provide a model for potential public health screening programs in the future. Other forms of qualitative and quantitative analyses can be utilized to assess certain issues regarding the NCAA mandatory SCT screening program. The current study was not able to address why some student-athletes at the University of Pittsburgh did not receive genetic counseling as part of their SCT screening process. Future studies may evaluate if this is a common occurrence and what steps may be taken to avoid such instances from happening. This study also revealed that those with SCT were initially concerned of how their status would affect their athletic involvement. Although, these concerns proved unfounded at the University of Pittsburgh, future studies may consider assessing the views of a larger number of student-athletes with SCT to determine whether this targeted population, revealed by screening, has to contend with an environment that infringes further on their liberties, through discrimination or stigma, as the ASH suggests may be occurring. Finally, additional evaluation is needed to determine student-athlete perceptions and attitudes at other institutions. Among the questions to explore are whether student-athletes lack knowledge of SCT and want genetic counseling as part of screening, as well as whether student-athletes are aware of the potential risks of SCT screening identified by the ASH, and if they are aware, whether they lack concern about these risks.

## **5.0 CONCLUSION**

This study offers insights into the perceptions of student-athletes in regard to the mandated NCAA SCT screening program, as well as ethical insight into the controversy in the literature that has surrounded the NCAA program. Participants interviewed were supportive of the NCAA policy and were not concerned about issues groups like the ASH suggest, for example, stigmatization and discrimination. What is unclear from this study is whether those interviewed actually evaluated those risks and were not concerned about them, or whether they were simply unaware of the history and future potential for stigma and discrimination. Student-athletes were in favor of genetic counseling. They were hesitant to favor universal interventions because they believed, correctly or not, that their performance as an athlete would be hindered. This study reflects the attitudes of a small number of student-athletes at the University of Pittsburgh. Therefore, future studies are needed in order to evaluate the perceptions of student-athletes at other institutions and gain a more comprehensive assessment of how this population views the NCAA SCT screening program, particularly by probing more carefully what the student-athletes understand about the broader implications of a mandatory screening program and about the social risks of testing positive for SCT.

## **APPENDIX A: RESEARCH PROJECT APPROVAL AND RELEVANT FORMS**

This research study was approved by the University of Pittsburgh Institutional Review Board.

Additional materials relating to the study procedure can be found below.



## A.1 INSTITUTIONAL REVIEW BOARD APPROVAL



### University of Pittsburgh *Institutional Review Board*

3500 Fifth Avenue  
Pittsburgh, PA 15213  
(412) 383-1480  
(412) 383-1508 (fax)  
<http://www.irb.pitt.edu>

#### **Memorandum**

To: Rosalie Ferrari  
From: Sue Beers, PhD, Vice Chair  
Date: 9/19/2013  
IRB#: [PRO13070107](#)  
Subject: University of Pittsburgh student-athlete perceptions of the NCAA SCT testing program

The University of Pittsburgh Institutional Review Board reviewed and approved the above referenced study by the expedited review procedure authorized under 45 CFR 46.110 and 21 CFR 56.110. Your research study was approved under: 45 CFR 46.110.(6)(7).

The IRB has approved the waiver for the requirement to obtain a written informed consent.

The risk level designation is Minimal Risk.

Approval Date: 9/19/2013  
Expiration Date: 9/18/2014

For studies being conducted in UPMC facilities, no clinical activities can be undertaken by investigators until they have received approval from the UPMC Fiscal Review Office.

Please note that it is the investigator's responsibility to report to the IRB any unanticipated problems involving risks to subjects or others [see 45 CFR 46.103(b)(5) and 21 CFR 56.108(b)]. Refer to the IRB Policy and Procedure Manual regarding the reporting requirements for unanticipated problems which include, but are not limited to, adverse events. If you have any questions about this process, please contact the Adverse Events Coordinator at 412-383-1480.

The protocol and consent forms, along with a brief progress report must be resubmitted at least one month prior to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00006000 (Children's Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).

**Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.**

## A.2 PARTICIPATION RECRUITMENT EMAIL



University of Pittsburgh



Dear potential participant,

When you had your test for sickle cell trait, I provided genetic counseling to you. I am in the process of conducting a research study here at the University of Pittsburgh regarding student-athlete perceptions of the sickle cell trait testing program. I would appreciate your participation in this research study by agreeing to a short interview. Participation in this study is voluntary and responses are kept confidential. You must be 18 years old or older in order to participate. A 30 minute individual interview with you will be digitally voice recorded in a private space. A small token of my appreciation for your participation will be provided to you at the end of the interview. If you are interested in participating, please contact me at [rof21@pitt.edu](mailto:rof21@pitt.edu) up till October 31<sup>st</sup> to schedule an interview at your convenience.

All the best,

Rosalie Ferrari  
Genetic Counseling Student  
Graduate School of Public Health  
University of Pittsburgh  
[rof21@pitt.edu](mailto:rof21@pitt.edu)

### A.3 SCRIPT FOR VERBAL CONSENT OF INTERVIEWS

Thank you for participating in an interview for our research study. Your participation in this study is voluntary. My name is Rosalie Ferrari, and I am a genetic counseling student at the University of Pittsburgh Graduate School of Public Health and the Principle Investigator for this study. As part of my education, I am conducting this research study to learn how student-athletes feel about the sickle cell trait testing program, what they think of it and of sickle cell trait, and any concerns they may have. Specifically, I would like to ask you what your feelings are regarding the SCT test, the testing process, and the possible impact testing for sickle cell trait has in your life. Your standing, relationship, or athletic involvement with the University of Pittsburgh or CHP/UPMC will not be affected whether you choose to participate or not, or if you choose to withdraw or not.

I would like to begin a 30 minute interview in which I'll ask you a series of questions. The interview will be digitally audio-recorded and the responses will later be typed up. When the interview ends, you will have a choice of two items from this basket as a 'thank you' for your participation. There is the potential risk of discomfort and breach of confidentiality in this study; however, efforts will be made to minimize these risks. You can refuse to answer any question, and you can stop the interview at any time. Your answers will be kept confidential, and the tapes and typed copy will be stored securely so that my research mentors and I have access to them. Furthermore, the University of Pittsburgh Research Conduct and Compliance Office may also have access to these research records in order to monitor the study. In the unusual event of an order from a court, the research records could also be released as well. There is no direct benefit from participating in this study. If you do have concerns regarding the study please contact the University of Pittsburgh IRB Human Subject Protection Advocate phone number at 1-866-212-2668. If you need to get in contact with me in the future, please feel free to contact me at (412) 361-4231.

Do I have your permission to conduct this interview with you?

{If No}: Thank you for your time.

{If Yes}: Thank you for participating. Shall we begin?

## A.4 INTERVIEW GUIDE

### *Opening*

**Tell me about how you first started playing sports?**

**Why did you decide to play sports at the college level?**

### *Thoughts about the testing process and results*

**Now, as you may remember, we first met when I did some counseling about sickle cell trait genetic testing. How did you first learn that you would have sickle cell trait testing?**

**Thinking back to when you learned you would have sickle cell trait testing, tell me what your thoughts were about the testing.**

**Would you have liked to know more about why student-athletes are tested for SCT? What would you have liked to know?**

**Tell me, did you have any concerns about the testing or learning the test result? What were they?**

**What types of benefits did you expect, if any, from learning your test result?**

**Did you foresee any risks regarding your test results?**

**As you may know, the reason the NCAA requires that student-athletes be tested for SCT is concern that those with SCT are at increased risk for negative health consequences including conditions similar to heat stroke, rhabdomyolysis, and in rare circumstances sudden death. Describe to me your feelings about these concerns?**

**What do you think are the most effective ways that the NCAA and the University can protect student-athletes from these health complications?**

**Some people suggest that student-athletes could be protected without any genetic testing just by having athletic programs set up universal precautions for everyone. What do you think?**

At the time you were being tested, how did you think your test results might affect your current life?

When you were having the SCT testing did you think about any long-term impact or implications of the test?

What did you think about?

When you had SCT testing, did you think that your test results might have implications for anyone else besides you?

What implications ... for whom ...

OR

Thinking about it now, do you think there are implications for anyone else involving this genetic test?

Closing

Before we end, I would like to ask you a couple questions about how you describe yourself:

If you were asked to list five things that you value, or want, or enjoy that really describe you and your life, what would you list?

If you're asked to check boxes on an application or survey to describe your race and ethnicity, which box or boxes would you check?

Finally, do you think that SCT testing or your test results affect any of those things that you listed as being important or describing who you are?

<If yes:> How?

<Then:> Thank you for taking the time to talk with me today.  
Please feel free to grab two items from the basket.

<If no:> Thank you for taking the time to talk with me today. Please feel free to grab two items from the basket.

## **APPENDIX B: OFFICIAL INSTITUTIONAL SCT DOCUMENTS**

The University of Pittsburgh has developed policies and procedures to ensure, and consequently exceed, compliance with the mandatory NCAA SCT screening program. The university has also, with the help of Children's Hospital of Pittsburgh, created informative literature for each student-athlete to receive during the SCT screening process. Various SCT materials relating to the University of Pittsburgh SCT screening program can be found below.

## B.1 SICKLE CELL TRAIT SCREENING INFORMED CONSENT



### CONSENT FORM

Patient Name \_\_\_\_\_

Date of Birth \_\_\_\_\_

I, \_\_\_\_\_, hereby authorize the submission of samples from:

\_\_\_\_\_  
(patient's name, birth date & relationship to individual granting consent if not self)

for hemoglobinopathy evaluation. This will determine if you have a variant form of hemoglobin which may be inherited.

#### ACCURACY

The studies performed are specific to the condition indicated in the statement at the top of this page. The accuracy of hemoglobinopathy evaluation is limited by the methods employed. It is the responsibility of the referring physician, or a health care professional designated by the physician, to understand the limitations of the testing ordered, and to educate the patient regarding these limitations.

Accurate interpretation of test results may require an accurate report of the patient's family medical history, and that the reported family relationships are the true biological relationships. An incorrect diagnosis in a family member can lead to incorrect diagnoses for other family members. There is always a small possibility of an error or failure in sample analysis; this is always a possibility with complex testing in any laboratory. Extensive measures are taken to avoid these errors.

#### IMPLICATIONS OF RESULTS

Because the implications of hemoglobinopathy evaluation results can be complex, involving both medical and emotional and social issues, results will only be reported through the genetic counselor. The issues associated with some types of testing are particularly sensitive. Therefore, the laboratory reserves the right to provide testing only if genetic counseling can be provided.

#### INCIDENTAL FINDINGS

On occasion, in the process of testing for one genetic condition, a separate abnormality may be identified. Such findings will be reported to the referring clinician, who will explain the implications of the finding.

Genetic studies of families can sometimes reveal that the true biological relationships are not consistent with the relationships reported in the family history (such as in cases of adoption or non-paternity). It is this laboratory's policy NOT to report these findings, except in rare circumstances in which the findings indicate a medical or reproductive risk for which intervention is possible. These decisions will be made by the laboratory directors in consultation with medical, counseling and legal professionals as well as medical professionals trained in ethics (moral questions) who will determine the most appropriate means of conveying the information.

**CONFIDENTIALITY**

Results and patient information are confidential and will only be released to the tested individual, unless written consent for further distribution is provided or the laboratory directors are required by law to release this information.

Patient or Legally Authorized Representative: \_\_\_\_\_ Date: \_\_\_\_\_

If Legally Authorized Representative please describe relationship to individual: \_\_\_\_\_

By signing this consent form, the referring clinician 1) indicates that this consent form has been reviewed with the patient and/or the patient's parent or guardian, and 2) accepts responsibility for pre- and post- test genetic counseling.

Referring clinician's Signature: \_\_\_\_\_ Date: \_\_\_\_\_



## B.2 SICKLE CELL TRAIT SCREENING WAIVER RELEASE

### University of Pittsburgh

#### Agreement, Waiver and Release of Claims

##### Sickle Cell Trait Screening

TO THE PROSPECTIVE STUDENT-ATHLETE OR STUDENT-ATHLETE: PLEASE READ THIS CAREFULLY. IF YOU HAVE ANY QUESTIONS REGARDING THIS FORM, PLEASE ASK AN ATHLETIC TRAINER TO REVIEW IT WITH YOU AND EXPLAIN ITS CONTENTS.

\_\_\_\_\_  
Print Name

I am aware that participation in intercollegiate athletics involves a risk of personal injury. I understand that I could be at increased risk of physical, and potentially life-threatening, problems, if I have an inherited condition known as sickle cell trait and I participate in certain activities as a prospective student-athlete and/or student-athlete. I have read and understood the section titled "The Student-Athlete with Sickle Cell Trait" from the 2010-11 NCAA Sports Medicine Handbook, which is attached to this form. I have had the opportunity to ask questions of the University of Pittsburgh's athletics trainers about sickle cell trait, and the screening for sickle cell trait, and all questions I have were answered to my satisfaction and in a way I understand.

I understand a simple blood test is available to determine if I have sickle cell trait. I understand that the University of Pittsburgh STRONGLY RECOMMENDS that I have the test done, and that it is available at no cost to me. However, I also understand that I may decline sickle cell trait testing if I sign this Agreement, Waiver and Release of Claims. Notwithstanding the above, if I decline sickle cell trait testing and if the University of Pittsburgh believes in its reasonable judgment, that I may be developing symptoms that could be related to sickle cell trait, the University may require testing in order to maximize my safety and may withhold me from practice and/or competition until I agree to sickle cell trait testing.

My signature below signifies that (choose one):

A. I wish to proceed to have the test done at no cost to me.

Signature: \_\_\_\_\_ Date \_\_\_\_\_  
Prospective Student-Athlete/Student-Athlete

Signature: \_\_\_\_\_ Date \_\_\_\_\_  
Parent/Legal Guardian  
(if prospective student-athlete/  
student-athlete is under age 18)

Signature: \_\_\_\_\_ Date \_\_\_\_\_  
Witness

B. I decline to have the test done at this time and I have shown the University the results of a prior test for sickle cell trait.

Signature: _____	Prospective Student-Athlete/Student-Athlete	_____	Date
------------------	---	-------	------

Signature: _____	Parent/Legal Guardian (if prospective student-athlete/ student-athlete is under age 18)	_____	Date
------------------	---	-------	------

Signature: _____	Witness	_____	Date
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C. I decline to have the test done at this time in spite of the University's recommendation and in spite of the potential risk to me. I understand the University will continue to make the test available at no cost to me, as long as I am a prospective student-athlete officially and actively trying out for a University of Pittsburgh intercollegiate athletics team and/or as long as I am a student-athlete at the University, provided I later inform a University athletics trainer in writing that I then wish to be tested.

Additionally, I agree to assume and take on myself all of the risks and responsibilities in any way associated with my participation in intercollegiate athletics at the University without having been tested for sickle cell trait. In consideration of and return for the opportunity to participate in intercollegiate athletics at the University without having been tested for sickle cell trait, I HEREBY RELEASE AND FOREVER DISCHARGE THE UNIVERSITY AND ITS TRUSTEES, OFFICERS, EMPLOYEES, STUDENTS, CONTRACTORS AND AGENTS (COLLECTIVELY THE "UNIVERSITY RELEASEES") FROM ANY AND ALL LIABILITY, CLAIMS AND ACTIONS THAT MAY ARISE FROM INJURY, ILLNESS OR HARM TO ME, UP TO AND INCLUDING DEATH, IN CONNECTION IN ANY WAY WITH MY PARTICIPATION IN SUCH ACTIVITIES WITHOUT HAVING BEEN TESTED FOR SICKLE CELL TRAIT. I UNDERSTAND THAT THIS RELEASE COVERS LIABILITY, CLAIMS AND ACTIONS CAUSED ENTIRELY OR IN PART BY ANY ACTS OR FAILURES TO ACT OF THE UNIVERSITY RELEASEES, INCLUDING BUT NOT LIMITED TO NEGLIGENCE, MISTAKE OR FAILURE TO SUPERVISE.

I recognize that this Release means I am giving up, among other things, rights to sue the University Releasees for injuries, illnesses, damages or losses I may incur. I also understand that this Release binds my heirs, executors, administrators and assigns, as well as myself.

\_\_\_\_\_  
Signature: Prospective Student-  
Athlete/Student-Athlete

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature: Parent/Legal Guardian  
(if prospective student-athlete/  
student-athlete is under age 18)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature: Witness

\_\_\_\_\_  
Date

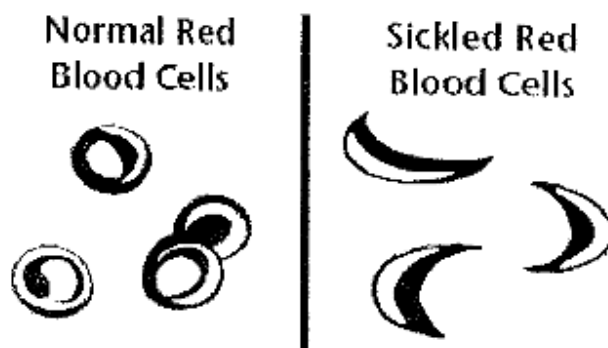
## Sickle Cell Trait and YOU, the Athlete

There has been increasing awareness regarding sickle cell trait and sudden death during exercise. *This occurrence is very rare and can be completely avoided by following a few simple guidelines.* This handout is intended to answer any questions you have about being an athlete with sickle cell trait. First, we need to explain the difference between sickle cell disease and trait.

### Sickle Cell Disease vs Sickle Cell Trait

Sickle cell disease is a serious blood disorder, in which a genetic change causes the red blood cells to change shape from round and soft to half-moon shaped and hard.

Sickled cells can group together and block blood vessels, causing harmful complications in the body. Individuals with sickle cell disease inherit one copy of the sickle cell gene from each of their parents.



Sickle cell trait is not a disease, and will never turn into a disease. Individuals with sickle cell trait have one copy of the gene for sickle cell and one copy of the gene for healthy red blood cells. Sickle cell trait is found in 8% of African-Americans. It is also common in people of African, Mediterranean, Middle Eastern and Indian origin.

### Exercise and the Athlete with Sick Cell Trait

During periods of extreme physical activity, athletes with sickle cell trait have an increased risk for sudden death, although it is important to remember that this is quite rare. While this association exists, there is no direct evidence as to why. It is hypothesized that if an athlete has sickle cell trait, intense exercise can cause changes in the body known to cause sickling. This occurrence is called exertional sickling. Over a ten year period, of 136 sudden, non-traumatic sports deaths in high school and college athletes, seven (5%) were thought to be due to exertional sickling.

### Exertional Sickling Collapse

Exertional sickling can lead to rapid muscle break down, called rhabdomyolysis, which can be fatal. If an athlete collapses from exertional sickling, it may be mistaken for heat or cardiac collapse. In cardiac collapse, the collapse is "instantaneous," without any cramping and the athlete unable to talk. Exertional sickling collapse typically occurs within the first 30 minutes of practice, with less pain than heat exhaustion collapse and no muscle twinges. While in heat exhaustion collapse the muscles lock up and feel hot to the touch, in an exertional sickling collapse the muscles feel weak, but normal to the touch.

Type	Muscle Twinges	Timing in Activity	Pain	Muscles
Heat	Yes	Later	More	Locked-up and hard to the touch
Sickling	No	Within first 30 minutes	Less	Weak and feel normal to the touch

If an exertional sickling collapse should be treated as an emergency. Call 911 and tell emergency personnel to expect rhabdomyolysis.

### New NCAA Recommendations

The National Collegiate Athletic Association (NCAA) recently began recommending that all of its athletes be tested for sickle cell trait. The NCAA also states that athletes with sickle cell trait should not be prevented from participating in competitive sports. One can be tested for sickle cell trait with a simple, inexpensive blood test.

### Prevention of Exertional Sickling

Although exertional sickling is a serious condition, it can easily be prevented. It is recommended that athletes with sickle cell trait be allowed to:

- acclimate themselves gradually to strenuous drills
- set their own pace and drink plenty of water
- Precaution should be taken especially at high altitudes, during hot days (greater than 90 degrees), or periods of illness.

If these guidelines are followed, exertional sickling can be avoided.

For more information, please contact us at:  
Children's Hospital of Pittsburgh of UPMC Sickle Cell Program  
Phone: 412-692-6059

## B.4 NCAA STUDENT-ATHLETE SCT FACT SHEET

**A FACT SHEET FOR STUDENT-ATHLETES**



# SICKLE CELL TRAIT



### WHAT IS SICKLE CELL TRAIT?

**Sickle cell trait** is not a disease. Sickle cell trait is the inheritance of one gene for sickle hemoglobin and one for normal hemoglobin. Sickle cell trait will not turn into the disease. Sickle cell trait is a life-long condition that will not change over time.

- ▶ During intense exercise, red blood cells containing the sickle hemoglobin can change shape from round to quarter-moon, or “sickle.”
- ▶ Sickled red cells may accumulate in the bloodstream during intense exercise, blocking normal blood flow to the tissues and muscles.
- ▶ During intense exercise, athletes with sickle cell trait have experienced significant physical distress, collapsed and even died.
- ▶ Heat, dehydration, altitude and asthma can increase the risk for and worsen complications associated with sickle cell trait, even when exercise is not intense.
- ▶ Athletes with sickle cell trait should not be excluded from participation as precautions can be put into place.

### DO YOU KNOW IF YOU HAVE SICKLE CELL TRAIT?

**People at high risk** for having sickle cell trait are those whose ancestors come from Africa, South or Central America, India, Saudi Arabia and Caribbean and Mediterranean countries.

- ▶ Sickle cell trait occurs in about 8 percent of the U.S. African-American population, and between one in 2,000 to one in 10,000 in the Caucasian population.
- ▶ Most U.S. states test at birth, but most athletes with sickle cell trait don't know they have it.
- ▶ The NCAA recommends that athletics departments confirm the sickle cell trait status in all student-athletes.
- ▶ Knowledge of sickle cell trait status can be a gateway to education and simple precautions that may prevent collapse among athletes with sickle cell trait, allowing you to thrive in your sport.

### HOW CAN I PREVENT A COLLAPSE?

- ▶ Know your sickle cell trait status.
- ▶ Engage in a slow and gradual preseason conditioning regimen.
- ▶ Build up your intensity slowly while training.
- ▶ Set your own pace. Use adequate rest and recovery between repetitions, especially during “gassers” and intense station or “mat” drills.
- ▶ Avoid pushing with all-out exertion longer than two to three minutes without a rest interval or a breather.
- ▶ If you experience symptoms such as muscle pain, abnormal weakness, undue fatigue or breathlessness, stop the activity immediately and notify your athletic trainer and/or coach.
- ▶ Stay well hydrated at all times, especially in hot and humid conditions.
- ▶ Avoid using high-caffeine energy drinks or supplements, or other stimulants, as they may contribute to dehydration.



- ▶ Maintain proper asthma management.
- ▶ Refrain from extreme exercise during acute illness, if feeling ill, or while experiencing a fever.
- ▶ Beware when adjusting to a change in altitude, e.g., a rise in altitude of as little as 2,000 feet. Modify your training and request that supplemental oxygen be available to you.
- ▶ Seek prompt medical care when experiencing unusual physical distress.

**For more information and resources, visit [www.NCAA.org/health-safety](http://www.NCAA.org/health-safety)**



## BIBLIOGRAPHY

- Aloe, A.E. Sickel cell trait testing in the athlete: experience at the University of Pittsburgh (2010).
- Aloe, A., Krishnamurti, L. & Kladny, B. Testing of collegiate athletes for sickle cell trait: what we, as genetic counselors should know. *Journal of genetic counseling* 20, 337–40 (2011).
- American Society of Hematology. Statement on screening for sickle cell trait and athletic participation. *Hematologist* 9, 7 (2012).
- Arnold, C. Two faces of patient advocacy: the current controversy in newborn screening. *Journal of medical ethics* (2013).
- Ashley-Koch, A., Yang, Q. & Olney, R. Sickel hemoglobin (Hb S) allele and sickle cell disease: a huge review. (2000).
- Atkin, K. & Ahmad, W. Genetic screening and haemoglobinopathies: ethics, politics and practice. (1998).
- Bender, M.A. & Hobbs, W. Sickel Cell Disease *GeneReviews* (2012).  
<<http://www.ncbi.nlm.nih.gov/books/NBK1377/>>
- Benson, J. & Therrell, B. History and current status of newborn screening for hemoglobinopathies. *Seminars in perinatology* 34, 134–44 (2010).
- Binder, R. & Jones, S. Prevalence and awareness of sickle cell hemoglobin in a military population: Determination by a rapid screening method. (1970).
- Bonham, V., Dover, G. & Lawrence, B. Screening student-athletes for sickle cell trait – a social and clinical experiment. *The New England Journal of Medicine* 363, 997–999 (2010).
- Braun, V. & Clarke, V. Using thematic analysis psychology. *Qualitative Research in Psychology* 3, 77-101 (2006).
- Brodine, C. & Uddin, D. Medical aspects of sickle hemoglobin in military personnel. (1977).
- Charache, S. *et al.* Effect of hydroxyurea on the frequency of painful crises in sickle cell anemia. Investigators of the Multicenter Study of Hydroxyurea in Sickle Cell Anemia. *The New England journal of medicine* 332, 1317–22 (1995).
- Chelcun, J. Sickel cell disease. *JAAPA: official journal of the American Academy of Physician Assistants* 27, 45–6 (2014).



- Costanzo, V.L. Sick cell trait counseling for student athletes (2011).
- Draper, Elaine. *Risky business: Genetic Testing and Exclusionary Practices in the Hazardous Workplace*. Cambridge: Cambridge University Press, (1991).
- Dunn, W., George, M., Churchill, L. & Spindler, K. Ethics in sports medicine. *The American journal of sports medicine* 35, 840–4 (2007).
- Edwards, H., Sabio, H. & Shihabi, Z. Rapid quantitation of hemoglobin S in sickle cell patients using the Variant II Turbo analyzer. *Annals of clinical and laboratory science* 39, 32–7 (2009).
- Francis, L. You are born with your genes: justice and protection against discrimination in the use of genetic information. *The Mount Sinai journal of medicine, New York* 77, 188–96 (2010).
- Francis, L., Jacobson, J., Smith, C. & Battin, M. Privacy, Confidentiality, or Both? *American Society for Bioethics and Humanities* 11, 7–9 (2008).
- Glover, D., Glover, D. & Maron, B. Evolution in the process of screening United States high school student-athletes for cardiovascular disease. *The American journal of cardiology* 100, 1709–12 (2007).
- Goldsmith, J. *et al.* Framing the research agenda for sickle cell trait: building on the current understanding of clinical events and their potential implications. *American journal of hematology* 87, 340–6 (2011).
- Gostin, Lawrence. *Public Health Law, Power, Duty, Restraint*. University of California Press, (2000).
- Grant, A. *et al.* Public health implications of sickle cell trait: a report of the CDC meeting. *American journal of preventive medicine* 41, S435–9 (2011).
- Grant, A. Sickle cell trait screening policies: lessons learned. National Center on Birth Defects and Developmental Disabilities, CDC (2013).
- Hara, S. Reliability and modification of Sickledex test. (1973).
- Harmon, K., Asif, I., Klossner, D. & Drezner, J. Incidence of sudden cardiac death in National Collegiate Athletic Association athletes. *Circulation* 123, 1594–600 (2011).
- Harris, K., Haas, T., Eichner, E. & Maron, B. Sickle cell trait associated with sudden death in competitive athletes. *The American journal of cardiology* 110, 1185–8 (2012).
- Harwood, C.E. Evaluation of the impact of a web-based education tool on awareness of newborn screening and carrier testing (2013).
- Hodge, J. Ethical issues concerning genetic testing and screening in public health. *American journal of medical genetics. Part C, Seminars in medical genetics* 125, 66–70 (2004).
- Hofmann, B. Is there a technological imperative in health care? *International Journal of Technology Assessment in Health Care*, 18, 675–689 (2002).

- Kark JA, Posey DM, Schumacher HR, Ruehle CJ. Sick cell trait as a risk factor for sudden death in physical training. *N Engl J Med.* 317:781-787 (1987).
- Kark, JA and Ward, FT. Exercise and Hemoglobin S. *Seminars. Hematology* 31(3):191-226 (1994).
- Kessler, S. Psychological aspects of genetic counseling: teaching and counseling. *Journal of Genetic Counseling* 6, 287-295 (1997).
- Key, N. & Derebail, V. Sick cell trait: novel clinical significance. *Hematology / the Education Program of the American Society of Hematology. American Society of Hematology* 210, 418-22 (2010).
- Kraszewski, J., Burke, T. & Rosenbaum, S. Legal issues in newborn screening: implications for public health practice and policy (2006).
- Lawrence, R. Athlete and coach knowledge, attitudes, and perceptions of Sick Cell trait and national collegiate athletic association mandated testing: recommendations for intervention (2010).
- Lawrence, R. & Shah, G. Athletes' perceptions of National Collegiate Athletic Association-mandated sickle cell trait screening: insight for academic institutions and college health professionals. *Journal of American College Health* 62, 343-350 (2014).
- Mitchell, B. Sick cell trait and sudden death- bringing it home. *Journal of the National Medical Association* 99, 300-305 (2007).
- National Heart, Lung, and Blood Institute, NIH. Sick cell anemia (2012).  
<<http://www.nhlbi.nih.gov/health/health-topics/topics/sca/>>
- NCAA Football Rules Committee 2009 – 2010 Point of Emphasis.  
<[www.ncaa.org](http://www.ncaa.org)>
- NCAA Sports Medicine Handbook 2013 – 2014  
<[www.ncaapublications.com](http://www.ncaapublications.com)>
- Nussbaum, R.L., McInnes, R.R. & Willard, H.F. *Thompson & Thompson Genetics in Medicine* Saunders Elsevier Inc, (2007).
- Nelson, S. Scaring athletes with sickle cell trait. *The American journal of cardiology* 111, 149 (2012).
- O'Connor, F. *et al.* ACSM and CHAMP summit on sickle cell trait: mitigating risks for warfighters and athletes. *Medicine and science in sports and exercise* 44, 2045-56 (2012).
- Rees, D., Williams, T. and Gladwin, M. Sick cell disease. *The Lancet* 376, 2018-2031 (2010).
- Rubin, Herbert & Rubin, Irene. *Qualitative Interviewing: the Art of Hearing Data.* Sage Publications, Inc. (2011).
- Rutkow, I. & Lipton, J. Some negative aspects of state health departments' policies related to screening for sickle cell anemia. (1974).
- Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC), Screening U.S. College Athletes for Their Sick Cell Disease Carrier Status (2010).

- Tarini, B. & Goldenberg, A. Ethical issues with newborn screening in the genomics era. *Annual review of genomics and human genetics* 13, 381–93 (2011).
- Tarini, B., Brooks, M. & Bundy, D. A policy impact analysis of the mandatory NCAA sickle cell trait screening program. *Health services research* 47, 446–61 (2012).
- Thompson, A. Sickle cell trait testing and athletic participation: a solution in search of a problem? *Hematology / the Education Program of the American Society of Hematology. American Society of Hematology. Education Program* 2013, 632–7 (2013).
- Thompson, N.E. The student-athlete's perceptions of genetic testing for sickle cell trait at Howard University. (2011)
- Tsaras, G., Owusu-Ansah, A., Boateng, F. & Amoateng-Adjepong, Y. Complications associated with sickle cell trait: a brief narrative review. *The American journal of medicine* 122, 507–12 (2009).
- Turner, Daniel. Qualitative interview design: a practical guide for novice investigators. *The Qualitative Report* 15, 754-760 (2010).
- Uhlmann, W., Schuette, J. & Yashar, B. *A Guide to Genetic Counseling*. Wiley-Blackwell: John Wiley & Sons Inc., (2009).
- U.S. Department of Health & Human Services. Understanding Health Information Privacy (2013).  
<<http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html>>