# Ethical Behavior and Accountability in Leadership, a Technological Framework & Design for Tracking Blood Disorders

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## Abstract
*To address the challenges associated with accountability in for and nonprofit organizations, a sequential explanatory mixed method design was employed, along with action research. The existing research produced a model where organizational accountability and rules formation were highly correlated to information access (those who have access to information).*

*The purpose of this study is to derive the components needed to provide transparent decision-making, track, and monitor blood disorders like Sickle Cell Anemia (SCA) in Africa and globally. Sickle cell anemia (HbSS) is responsible for most cases of sickle cell disease. The improvement of mortality rates has been an exhausted topic both in the United States and parts of Africa, where Sickle cell hemoglobin or HbS is concerned. In Africa alone, where 80% of affected births occur, babies born with the disease die undiagnosed in early childhood. According to Fleming (1989), of the patients in Nigeria with SCA, approximately 50% die before the age of 1 year. The lack of information distributed in resource-poor countries like Nigeria, remains an ethical challenge with accountability in leadership. We propose the framework from this case study as the component required to track, organize and maintain the data for SCA decision making efforts.*

## Introduction
In The Elgar Companion to Social Economics, the authors present the future of work place dynamics as one that will be more democratic in nature [1]. In their analysis, workers and stakeholders (e.g. vendors suppliers and other interest groups outside of the organization) become both part owners and decision makers of the organization. As collaboration efforts increase through information sharing, so will the influence of group innovators to impact decision making [2]. Management Information Systems (MIS) provide the health care industry with a method to adequately address the morbidity and mortality rate of sickle cell anemia. Evidence-based research allows health care practitioners to make adept decisions using relevant, valid information to treat patients.

However, in the case of situational ethics, the accountability of the actor/practitioner may come into question without collaboration and clear communication reflecting the organization's accountability and observed ethical behavior. Take for instance the example of the University of California and Ted Ague. In January 2016, the University of California admitted its negligence in the death of Ted Agu in 2014 after a strenuous workout [3]. Agu, a defensive line back, died after a team drill in 2014 outside Cal Memorial Stadium. Interestingly, the school, doctors, and coach knew of Ted's sickle cell trait (SCT) since his freshman year in 2010. Besides the financial settlement, the outcome of Ted's death resulted in the deal to health and safety reforms for Cal athletics, some of which campus officials began on their own volition following Agu's death Feb. 7, 2014 [4]. Furthermore, a new policy stipulated that coaches and team doctors increase their education of sickle cell trait and the medical complications that can stem from it, since that time. In this scenario perhaps a demographic surveillance system containing SCT may have been formidable. The objective of this study is to evaluate global health demographic surveillance systems that can be used to track and monitor sickle cell disease (SCD). The study will identify and explore various MIS frameworks for organizing, collecting, analyzing, and interpreting data for healthy communities.

## Materials and Methods
To achieve the objectives for this study, the author revisited the initial pilot study that captured the qualitative responses from participants. Through meta-analysis, three qualitative areas of accountability were derived; (1) personal accountability: the willingness to claim ownership of one's actions [5], (2) Organizational Accountability: the agreed upon communication standards that measure an organization's success or failure [1], and financial accountability: the assessment of an organization's success based on financial gain or loss (1998). The definitions for information access, information capture, information sharing and decision making were initially derived by Majchrzak (2000) [6].

The reliability and validity tests performed on these quantitative measures [7] were the precursor to their utility in this study.

Additionally, the materials are also inclusive of revisions based on the technical and cultural similarities, and the updates to diagnoses seen in literature, and are not limited to: 1) the Health Demographic Surveillance System - a global systems used to track diagnoses and decision-making, and managed by universities for networked hospitals; 2) Using Accountability as an Institutional arrangement [5], where the institution is seen as the Forum/Principal (develops processes, maintains advocacy, leadership and stays abreast of technology and research); 3) Agents - as the actors of accountability (within their practice); 4) Observed Ethical Behavior - a measurement of what the Agent will do given information access; 5) Situational Ethics - standards for decision-making based on cultural roots, immediate scenarios/accepted protocols, societal influence and financial beneficiaries; and 6) Democratic System - a cloud based system where the decisions of agents, principals and institutions meet [8], supported by structural features [6], logarithmic rule formation [9] for health care surveillance of blood disorders like Anemia.

## Results

With a significance level of .000, the current study showed that there was a statistically significant relationship between the IV constructs - Personal and Organizational Accountability, and DV - Observed Ethical Behavior. Results of the principal component analysis showed that with Information access, organizational leaders were observed to exhibit increased knowledge and application of personal and organizational accountability. In addition, the factor loading of the Personal and Organizational accountability observed by participants explained 60% of the variance in the model. The combination of information access and information sharing with personal and observational accountability presents a formidable foundation towards the development of a framework toward ethical decision making framework. The components of this model are operationalized and then applied to the development of logarithms and terminology seen in the Hemoglobin Variants table (Table 1 and 2).

| Type | Hemoglobin Variants Name | Description | Diagnosis Codes |
|---|---|---|---|
| Normal | HbA | Exist after birth (Normal RBCs contain) | NA |
| | HbA2 | Found after birth | NA |
| | HbF | During fetal development, but decrease after birth | D56.4 |
| Abnormal | HbS variant | Sickle hemoglobin (common in people with SCD-Sickle cell trait) Africa, Uncommon in the US. When isolated it has no clinical or hematological consequences. | D57.2 |
| | HbD variant | Doubly heterozygous HbD/HbS, the HbD is able to enhance the sickling. Europe/India | D58.2 |

| | HbE | Benign, mild hemolytic anemia and splenomegaly (common in SE Asia) | D58.2 |
|---|---|---|---|
| Abnormal | HbH | Tetramer composed of 4 beta globin chains Uncommon in the US. Rare among the Arab population. No clinical or hematological consequences. | D56.0 |
| | HbO Arab variant | Associated with a mild to moderate anemia. Doubly heterozygous HbSO is associated with a sickling anemia similar in severity to sickle cell disease | D57.80 |
| | HbSS variant | Sickle cell anemia | D57.1 |
| | HbC variant | Benign, mild hemolytic anemia and splenomegaly (Africa) | D58.2 |
| | Hemoglobin Constant Spring | The globin chain is long. Chinese background | D56.0 |
| | Hemoglobin Bart's | Develops in fetuses with 4 gene deletion alpha thalassemia. Most die in utero (hydrops fetalis) | D56.0 |

**Table 1:** Hemoglobin Variants table.

| Complete Blood Count (CBC) | routine blood test that provides an overview of the number of cells in the bloodstream/body. This test can determine how many RBCs are present, and the hemoglobin amount.of cells in the bloodstream/body. This test can determine how many RBCs are present, and the hemoglobin amount. |
|---|---|
| Hemoglobin Electrophoresis | Identifies various hemoglobin's |
| Hemoglobin Fractionation | Screens for hemoglobin variants (S, etc.) |
| Hemoglobinopathy Evaluation | Evaluate types of hemoglobin types (normal and abnormal) |
| Blood smear | Also known as a manual differentiation, a blood smear is viewed under a microscope to determine the number and type of RBCs (sickle, etc.). |
| Iron test | Measures iron storage and usage in the body. Determines anemia. |

**Table 2:** Testing RBCs to determine Sickle cell Anemia.

The implementation of the table would appear outside of the Health-care surveillance system but managed by principals as seen in the diagram (Figure 1).
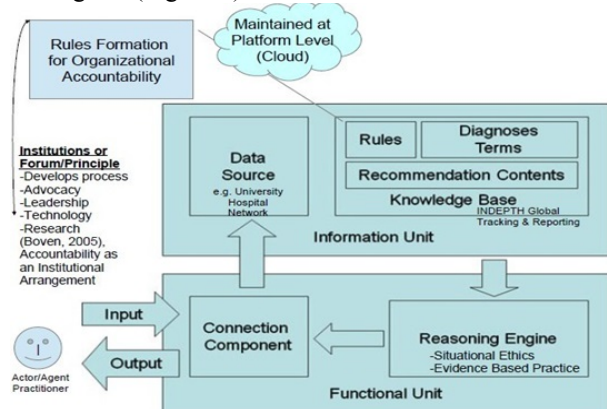
**Figure 1:** Architecture for the Sickle Cell Anemia Surveillance Tracking system.

## Discussion

Exertional sickling results from physical exertion. In the athletic forum, the first known sickling death in college football was in 1974, when a defensive back from Florida collapsed at the end of a 700- meter sprint on the first day of practice that season and died the next day. Devard Darling, a wide receiver for the Omaha Nighthawks, lost his twin brother, Devaughn, from complications of SCT in 2001 [10]. Known by many of his teammates as one of the most enthusiastic and hardworking teammates, Solomon Jackson died one week after he was hospitalized as a result of a medical emergency he suffered during an off-season conditioning workout the team held [11].

In less than 24 hours after a training session, Joshua Warren died from one of the top non-traumatic killers, exertional sickling caused by the sickle cell trait. A student and defensive back of Pine Tree High School football team, Joshua died after participating in a strength and conditioning workout at Pine Tree High School on July 1, 2015 (Sickle cell was seen as the cause in the Pine Tree athlete's death - Longview news-journal, 2016). The National Athletic Trainers Association (NATA) say that it is the third leading cause of non-traumatic death among high school and college athletes (2016). Therefore a demographic surveillance system containing the diagnoses of SCA cases beyond infancy may be the most appropriate means to assess the patient care of adults with the disease. Knowledge based systems, like the one proposed in this study are instrumental in helping stakeholders (physicians and coaches alike) as well as provide the highest level of transparency in the decision-making process.

The proposed architecture may enable communities to conduct various queries (ex. New services and infrastructure), identify underserved areas, evaluate quality and accessibility of health services, and locate health care facilities and assets, conduct reliable health surveillance. For the best communication and decision making, we recommend:

- Stronger collaborations: urban planners, health policy-makers, public health practitioners and community members
- Model of planning known as "collaborative health planning"
- Grounded in both 'communicative planning theory' and 'population health theory'
- Combine information, knowledge and skills from multiple stakeholders and generate agreement over solution.

## Conclusion

Advancements in information transparency as a communication process toward collaboration yield relationships in personal, financial and organizational accountability [12]. With the advent of human-agents, expert systems become a real possibility, prompting humans about the feasibility of choice before making it. Even after a selection/choice is made, it is also clear that information transparency will ensure the quality of the decisions being made in the near future.

The country of Africa is independently working to understand and face the challenge of SCD. Certain areas in Africa have a few guidelines in place for tracking the disease, but the country is nowhere near the undertaking North America has achieved at decreasing mortality rates in individuals with SCA. Cameroon has a national program that has not been implemented; Angola is taking measures that include follow-up from diagnosed patients achieving significant results in its effort, Ghana has newborn screening but is deficient in counseling the families of the disease. Uganda does not have a systematized process of diagnosing or tracking the SCD; their care is through support. The Nahuche HDSS study in Nigeria, have collected data (residing in the INDepth repository), and come up with solutions for improvement in mortality. The objective of this study is to provide a platform for conducting research that is certainly needed to drive health policies and programs for mothers and children dealing with SCA. Overall, prenatal diagnosis is in developed countries, but this should be considered in Africa especially in the areas that are stricken the most.

Through cloud technology, information transparency will also provide global tracking of decisions were necessary. Deaths in Africa are not only due to unemployment or healthcare, but is astonishingly due to the lack of information and knowledge surrounding Sickle Cell Anemia (SCA). Thus, the prescribed framework is recommended to improve the monitoring of the disease toward the overall health of citizens [13-41].

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