

Thesis Project Portfolio

Reforming the Informed Consent Process and Embedding Key Cultural Aspects

(Technical Report)

**Adequacy of the Informed Consent Process in Properly Serving the Black Community in
Charlottesville**

(STS Research Paper)

An Undergraduate Thesis

Presented to the Faculty of the School of Engineering and Applied Science

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In Fulfillment of the Requirements for the Degree

Bachelor of Science, School of Engineering

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Department of Engineering Science

On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Introduction

The topic of interest of both my research paper and technical project is informed consent. Informed consent is an ethical and legal requirement that takes place before a patient undergoes a medical procedure or research study. Its purpose is to inform the patient of the nature of the procedure, risks, benefits, and alternatives so that the patient is able to make a voluntary and informed decision of whether or not to participate in the research study or procedure. In my capstone project, I focused on the shortcomings of the structure of the informed consent process with regards to its content and how it is administered. In my research paper, I once again focused on the shortcomings of the informed consent process, this time with a focus on its role in enhancing racial inequities in the healthcare sphere, specifically in Charlottesville.

STS Research

In my research paper, the thesis statement I sought to support was that the history of informed consent and medical racism in Charlottesville has perpetuated a broken relationship between medical research and Black Charlottesville residents. In order to conduct a thorough analysis, I gathered a host of resources including academic journal articles, books, newspapers, and blog posts. For my literature review, I conducted a historical analysis, and for my analysis, I conducted a historical analysis from an ethnographic lens. I explored the racial history of Charlottesville, dove into the history of medical racism, and discovered the specific history of medical racism in Charlottesville. I conducted my research from the lens of Ruha Benjamin's

New Jim Code framework. I selected this as my framework as it specifically addresses the inherent and unintentional coding of racism into technology and society.

Through my analysis, I uncovered racial inequities regarding healthcare qualities and outcomes in Charlottesville. My findings shed light on the mistreatment of the Charlottesville Black community in medical procedures, a topic little is known about. Those who read my thesis will hopefully gain a better understanding of the racial history of Charlottesville's healthcare system and the ways in which it has failed to properly serve the Black community there. I hope this research is applicable to medical practitioners in Charlottesville to help them understand the complex history within which they are operating. It may also be beneficial for amending certain medical policies and practices that have failed to properly serve the Black community in Charlottesville.

Capstone Project

The requirements for the informed consent process are governed by a national healthcare-organization accreditation organization known as the Joint Commission. The entirety of the process must be documented, with five key elements, "(1) the nature of the procedure, (2) the risks and benefits and the procedure, (3) reasonable alternatives, (4) risks and benefits of alternatives, (5) and assessment of the patient's understanding of elements 1 through 4" (Shah et al., 2023, p.1). The documentation is often long, wordy, and places a heavy burden on the physician to properly communicate the procedure or study to the patient. Therefore, the patient is often not adequately equipped to make a voluntary, informed decision. The disparities of informed consent are only magnified by specific cultural beliefs and values, language barriers and socioeconomic status of members of minority communities.

In order to tackle these issues, in my capstone project, I created the framework for an application to enhance the informed consent process, specifically embedding cultural factors that previously stood as barriers for those with backgrounds in a cultural minority. It will be administered via iPad specifically for residents of the United States, and utilize video components with transcripts. The first section of the application asks preliminary questions to gather information such as language, level of education, and if the patient would like to invite anyone as a collaborator during the process. This information will be used to tailor the rest of the sections to accommodate the background and culture of the specific user. The next section will contain a video detailing the background and nature of the research study. Next, patients will be given a quiz to assess their knowledge and comprehension of the material they just observed. The next video patients are required to interact with details the other key elements of the informed consent process; the risks, benefits, alternatives, and the risks and benefits of the alternatives. Once again, the patient will be quizzed on their knowledge and comprehension. It is important to note that if at any time a question is answered incorrectly, the patient cannot move on until it is answered correctly. Finally, the application will require the patient to sign their name indicating they give their consent to participate in the study or procedure.

Conclusion

Due to the heavy overlap in content between my capstone project and research paper, I was constantly focusing on and studying more about informed consent which was beneficial to both projects. Since I was focusing specifically on the role of race in informed consent while writing my research paper, this was at the forefront of my mind while working on my capstone project as well. This aided me in ensuring that cultural factors were truly embedded into the

application I was designing. While working on this application, studying Ruha Benjamin's framework made me hyper aware of the ways in which race and racism become unintentionally encoded into technology so I could ensure this did not occur. Through my capstone project, I studied the informed consent process in depth. Since my research paper was more about the effects of informed consent rather than the process itself, working on my capstone project kept the elements of informed consent fresh in my mind. Therefore, I was able to write about informed consent thoroughly and accurately in my research.

Works Cited

Shah, P., Thornton, I., Turrin, D., & Hipskind, J. “Informed Consent.” (2023). *StatPearls*,

<https://www.ncbi.nlm.nih.gov/books/NBK430827/>