Research Ethics: The Tuskegee Syphilis Study (as quoted from the Tuskegee University website (http://www.tuskegee.edu))

“The Tuskegee Syphilis Study is one of the most horrendous examples of research carried out in disregard of basic ethical principles of conduct. The publicity surrounding the study was one of the major influences leading to the codification of protection for human subjects.

In 1928, the director of medical services for the Julius Rosenwald Fund, a Chicago-based charity, approached the U.S. Public Health Service (PHS) to consider ways to improve the health of African Americans in the South. At the time, the PHS had just finished a study of the prevalence of syphilis among black employees of the Delta Pine and Land Company of Mississippi. About 25% of the sample of over 2000 had tested positive for syphilis.

The PHS and the Rosenwald fund collaborated in treating these individuals. Subsequently, the treatment program was expanded to include five additional counties in the southern U.S.: Albemarle County, Virginia; Glynn County, Georgia; Macon County, Alabama; Pitt County, North Carolina; and Tipton County, Tennessee (Jones, 1981).

During the set-up phase of the treatment program, the Great Depression began. The Rosenwald Fund was hit hard and had to withdraw its support. Without the Rosenwald Fund, the PHS did not have the resources to implement treatment.

During this period, there was a debate occurring in health circles about possible racial variation in the effects of syphilis. Dr. Taliaferro Clark of the PHS suggested that the project could be partially "salvaged" by conducting a prospective study on the effects of untreated syphilis on living subjects. Clark's suggestion was adopted.

In the beginning stages of the project, the PHS enlisted the support of the Tuskegee Institute. Since the Tuskegee Institute had a history of service to local African Americans, its participation increased the likelihood of the "success" of the experiment. In return, Tuskegee Institute received money, training for its interns, and employment for its nurses. In addition, the PHS recruited black church leaders, community leaders, and plantation owners to encourage participation.

At the time of the project, African Americans had almost no access to medical care. For many participants, the examination by the PHS physician was the first health examination they had ever received. Along with free health examinations, food and transportation were supplied to participants. Thus, it was not difficult to recruit African American men as participants in the study. Burial stipends were used to get permission from family members to perform autopsies on study participants (Jones, 1981).

While study participants received medical examinations, none were told that they were infected with syphilis. They were either not treated or were treated at a level that was judged to be insufficient to cure the disease.

Over the course of the project, PHS officials not only denied study participants treatment, but prevented other agencies from supplying treatment.
During World War II, about 50 of the study subjects were ordered by their draft boards to undergo treatment for syphilis. The PHS requested that the draft boards exclude study subjects from the requirement for treatment. The draft boards agreed. In 1943, the PHS began to administer penicillin to patients with syphilis. Study subjects were excluded.

Beginning in 1952, the PHS began utilizing local health departments to track study participants who had left Macon County. Until the end of the study in the 1970s, local health departments worked with the PHS to keep the study subjects from receiving treatment.

The project was finally brought to a stop 1972 when Peter Buxton told the story of the Tuskegee Study to an Associated Press reporter. Buxton was a venereal disease interviewer and investigator for the PHS who had been attempting to raise the issue within the PHS since 1966. Despite his protestations, the "experiment" was still being carried out when the story appeared on the front pages of newspapers around the country (Jones, 1981).

Congressional subcommittee meetings were held in early 1973 by Senator Edward Kennedy. These resulted in a complete rewrite of the Health, Education, and Welfare regulations on working with human subjects. In the same year a $1.8 billion class action suit was filed in U.S. District Court on behalf of the study subjects. In December of 1974, the U.S. government paid $10 million in an out of court settlement.

The Tuskegee Syphilis Study remains one of the most outrageous examples of disregard of basic ethical principles of conduct (not to mention violation of standards for ethical research). In 1976, historian James Jones (1981) interviewed John Heller, director of the Venereal Diseases unit of the PHS from 1943 to 1948. Among Heller's remarks were the following: "The men's status did not warrant ethical debate. They were subjects, not patients; clinical material, not sick people" (p. 179).

The suspicion and fear generated by the Tuskegee Syphilis Study are evident today. Community workers report mistrust of public health institutions within the African American community. Alpha Thomas of the Dallas Urban League testified before the National Commission on AIDS: "So many African American people I work with do not trust hospitals or any of the other community health care service providers because of that Tuskegee Experiment" (National Commission on AIDS, 1990).

The Southern Christian Leadership Conference (SCLC), one of the country's major civil rights organizations, has been providing AIDS awareness education through a program called RACE (Reducing AIDS through Community Education). In 1990, the SCLC conducted a survey among 1056 African American Church members in five cities. They found that 34% of the respondents believed that AIDS was an artificial virus, 35% believed that AIDS is a form of genocide, and 44% believed that the government is not telling the truth about AIDS.

The materials for this page were largely derived from --

**Discussion Questions: Human Experimentation**
1. What benefits were gained from the study?
2. What evidence do we have that participation in the project was harmful?
3. Was it possible to inform the participants about the true goals of the study?
4. Given that participants who participated in this study received benefits, could they reasonably be expected to exercise good judgment about their participation in this project?
5. Are there circumstances that you could imagine where informed consent would interfere with an experiment?
6. Are there any circumstances where the overall good of an experiment to society overrides the harm done to a small group?
7. What do you think John Heller, director of the Venereal Diseases unit of the PHS from 1943 to 1948, meant when he stated in 1976: “The men's status did not warrant ethical debate. They were subjects, not patients; clinical material, not sick people.”