# E-mail Interview with Carol Yoon

Interviewer: What was the reaction within the community to the experiment?

Yoon: By the time I was talking to people, mostly descendants and people who had spoken with descendants, the overwhelming emotion around the experiment was a powerful mixture of anger and shame. Of course, during the experiment there was no reaction, since no one, except the researchers, had any idea what was going on. They just thought they were getting medical care.

Interview: When you talked to the surviving Tuskegee patients, what were their feelings?

Yoon: The one actual survivor of the experiments that I spoke with was Herman Shaw who was quite elderly when I met him. We sat on his porch and chatted. He seemed, as I recall, like a gentle person and I don't remember him seeming angry at all. This could have been a matter of politeness, but my sense really was more that, in general, there was a kind of bewilderment or even detachment about the whole thing. Imagine that first you're told your getting medical care, then you're told you've been used as a human guinea pig. After a while, I imagine you don't put much stock or take a whole lot of interest in what the government might have to say to you in any case.

Interviewer: How important was Clinton's apology in moving past this event? To what extent did it provide closure to the Tuskegee patients?

Yoon: That is an excellent question and I wish I knew the answer. I did attend the event but I finished writing the story before it took place. If you did end up talking with Ms. Head, that would be a great question for her.

Interviewer: What was the impact of the study on the family members of Tuskegee patients?

Yoon: The overwhelming impact, from what I could see, was a lingering anger, shame, shock and a strong distrust of the government, a really strong sense of having been used. It was very painful to learn how much shame was felt by descendants. Why should anyone feel shame except the experimenters? But the issue is, in part, the fact that the disease was syphilis, which is a sexually transmitted disease. There's the irrational idea that if people have a sexually transmitted disease, and in this case, that their ancestor did, that they're bad in some way, as opposed to people who have other diseases.

Interviewer: What impact of the Tuskegee Study do you see today?

Yoon: I think the broadest impact has been a deep distrust of the government and maybe of white people in positions of power, generally. And it's a legacy not just among families impacted directly by the study but by black Americans generally and really, I would think, by people of color in America. Maybe even by anyone who sees themselves as

outsiders to the mainstream power structures in the country, whether because of race or economic status etc.

Interviewer: What has the government done to compensate for the losses tithe families of Tuskegee patients?

Yoon: They were offered free medical care if they tested positive for syphilis. That makes sense, since their having syphilis could well be a result of the experiment's non-treatment of the men. But the irony of course is that - that's what the initial experiment offered in the first place! Understandably there have been people who don't want anything to do with it.

Interviewer: How do responsibilities play a role in the Tuskegee study?

Yoon: I would say the one really interesting person I spoke to, regarding responsibility, was Dr. Jenkins who struck me as the one person who exhibited a deep sense of personal responsibility regarding the study. He told me that he'd tried to stop the work when it was going on but was unable to. He later ran the program getting families of the original patients the medical care they were owed by the government. He was very clear that he wanted to protect the families from any use of their health status as part of any kind of study, given what had happened. He was really trying to make amends for what he felt had been done to them. And of course, the presidential apology was a way of the Federal government taking responsibility at last for what had been done. And while in some ways it's so much after the fact that it seems quite abstract, like other apologies the government has made, I think it's meaningful in that it tells us that society has changed to the degree that something like the Tuskegee study that was once acceptable, at least acceptable enough to enough people that it actually happened, is no longer acceptable.