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# Moving Forward: No Scientific Integrity without an Acknowledgment of Past Wrongs

*Felicia Schanche Hodge*

The recent presidential action, “Memorandum on Restoring Trust in Government through Scientific Integrity and Evidence-Based Policymaking” paints an interesting commitment to truth and reconciliation in restoring trust in government through scientific integrity and evidence-based policymaking across the federal government.<sup>1</sup> Biden’s “Memorandum for the Heads of Executive Departments and Agencies” serves as a timely reminder of past injustices and unethical research in communities of color and brings attention to the need for equality and trust during the current COVID-19 pandemic. Acknowledgment of historical wrongs is germane particularly in restoring trust in public health directives for COVID-19, including encouraging community participation in vaccination programs and the wearing of masks, social distancing, and handwashing, all critical for the management and control of the virus. Distrust of government-sponsored research and health programs continues, however, largely due to ongoing discriminatory and unethical behavior in the health profession.

A hospital in New Mexico, for instance, recently enacted a COVID-19 testing policy that singled out American Indian women based on their race and zip code. Further, while they awaited test results, many were separated from their newborns, depriving them of significant bonding.<sup>2</sup> Only one of many examples in a long list of medical and research abuses experienced by American Indians, distrust of government-sponsored research and medical programs has been fueled by past horrific incidents. The military and the federal government led a significant number of medical and

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research abuses experienced by American Indians and Alaska Natives since European colonization. Among the most egregious, well-documented cases of abuse are forced procedures, one that cut off both upper and lower eyelids (called a “tarsectomy,” supposedly a treatment for trachoma);<sup>3</sup> sterilization of women and girls as young as fifteen;<sup>4</sup> and a radioactive isotope given to non-English-speaking Alaska Natives to examine its impact on the thyroid gland.<sup>5</sup> Medical consent forms were often absent or inadequate, illegally obtained (often under threat), and not in compliance with appropriate regulations.

Research continues nonetheless, with little or no reference or consideration given to past abuses. For instance, a university Institutional Review Board (IRB) breached IRB agreements with an Arizona tribe regarding blood sample storage, publications, and methods/topics.<sup>6</sup> Only after the tribe filed a lawsuit did the university agree to return some of the blood samples; however, the researchers incurred little or no consequences for these irregularities.<sup>7</sup> Perhaps due to the small numbers of tribal members, cultural differences, and relatively little impact upon larger society, such research abuses may generate minimal attention.

Partial acknowledgment of past research abuse has occurred in other contexts, but American Indians have yet to experience visible federal acknowledgment in the United States. In 1997 President Clinton issued a highly visible public apology to the African American survivors of the Tuskegee syphilis experiment, in 1998 President Reagan made a formal statement and signed the Japanese Internment Apology, and in 2010 President Obama called the Guatemalans to apologize for US research.<sup>8</sup> For American Indians only a weak statement has been issued, lost in the volumes of a 2009 defense spending bill, that simply states regret for many wrongs without specifying medical or research abuses and apologizes for many instances of violence, maltreatment, and neglect.<sup>9</sup> Moreover, because few are aware of this resolution and a formal apology was not voiced, presented, or disseminated to American Indians, this statement can hardly be seen as a meaningful apology.

Multiple research insults perpetrated on American Indians, especially those that violated basic human rights, and in some cases resulted in genocide, cannot be easily forgotten. The wounds of prior medical and research abuses will not heal without a meaningful apology coupled with protective steps, such as strong policies and legal consequences for failure to protect vulnerable populations from such abuses. To guarantee ethical research in which benefits outweigh risks and findings are not value-laden or misrepresented, many tribes have instituted their own IRBs combined with community-participatory activities to facilitate identification of the research problem, guidance in the steps to address the health issue being studied, and more control via review and approval of emerging scholarly publications. The implementation of tribal IRBs has strengthened tribal control over research and created a protective measure without being excluded from research and medical programs.

In response to President Biden’s memorandum, there can be no scientific integrity without an acknowledgment of past wrongs and pledges to do better in the future. Fundamental changes are needed that go beyond the President’s Memorandum to ensure existing scientific-integrity policies do not disproportionately harm historically

underrepresented federal scientists and researchers in science and technology or present barriers to equitable delivery of federal government programs. Moreover, expanding open access to routinely collected federal, state, and tribal data is essential for researchers to evaluate equitable delivery of policies and inform future steps. Past harm to communities and to individuals need to be acknowledged and corrected. Methods of culturally appropriate data collection (such as Talking Circles) and participatory research models need to be considered. Existing policies need to be inclusive allowing tribes to collect, analyze, and take part in reporting. Truth and reconciliation are needed in order to move forward and regain trust in scientific integrity and evidence-based policymaking.

## NOTES

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