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Bioethicists call for investigation into nutritional experiments on Aboriginals

Leading bioethicists say that the nutritional research on Aboriginals in the 1940s and 1950s that came to light last month, sparking an outcry from the Chiefs of First Nations and nationwide rallies, requires a comprehensive investigation.

The research "is of a piece with Tuskegee and other infamous research," said bioethicist Michael McDonald, Professor Emeritus at the University of British Columbia in Vancouver. An investigation with "access to records that even historians can't get hold of" is essential, he said.

Richard Sugarman, chair of the research ethics board at the Hospital for Sick Children in Toronto, Ontario, also cited the *Tuskegee Syphilis Study*, during which United States government researchers observed African American men with syphilis for 30 years without providing treatment, to document the progress of the infection.

In Canada's nutrition studies, government-sponsored researchers working with Aboriginals knew they were undernourished, "and they weren't treating it," said Sugarman. "Who knows what happened here?" he said. "There needs to be an investigation."

The question now is: Who will conduct that investigation? The federal government's Truth and Reconciliation Commission has the authority to investigate, but its five-year mandate expires in July 2014. "With the end date as it is, we will be very hard pressed to receive and review everything," said commission spokesperson, Heather Frayne.

Several opposition members of Parliament have called for an extension of the commission's mandate and the Manitoba Legislative Assembly passed a resolution in late July, calling on the government to extend the mandate beyond five years specifically to enable the commission to investigate the nutritional research.

It has long been known that students at residential schools were undernourished, but the nutritional research study was less known until historian Ian Mosby, a postdoctoral fellow at the University of Guelph, published a description of the experiments in the Journal of <u>Social History</u>.

Mosby was combing through federal records on nutrition policies and found that hundreds of Aboriginal adults and children were unknowingly test subjects in studies of nutritional supplements. The research began in 1942, when experts including Frederick Tisdall, the physician credited with inventing Pablum, travelled to Aboriginal communities in Northern Manitoba and documented the hunger there, describing certain individuals as "almost starved." Tisdall and the other scientists tested the effect of vitamin supplements, giving riboflavin, thiamine or ascorbic acid supplements to 125

Aboriginals, while 175 served as controls. Mosby said he did not find any results from that study.

Susan Zimmerman, the lawyer who directs the federal government's Secretariat on Responsible Conduct of Research, said the nutritional research is the worst case of research abuse against /aboriginals that she knows of.

Truth and Reconciliation Commission Chair, Justice Murray Sinclair, has said that at the time of the nutrition research "everybody involved in scientific work knew it was wrong to put people into an experimental situation without informing them what they were doing." But recently another example emerged of research done on Aboriginals without consent: the commission found evidence that <u>drugs were tested on Aboriginal adults and children</u> prior to their use in the rest of Canada.

Nor are these isolated cases. A few years after Tisdall's research, controlled studies were part of a research project led by federal nutrition expert Lionel Pett at six residential schools. During the studies, the researchers discontinued services by Indian Health Services dentists at the six schools, because the development of caries and gingivitis was considered important for assessing nutritional status. As a result, care was withheld to ensure the accuracy of study results.

Children at the school in Port Alberni, British Columbia, were receiving eight ounces of milk per day though Canada's Food Rules recommended more than twice that amount. Pett's team collected baseline data for two years on children under the 8-ounce policy, before increasing their rations to 24 ounces, in order to study the effects of tripling the milk intake.

Another contentious research project involved a school in Nova Scotia where a placebo-controlled study of vitamin C supplementation using 100 mg ascorbic acid tablets took place.

Trent University professor John Milloy, a former Truth and Reconciliation Commission research director, believes more human experiments will emerge, based on what he read in archives. "There were whispers in the files about dental experimentation," he said.

An Aboriginal Affairs and Northern Development Canada spokesperson called the nutritional research "abhorrent," and said the agency gave the Truth and Reconciliation Commission 900 documents related to it.

Mosby believes there should be more than 900 documents. "That seems like a low number in my mind for an experiment that in residential schools alone, went on for five years at six schools," he said.

When records from a <u>series of unethical experiments</u>, also from the 1940s, were discovered in the US in 2010, the Presidential Commission for the Study of Bioethical Issues investigated, gathering tens of thousands of pages of archival records and reviewing more than 125 000 pages of records.

The Truth and Reconciliation Commission needs documents from 80 church archives and 24 different government departments, according to the Auditor General of Canada's 2013 Spring Report on the commission's work. But the government initially said federal librarians and archivists were not obliged to produce documents. The

commission took the issue to court and on Jan. 30, 2013, the Ontario Superior Court ordered the government to provide the commission with all relevant documents.

Even with the court decision, obtaining documents from Library and Archives Canada has been "a very slow process," said the commission's Heather Frayne. But the events triggered by the nutrition experiments may have turned the wheels. Commission contractors were allowed into the federal archives on Aug. 6 and will work there for three months. — Miriam Shuchman, Toronto, Ont.

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