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Capturing Indigenous Health and Research Data: Suggestions for Escaping the Cycle of Mistrust

Indigenous peoples on an international scale experience much poorer health conditions than non-Indigenous peoples.¹ While there is enough statistical evidence to infer that a serious health gap exists between Indigenous and non-Indigenous peoples, accurate and wide-ranging data are very hard to come by.² Since many Indigenous peoples are unseen by international organizations and many national censuses, the health data available are skewed.³ This lack of data serves as a serious shortcoming to global efforts aimed at improving Indigenous health conditions. It also makes evident the pressing need for high quality research to be conducted in the world's Indigenous communities.

The challenge with conducting this high quality research is that a cyclical system of mistrust can be observed on a world scale between Indigenous communities and the non-Indigenous communities that surround them. This cyclical mistrust can generally be understood as the Indigenous community viewing the state as a distrustful entity seeking census data solely for managerial or control purposes. The state, in turn, may also mistrust the Indigenous community for deviating from the Western conception of social organization. This paper will argue that this system of mistrust is cyclical in nature and must be broken if future research collaboration efforts are to be successful. While

¹ State of the World's Indigenous Peoples Report, UN. Page 161.

² Ibid.

³ State of the World's Indigenous Peoples Report, UN. Page 162.

cooperation between state institutions and Indigenous communities is important, it is also equally important to emphasize the ever-increasing strength of Indigenous communities and their ability to respond to these health-related issues themselves.

It is first necessary to paint a clear picture of the adverse health conditions Indigenous people face on an international scale. According to a health report provided by the United Nations, Indigenous people experience much poorer health conditions than non-Indigenous people in a variety of ways. Indigenous peoples experience “disproportionately high levels of maternal and infant mortality, malnutrition, cardiovascular illnesses, HIV/AIDS and other infectious diseases like tuberculosis and malaria.”⁴ On a global scale, the health disparities between Indigenous and non-Indigenous populations exist no matter what health condition is being examined.⁵

While the current epidemiological data available allows researchers to generally sketch out the health disparities that exist between Indigenous and non-indigenous communities, there is a serious lack of census data on Indigenous communities. A study conducted by the Pan American Health Organization observed that Indigenous peoples are somehow unseen by international organizations and most national censuses during the collection of data.⁶ This means that it is impossible to have a comprehensive and accurate sense of the health disparities between Indigenous and non-Indigenous communities. PAHO argues that the lack of statistics sorted by ethnic group, gender, and age make the development of health policies aimed at improving global Indigenous health very difficult.⁷

⁴ State of the World’s Indigenous Peoples Report, UN. Page 161.

⁵ State of the World’s Indigenous Peoples Report, UN. Page 162.

⁶ State of the World’s Indigenous Peoples Report, UN. Page 165.

⁷ State of the World’s Indigenous Peoples Report, UN. Page 165-166.

To better understand why policy decisions from wider epidemiological research are invalid for Indigenous communities, it is helpful to consider the prevalence of type 2 diabetes mellitus (T2DM) among Indigenous communities in North America. The frequency of T2DM in these communities is not only disproportionately higher than in non-Indigenous communities, it is also increasing at rapid rates.⁸ According to doctors Hasu Gosh and James Gomes, it is essential to establish population-based risk factors specific to the Indigenous communities themselves.⁹ This is because diabetes is a disease that permeates through the “web of interactions” within a specific community. Gosh and Gomes agree with the argument made within Indigenous communities that diabetes reduction efforts have been unsuccessful because they fail to offer population-particular reduction methods.¹⁰ The scientific justification for this argument is that there are specific biomedical risk factors that are born within these Indigenous communities and continue to be perpetuated within the communities themselves.¹¹ Thus policies arising from wider epidemiological data cannot adequately account for the diverse biomedical conditions of individual Indigenous communities. These conditions are a product of population-specific processes of interaction.

Based on the importance of population-level data for mitigating diabetes, Gosh and Gomes criticize the lack of state support for disease prevention and management solutions that arise from local Indigenous communities.¹² They point to the reality that

⁸ Ghosh, Hasu, and Gomes, James. *Type 2 Diabetes Among Aboriginal People in Canada: A Focus and Direct and Associated Risk Factors*. Page 246.

⁹ Ibid.

¹⁰ Ghosh, Hasu, and Gomes, James. *Type 2 Diabetes Among Aboriginal People in Canada: A Focus and Direct and Associated Risk Factors*. Page 247.

¹¹ Ibid.

¹² Ghosh, Hasu, and Gomes, James. *Type 2 Diabetes Among Aboriginal People in Canada: A Focus and Direct and Associated Risk Factors*. Page 267.

T2DM is a fairly new disease in Indigenous communities and is caused by a variety of factors. In general, all of these factors derive from the transition of Indigenous peoples from traditional hunter-gatherers to more westernized citizens.¹³ This western lifestyle can be equated with things like “decreased physical activity, increased prevalence of obesity, and major shifts in diet.”¹⁴ These factors, combined with general genetic susceptibility to the disease, have led to the T2DM outbreak.¹⁵ Since the problem has arguably arisen from an external factor, perhaps the solution needs to arise internally. Establishing a solution internal to Indigenous communities themselves becomes complicated by the fact that consuming unprocessed foods is very expensive in Northern communities. If Indigenous communities in North America are going to make wiser dietary decisions, they need look to food markets that inevitably extend into the national and global economic market. So while local Indigenous solutions are indeed important for mitigating the disease, the national and even international scope of the problem requires cooperation with non-Indigenous entities.

The pressing need for more accurate health data, as illustrated by the T2DM example, introduces the cyclical nature of the Indigenous health problem. While it is clear that collecting more accurate Indigenous health data could mean improving Indigenous health, Indigenous people may refuse or be reluctant to cooperate with state entities or non-Indigenous researchers. This distrust is rooted in the colonial structures of the past. The residential school systems instituted in Canada, for example, forcibly removed children from their homes and assimilated them into the common Western

¹³ Ghosh, Hasu, and Gomes, James. *Type 2 Diabetes Among Aboriginal People in Canada: A Focus and Direct and Associated Risk Factors*. Page 267.

¹⁴ Ghosh, Hasu, and Gomes, James. *Type 2 Diabetes Among Aboriginal People in Canada: A Focus and Direct and Associated Risk Factors*. Page 268

¹⁵ Ibid.

culture.¹⁶ Aboriginal parents were told that their children would become suited for the modern economy, but instead were violently disciplined and taught to forget their own language and cultural practices. These residential school systems, rather than assist Aboriginal children find jobs in the modern economy, selected them for domestic and manual labor duties.¹⁷ The Canadian state offered to better the situation of the Indigenous people, but instead, betrayed them in favor of their own disguised interests. This creates historical context for understanding why Indigenous people might be resistant to state development initiatives like gathering more accurate census data. While the state or state-represented researchers may claim that gathering this data will better the health position of the Indigenous community, the colonial past makes it hard for Indigenous people not to assume that this could be some guise for pursuing the state's own hidden interest.

A more modern root of the distrust can be seen in the Indigenous resistance to development projects being carried out on their land. According to a report provided by the International Work Group of Indigenous Affairs (IWGIA), most states distrust Indigenous people's institutions and modes of development. Indigenous people do promote development, but only development that respects the environment and tries to encompass "rights, culture, and spiritual values and are seeking sustainable ways of life built on traditional knowledge."¹⁸ This may create state frustration because the Indigenous model of development is an obstacle to the state model.

A modern example of how conflicting values surrounding development and social organization can lead to mistrust is the Botswana state and its Indigenous San people. In

¹⁶ Smith, Linda Tuhiwai. *Decolonizing Methodologies*. Page 68.

¹⁷ Smith, Linda Tuhiwai. *Decolonizing Methodologies*. Page 68-69.

¹⁸ International Indigenous Working Group on HIV/AIDS. *Report of the Working Group on the Issue of Human Rights and Transnational Corporations*. Page 15.

the mid 1990s, the government of Botswana relocated the San people from their ancestral territory, XamKhomani, to newly created settlements, like New Xade.¹⁹ The government justified this relocation policy by arguing that the XamKhomani territory, resting on the Central Kalahari Game Reserve (CKGR), was threatening the wildlife preservation efforts going on within the reserve.²⁰ According to Keikabile Mogodu, the director of Khwedom, a San rights group, rather the opposite is true. Mogodu argues that the San people have been caretakers of the land, its plants, and its wildlife in the CKGR for generations.²¹ The Khwedom Council views the government's decision to relocate the San people from their traditional territory as part of a strategic nation-building project. The San people believe that the government wants to integrate them into the dominant Tswana culture and destroy their language and culture.²² Proponents of this view hold that the government wants to take the San people's land away and use it for cattle farming, tourist trade, or diamond mining.²³

According to Professor Steven Robins, a South African anthropologist and social theorist, the government's relocation policy not only created distrust between the government and the San people, but also between different San tribes.²⁴ The government distrust was depicted in media portrayals of San people as uncivilized or as a tribal "other."²⁵ When the government introduced the relocation policy, the San people were

¹⁹ Robins, Steven. *NGOs, "Bushmen" and Double Vision: The Khomani San Land Claim and the Cultural Politics of Community and Development*. Page 833.

²⁰ Lee, Richard. *Botswana Government at War with San*. Page 1.

²¹ Ibid.

²² Ibid.

²³ Ibid.

²⁴ Robins, Steven. *NGOs, "Bushmen" and Double Vision: The Khomani San Land Claim and the Cultural Politics of Community and Development*. Page 834.

²⁵ Robins, Steven. *NGOs, "Bushmen" and Double Vision: The Khomani San Land Claim and the Cultural Politics of Community and Development*. Page 834.

dehumanized for their hunter-gatherer nature, and this perpetuated a “Bushmen” narrative that rung through the social structure. In turn, the San people distrusted the government because they felt their relocation symbolized a government effort to destroy San culture. The government justified its policy in the name of wildlife preservation, but for the San people, this was just a guise to stimulate the national economy.

Whether or not the government intended to harm San culture, what the relocation policy certainly did was create intra-community tensions between San peoples post-settlement. These tensions can be described as a divide between “traditionalists” and the “western” Bushmen.²⁶ Robins traces the origins of this conflict to the view among donors and NGOs that the San people were both “First People” and “modern citizens in the making.”²⁷ Based on these views, the South African San Institute (SASI) aimed at combining traditional leadership practices with modern democratic principles.²⁸ This created a tension between westernized bushmen, advocating these modern democratic principles, and more traditional San people, advocating traditional leadership practices. Robins argues that a previously peaceful San people had become plagued with problems like social segregation, homicide, alcoholism, and disease.²⁹

The distrust between the San people, the government, the traditionalists and the western bushmen illustrates the cyclical nature of the problem, but also the danger of failing to create an open dialogue between parties with conflicting values. Jürgen Habermas offers a helpful theoretical framework for understanding the mistrust that

²⁶ Robins, Steven. *NGOs, “Bushmen” and Double Vision: The Khomani San Land Claim and the Cultural Politics of Community and Development*. Page 844.

²⁷ Ibid.

²⁸ Ibid.

²⁹ Robins, Steven. *NGOs, “Bushmen” and Double Vision: The Khomani San Land Claim and the Cultural Politics of Community and Development*. Page 834.

exists between Indigenous and non-Indigenous communities. The theoretical framework he provides also offers promising solutions for how to overcome mistrust and foster cooperation through a dialogical and communicative approach.

Habermas, like Rawls, believes that one of the most fundamental challenges society faces is how to establish normative agreements under conditions of deep pluralism.³⁰ Habermas's discourse ethics is his solution to the problem of how norms can be justified in a post metaphysical world with different and often conflicting value spheres.³¹ Given that societies lack a shared metaphysical framework, meaning different conceptions of the good and morality, normative validity derives from the mutual obligations people share and that are affirmed through speech. Habermas describes an intersubjective web of meaning that already exists in society.³² According to Habermas, a society already intuitively shares obligations that form norms of conduct and these norms are affirmed through an ongoing creative dialogue. This theoretical framework proves helpful and challenging at the same time. The idea of an intersubjective web of meaning is helpful for understanding how a certain set of shared norms can exist in a society, but it is challenging because Indigenous communities are usually isolated from the rest of the non-Indigenous community. While conditions of pluralism do exist in non-Indigenous societies, these societies live together more harmoniously and are more synchronized to Western models of social organization and practice. Indigenous communities, usually situated in isolated reserves, share a different intersubjective web of meaning that is the result of their own unique cultural and spiritual traditions. The argument here is that to engender more trust between Indigenous and non-indigenous communities, it is necessary

³⁰ Jürgen Habermas, *The Inclusion of the Other*. Page 4.

³¹ Ibid.

³² Jürgen Habermas, *The Inclusion of the Other*. Page 7.

to develop at the very least toleration and respect for the different normative commitments these communities share.

According to the Khwedom Council of the San people, they have made frequent attempts to consult with the government of Botswana.³³ In light of a new government threat to relocate a San community of over 600 people, the need for a creative dialogue between these two conflicting parties becomes ever-pressing. It is clear that attempts at modernizing the San people, as seen through the original relocation project, have created distrust even between San communities. In this case, from a Habermasian view, these conflicting parties need communicate with each other and try at minimum to understand and tolerate the conflicting conceptions of social organization that are at the root of this distrust. While this is a minimum standard, a maximum standard would be to find middle ground where the normative commitments internal to the different conceptions of social organization overlap. If the conflicting parties can identify and focus on the normative values that they share, rather than the normative values that set them apart, this is a step closer to mitigating distrust and achieving resolution. Based on Robins' analysis of the conflict, the government of Botswana originally valued the San people for their sense of community.³⁴ These communal values had characterized the San people prior to the resettlement and had been compromised as a result of the western bushmen-traditionalist divide. It would appear that not only had these competing conceptions of social organization set the government of Botswana and the San people apart, it had also set apart the San people internally. Based on Robins' observations, and Habermas's theoretical framework, the most hopeful solution is for all parties to engage in a

³³ Jürgen Habermas, *The Inclusion of the Other*. Page 7.

³⁴ Robins, Steven. *NGOs, "Bushmen" and Double Vision: The Khomani San Land Claim and the Cultural Politics of Community and Development*. Page 834.

communicative dialogue that starts from a place of respect for communal values. If these parties allow a norm that they share to guide the discussion rather than the norms that set them apart, perhaps distrust can be mitigated and a future of compromise is possible.

Michel Foucault offers another interesting theoretical model for understanding the distrust that exists between Indigenous and non-Indigenous communities. Foucault understands the modern state as an entity that expresses power through managing its population.³⁵ This conception of the state provides a theoretical account of why Indigenous people, often viewed as a rogue social group in society, might resist being managed or being assimilated into the common culture. Foucault calls the state's management function biopower. Biopower is expressed through controlling life, maintaining it, and bettering it.³⁶ The two forms biopower takes, discipline of the body and the regulation of the population, are tools invoked by the state to control or regulate its people. Discipline of the body is the idea that power sees the human body as a productive instrument that has economic uses, military uses, and other state benefiting uses.³⁷ Indigenous people saw the exploitation of their children during the colonial period for the purpose of providing manual and domestic labor for the state. The state may also view Indigenous communities as being obstacles to economic development initiatives because of their differing viewpoints. The regulation of the population focuses on the ability of the body to reproduce life and seeks to control the population statistically through things like demography and studies of wealth.³⁸ This second way power is expressed by the state provides a perfect theoretical account of why Indigenous

³⁵ Foucault, Michel. *The History of Sexuality*. Page 136.

³⁶ Ibid.

³⁷ Foucault, Michel. *The History of Sexuality*. Page 139-140.

³⁸ Ibid.

communities might be resistant to national forums or state census gathering efforts. From the Indigenous perspective, the more information the state has on an Indigenous community, the more equipped they will be to manage or control the population.

Foucault's analysis of how the state uses statistics to control its population can be extended to show how the state uses censuses about identification to trap Indigenous people into a state-manufactured category or stereotype. Part of the reason Indigenous people or Indigenous communities are unseen by national censuses in particular is because many Indigenous people choose not to self-identify. According to a study conducted by the International Journal of Circumpolar Health, many Indigenous people may not identify as Indigenous because they wish to avoid institutionalized racism and discrimination.³⁹ Many Indigenous groups argue that stereotypical ideas about what it means to be Indigenous resonate based on narratives of savagery and barbarism.⁴⁰ These groups point to an ongoing Western narrative that locks Indigenous people in a time capsule, where they are untouched by modernity and Western conceptions of social organization.⁴¹ A powerful example of these sentiments can be seen in a quote by Quechua, an Indigenous leader from Ecuador: "Why can't I be Quechua running COICA, the biggest multinational Indigenous organization in the Americas? All they [Western academics] see are the externals – dress, language, socio-economic condition... These characterizations do not match the present-day reality of the heterogeneity among Indigenous Peoples in terms of social organization, cultural beliefs and practices."⁴²

³⁹ Bartlett, Judith G. *Identifying Indigenous Peoples for Health Research In a Global Context: A Review of Perspectives and Challenges*. Page 292.

⁴⁰ Ibid.

⁴¹ Bartlett, Judith G. *Identifying Indigenous Peoples for Health Research In a Global Context: A Review of Perspectives and Challenges*. Page 293.

⁴² Ibid.

Quechua captures the sentiment of many Indigenous groups, who feel like the idea of identifying as an Indigenous person only perpetuates a false image created by Western society. To identify as Indigenous within a given society today, for many Indigenous people, only means to fall into false stereotypes and images of “indigenusness” that are created by people who view Western conceptions of social organization as superior.

The argument made by Quechua and other Indigenous groups gives Foucault’s argument about biopower more meaning. Not only does the state have the capacity to control Indigenous populations by acquiring identity statistics, it also has the capacity to trap Indigenous people in stereotypical model of anti-modernity generated by Western bias. Indigenous people may be resistant to identifying as Indigenous because to identify would be to consent to the stigma and discrimination generated by Western norms about social organization and modern value. Quechua felt that his identity was being shaped by Western perceptions of his material self, the way he dressed, or the perceived socio-economic status of his people. From this perspective, it seems that Western societies want to identify an Indigenous person’s indigenusness, rather than let Indigenous people define indigenusness for themselves. If Indigenous people are going to start identifying as Indigenous, then it is up to society to allow them to make that identification in their own right. The idea that there is a superior Western way of living, dressing, and being only creates an otherness framework and perpetuates the current mistrust. For Indigenous people to start self-identifying, there is going to have to be a shift in the way Indigenous identity is conceptualized.

Linda Tuhiwai-Smith, an Indigenous researcher and theorist, offers another model for understanding the mistrust and solving the conflict. For Tuhiwai, the pinnacle of the

mistrust exists because an inherently Western model of research dominates and has dominated interaction between Indigenous and non-Indigenous communities. To establish a decolonizing procedure for research, there must be a basic understanding of the fact that colonialism was not just an enterprise that displaced people from their land through military might and unjustified political control. Indigenous peoples also experienced a colonization of the mind that continues to have grave psychological implications in a modern world where “independence” has been gained.⁴³ What this means is that decolonization is not just about colonizers handing over the formal institutions of government. Establishing a truly decolonizing methodology must be about the long-term process of removing the cultural, syntactical, and psychological influences of the colonial past.⁴⁴ The Western research model, from an Indigenous perspective, is one that can be best understood as a process of classifying the other based on reasons specific to the Western narrative rather than the distinct and internal narrative of an Indigenous community itself. The West perpetuates a neocolonial worldview by analyzing Indigenous communities using Western conceptions of gender, race, and socio-political organization.⁴⁵

According to a recent study of the Brazilian government’s relationship with the Indigenous people in the Amazon, government respect for traditional Indigenous conversation methods has helped promote trust between the two parties. The study is relevant because according to Tuhiwai-Smith’s analysis, greater respect for Indigenous models of social organization can mitigate mistrust between Indigenous communities and non-Indigenous communities. Until recently, Indigenous people in the Amazon were

⁴³ Smith, Linda Tuhiwai. *Decolonizing Methodologies*. Page 65-68.

⁴⁴ Smith, Linda Tuhiwai. *Decolonizing Methodologies*. Page 43-45.

⁴⁵ Smith, Linda Tuhiwai. *Decolonizing Methodologies*. Page 43-45.

viewed as obstacles to development but are now being viewed with respect for their successful conservation methods.⁴⁶ In the 1980s, the dominant view was that the Indigenous population was far too small to take care of the large amount of land that it possessed.⁴⁷ To put this view into context, it is necessary to include some statistics included in the study. Currently, Indigenous tribes collectively possess about 20 percent of the Brazilian Amazon. Brazil's Indigenous population is only 310,000, with 280,000 actually occupying Indigenous territory.⁴⁸ Despite the fact that a very small number of Indigenous people occupy a very large amount of land, the observed effects of such occupation have been inherently positive.⁴⁹ According to *Veja*, a popular Brazilian journal, 3,600 Xingu Indigenous people were responsible for "preserving an ecological paradise the size of Belgium."⁵⁰ These findings played a huge role in the Brazilian government's decision to create extractive reserves where Indigenous people were given conservation jurisdiction. The government found that the Indigenous people have lived and sustained themselves in these areas successfully for a long period of time and so should be granted the ability to continue to do so.⁵¹ The Brazilian government also found that any kind of sound ecological policy would involve and include local Indigenous communities, rather than view them as obstacles or hindrances to development.⁵²

⁴⁶ Carneiro da Cunha, Manuela. W.B de Almeida, Mauro. *Indigenous People, Traditional People, and Conservation in the Amazon*. Page 315.

⁴⁷ Carneiro da Cunha, Manuela. W.B de Almeida, Mauro. *Indigenous People, Traditional People, and Conservation in the Amazon*. Page 322.

⁴⁸ *Ibid.*

⁴⁹ Carneiro da Cunha, Manuela. W.B de Almeida, Mauro. *Indigenous People, Traditional People, and Conservation in the Amazon*. Page 323.

⁵⁰ Carneiro da Cunha, Manuela. W.B de Almeida, Mauro. *Indigenous People, Traditional People, and Conservation in the Amazon*. Page 323.

⁵¹ *Ibid.*

⁵² *Ibid.*

The Brazilian government's decision to grant Indigenous communities control over conservation efforts represents a decolonizing methodology that seems to fit within Tuhiwai-Smith's theoretical framework. Rather than impose a Western narrative of development upon these Indigenous communities, the Brazilian government accepted that the conservation efforts inspired by traditional Indigenous practices have yielded and continue to yield positive results for the environment. An important side benefit of granting these Indigenous communities conservation control is that it fosters mutual trust between the government and the Indigenous communities. By the government granting these communities conservation control over their own territory, it sends a message that traditional perspectives and their benefits are being celebrated and valued by the larger society. To again invoke Habermasian reasoning, if these two parties can start from a place of mutual respect for conservation norms, perhaps this will pave the way for cooperative dialogue regarding issues of public health. What is most clear from this example is that cooperation between Indigenous and non-Indigenous communities on issues of mutual concern is possible. To achieve this cooperation, it is necessary to step outside of an inherently Western narrative to consider traditional and cultural methodologies. As the Brazilian case exemplifies, these methodologies foster legitimacy, mutual respect, and produce positive benefits, like a sustainable and healthy environment.

Another important method for decolonizing Western research processes comes from the Principles of Research Collaboration contract provided by CAAN. CAAN argues that the first step towards decolonizing the dominant Western research processes is to establish respect for principles of research collaboration between an Indigenous community and a research team. The most important principle is ensuring that Indigenous

people, and an Indigenous perspective, is valued through every step of the research process. CAAN argues that there should be free, prior and informed consent on a research project and that all parties should be included in the entire process from the construction of the research question, to data collection, to the research findings.⁵³

The right to free, prior, and informed consent (FPIC) is the right of Indigenous communities to make free and informed decisions regarding the exploitation of their lands and resources.⁵⁴ The FPIC is a keystone right because it necessitates other associated rights of participation. Under the FPIC principle, the Indigenous community must be granted equal participation in the dialogue concerning projects or policies that will impact their territory.⁵⁵ The FPIC is unique because it does not just require that the state vaguely consult with the Indigenous community at some point before undergoing a research project. The FPIC aims at fostering an open and informed dialogue between the state government and the Indigenous community. The FPIC rejects situations in which the Indigenous community is forced or intimidated into a project. As a way to protect against this, the FPIC requires that the Indigenous community have all relevant information about the project and the imminent and non-imminent results of the proposal's implementation.⁵⁶

While the FPIC does take some of the necessary steps towards including Indigenous people in the research process, the principle fails to go the whole way. A potential flaw of the FPIC is that it implies that it must always be the non-Indigenous researcher that proposes the research question to the Indigenous community. The FPIC

⁵³ Principles of Research Collaboration. CAAN. Page 2.

⁵⁴ Ward, Tara. *The Right to Free, Prior, and Informed Consent* (pg. 55)

⁵⁵ Ward, Tara. *The Right to Free, Prior, and Informed Consent* (pg 54)

⁵⁶ *Ibid* (pg 54)

focuses on ensuring that Indigenous people are included every step of the way, from the formation of the research question, to the collection of research data, to the consequent research findings, but it does not contain any clause about empowering the Indigenous community to propose their own research questions. As the T2DM example illustrated, accurate population-specific data is a precursor to any policy aimed at improving Indigenous health. T2DM is a disease that permeates through a web of risk factors within a specific local community. It seems fitting, based on these findings, that local Indigenous people would have a good sense of the kind of research questions that should be investigated based on specific community needs. Instead of the Indigenous communities merely consenting freely to research projects that are imposed on them, Indigenous communities should be asking their own research questions, which could be pursued autonomously or through government support. If more of the power rested within the Indigenous communities themselves, rather than the Western institutions, then Indigenous people might feel more inclined to cooperate in research projects. As the T2DM case also illustrated, questions of dietary health concern are national and international in scope, and as such minimum cooperation with state institutions is necessary for a brighter future for Indigenous health.

Another solution for escaping the cycle of mistrust that aims to allocate more power to Indigenous communities is The First Nations Statistical Institute (FSNI). The Institute was founded in 2006 and was a First Nations-led Crown Corporation. The FSNI was responsible for gathering First Nations data and also improving the availability of such data.⁵⁷ The FSNI helped improve planning and decision making procedures through working directly with Indigenous people to collect data and bridge gaps between all

⁵⁷ Voices-Voix Coalition. The First Nations Statistical Institute. Page 1-2.

levels of Canadian government and First Nations governments.⁵⁸ In 2012, the FNSI Chief Operating Officer, Keith Conn, argued that the FSNI had established the cooperative networks necessary to fill in big data gaps that existed with First Nations, Metis, and Inuit people that are unseen or omitted from census survey collection.⁵⁹ During the same year, the Canadian government announced that the federal budget allocated for the FSNI would be cut in half and then completely revoked by 2013-14.

Within the short time the FSNI existed, it had already begun to foster the kind of communicative cooperation that Habermas envisioned for escaping the cycle of mistrust. The FSNI was a government institution led by Indigenous people and was designed to promote cooperation and dialogue between all levels of Canadian government and First Nations governments. As Foucault's argument about biopower illustrates, the modern state in general is an institution that gathers statistics about its population as a means to control it. This idea, combined with the colonial past of most settler communities, reasonably justifies why Indigenous communities would mistrust any state led effort to collect more accurate health data. Most settler states in the past have collected data about Indigenous communities and used it to exploit them. The FSNI was an institution that not only encompassed an Indigenous perspective, but also gave Indigenous people a leading role in the gathering of statistical information about their communities.

After only 6 years, the FSNI's chief officer felt that they had established the kind of cooperative networks that were needed to bridge gaps in Indigenous health data. The fact that these networks had even been established shows that some mutual systems of distrust between state and Indigenous entities have already been overcome. These

⁵⁸ Voices-Voix Coalition. The First Nations Statistical Institute. Page 1-2.

⁵⁹ Voices-Voix Coalition. The First Nations Statistical Institute. Page 1-2.

cooperative networks bridged by the FSNI served as the kind of public forums necessary for the exchange of dialogue between Indigenous and non-Indigenous stakeholders. The FSNI created the kind of communicative dialogue forums that are necessary to establish respect and toleration for the intersubjective webs of meaning that exist within and between Indigenous and non-Indigenous communities. When looking to the future, it is necessary to promote institutions that aim to promote trust between Indigenous and non-Indigenous communities through public dialogue.

In conclusion, Indigenous people experience much poorer health conditions than non-Indigenous people on a global scale. The cycle of mistrust that exists between Indigenous and non-Indigenous communities presents the greatest challenge for improving Indigenous health. The case study of the T2DM in Northern American Indigenous communities showed why the collection of population-level statistical data is essential towards generating health policies that will improve Indigenous health. These kinds of policies will require local Indigenous solutions but will also require cooperation with non-Indigenous entities due to the national and international scope of the problem.

This cyclical mistrust can generally be understood as the Indigenous community viewing the state as a distrustful entity seeking census data solely for managerial or control purposes. The state, in turn, may also mistrust the Indigenous community for deviating from the Western conception of social organization. Examination of the residential school system instituted in Canada showed where Indigenous mistrust towards state institutions was reasonably born. The example of the government of Botswana and the San people illustrated how mutual distrust over conceptions of social organization, namely, modern democratic principles versus traditional hunter-gatherer ones, can have

detrimental consequences. As Habermas would argue, establishing communicative dialogues between conflicting parties is essential for mitigating mistrust. The FSNI showed how creating an institution that fosters direct dialogue and cooperation between Indigenous and non-Indigenous communities could present the potential for more accurate health data. Foucault helped show why Indigenous people might resist self-identifying in national censuses. Self-identifying within the current social context would mean consenting to Western stereotypes about Indigenous identity. If there can be a move towards allowing Indigenous people to identify their own indigeness, then this could also be a way to collect more accurate health data.

Some other important solutions include decolonizing Western research processes and promoting the FPIC principle. Decolonizing Western research processes involves, as Tuhiwai-Smith argues, removal of the influences of the colonial past but also an end to classifying Indigenous people based on Western conceptions of gender, race, and socio-political organization. The FPIC principle is also important, but should be revised to empower Indigenous communities to propose research questions for themselves based on their population-level position.

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