

# **Governmental fiduciary failure in Indigenous environmental health justice: The case of Pictou Landing First Nation**

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# Governmental Fiduciary Failure in Indigenous Environmental Health Justice: The Case of Pictou Landing First Nation

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From 1967 until 2020, Pictou Landing First Nation (PLFN) has had 85 million litres of pulp and paper mill effluent dumped every day into an estuary that borders the community. A federal government appointed Joint Environmental Health Monitoring Committee, mandated to oversee the health of the community, has never addressed PLFN concerns about cancer in the community. In this study we accessed the 2013 Canadian Cancer Registry microdata file, and using the standard geographical classification code, accessed the cancer data for PLFN, and provided comparable data for all Nova Scotia First Nations, as well as the county, provincial, and national populations. We determined that digestive organ cancers, respiratory organ cancers, male genital organ cancers, and urinary tract cancers are higher in PLFN than at all comparable levels. Female breast and genital organ cancers are lowest in PLFN than at all other comparable levels. A limitation of this study was not being able to capture cancer data for off-reserve members at the time of diagnosis and the lapse in availability of up-to-date Canadian Cancer Registry data. As this study demonstrates, when governmental regulatory agencies do not fulfill their mandates, First Nations can mobilize to get the data they need. Moreover, as Indigenous scholars acquire the statistical skills to work with quantitative data to address concerns in their own and other Indigenous communities, we can achieve environmental health justice for Indigenous nations, not only in Canada, but around the world.

**Keywords:** *First Nation, Indigenous, health, cancer; pulp mill, environmental health justice, Cancer Registries*

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## Introduction

Pictou Landing First Nation (PLFN) is a Mi'kmaw community of approximately 490 on-reserve members located on the northern shore of Nova Scotia, Canada (Indigenous and Northern Affairs Canada, 2019). Since 1967, the provincial government of Nova Scotia has allowed a pulp and paper mill to pump 85 million litres of effluent per day into a lagoon that was once a culturally significant place known as *A'se'k*, and which borders the community (Castleden et al., 2017; Lewis et al., 2016; Pictou Landing Native Women's Group et al., 2016). The women in the community were concerned about the health of their families, and in 2010, the Pictou Landing Native Women's Group (NWG) initiated a research collaboration with researchers at Dalhousie University that would help them determine whether the health of their community has been impacted. Of the many health concerns addressed by the research collaboration (see Castleden et al., 2017; Lewis et al., 2016, 2020; Pictou Landing Native Women's Group et al., 2016), the NWG were concerned about what they perceived to be an increase in the incidence of cancer in the community since 1967, possibly as a result of the effects from air emissions from the mill's stacks and exposure to the waters and sediments of the Boat Harbour Effluent Treatment Facility (BHETF) (Pictou Landing Native Women's Group, 2010). This concern has also been raised in several other public venues (Andreatta, 2013; Hoffman et al., 2015).

Investigating potential health impacts from the mill and the BHETF has been the responsibility of a Joint Environmental Health Monitoring Committee (JEHMC), comprised of representatives from Indigenous and Northern Affairs Canada (INAC), Health Canada, the Department of Justice, and Environment Canada, and representatives of PLFN. The JEHMC was structured in 1993 after PLFN sued the

federal government for breach of fiduciary duty to safeguard the community members by allowing the effluent treatment facility to be built on its' shores (Lewis et al., 2020). The federal government settled for \$35 million, and the PLFN *Indian Band Agreement Act (The Act)*, ratified in Parliament in 1995, formalized the PLFN *Indian Band Settlement Agreement* (1993) to ensure that the Government of Canada could never be held liable for damages related to the BHETF again (Parliament of Canada, 1995). The JEHMC, established by *The Act*, has been mandated since then to establish and implement programs that would be "reasonably required to monitor the health of the band members, and the extent of environmental contamination on reserve lands and in Boat Harbour..." (Joint Environmental and Health Monitoring Committee, 1996, p. 1), but maintains that the health of PLFN has not been impacted.

In their first report in 1996, JEHMC noted that concerns of community members would be investigated by specialists in assessment of environmental health risks and would be compared to other communities (Joint Environmental and Health Monitoring Committee, 1996, p. 5). In 1997, JEHMC hired CanTox, a consulting company specializing in environmental health risks, which determined that no measurable adverse effects would occur as a result of current exposures, or the lowering of water levels in the lagoon. A future scenario which saw the effluent no longer pumped into Boat Harbour, and the return of the lagoon to a tidal estuary, "would not be expected to result in measurable adverse health effects with the exception of exposures to chlorinated dioxins and furans...but only under the assumption that PLFN residents would catch and eat fish on a daily basis from the lagoon" (Joint Environmental and Health Monitoring Committee, 1998, p. 6).

Many other studies were conducted over the years and in 2008, Dillon Consulting was hired to review all of the existing studies ( $n = 106$ ) conducted under the auspices of JEHMC, to hold community consultations to identify concerns, and to identify the types of information that would be required to address those concerns (Joint Environmental and Health Monitoring Committee, 2015). The study concluded that a human health risk assessment was not recommended (Joint Environmental and Health Monitoring Committee, 2015).

For over 25 years, the JEHMC never gathered baseline health data in the community (Lewis et al., 2020). Had they done so, the federal government representatives on JEHMC, who have access to data held at Statistics Canada, could have compared the health outcomes in PLFN to other populations that might have signaled whether further investigation was warranted (Lewis et al., 2020). Despite the fact that health concerns were raised frequently by community members over the decades, the JEHMC has never addressed any of these concerns (Pictou Landing Native Women's Group, 2010), including those about the perceived increase in cancers. The PLFN representatives on the JEHMC seemingly have had little influence in changing that stance (Lewis et al., 2020).

It is suggested that cancer is understudied among Indigenous Peoples because there are no ethnic identifiers in the Canadian Cancer Registry (CCR) (Mazereeuw et al., 2017, 2018; Withrow et al., 2017). The Alberta First Nation Information Governance Centre (2015), Chiefs of Ontario (2016), and Institut National de Santé Publique Québec (2009) report that the lack of identifiers in the CCR leads to gaps in information, which hamper the ability of these organizations to effectively plan to reduce cancer risks and burdens in their communities.

There are, however, a few studies that have used First Nation identity to look at cancer rates. One such study linked the CCR to adults age 25 years and older from the 1991 Long Form Census who self-reported First Nation identity (reported North American Indian ancestry, reported registration under the Indian Act, and/or were a member of an Indian Band or First Nation) (Mazereeuw et al., 2018). The issue with this study, however, is that the relationship to government, and their efforts to conduct censuses, has been marked by resistance, avoidance, and suspicion on the part of Indigenous communities, mainly because of the legacy of the colonial relationship with Canada, and therefore, the likelihood of underreporting is very real (Hamilton, 2007). In the early 1990s, Statistics Canada launched three major national longitudinal surveys – the Survey of Labour and Income Dynamics (1993), the National Longitudinal Survey of Children and Youth (1994), and the National Population Health Survey (1994) (Picot et al., 2006) – that “specifically excluded First Nation people living on-reserve” (First Nations Information Governance Centre, 2019, p. 1). Further, Statistics Canada (2009) reported they continued to have issues in conducting the 1996, 2001 and 2006 census processes with some Indian reserves and settlements refusing to participate or being interrupted before the processes were complete.

One study conducted in Manitoba was able to compile a First Nation cohort to compare cancer incidence, morbidity, and survival in First Nation children versus non-First Nation children by using data from the Cancer in Young People in Canada Registry (CYPCR), a national population-based registry which tracks data using self-reported racial origin (Stammers et al., 2014). The CYPCR records if patients are First Nation, and those with formal treaty numbers are assigned to a First Nation category, while

those without formal treaty numbers are assigned as Aboriginal (excluding Métis, Inuit, and mixed ancestry from the sample), both categories then making up the First Nation cohort (Stammers et al., 2014). This is an excellent method to track cancer among First Nation children and youth. Another study linked records in the Alberta cancer registry using the postal codes associated with 140 reserves and linked those to the Alberta provincial health registry, which has First Nation identifiers (Erickson et al., 2015). Postal codes boundaries, however, do not delineate along reserve boundaries, so First Nation identifiers may be capturing patients who live outside of reserve boundaries as well.

Other studies have tracked First Nation patients through the use of the Indian Registry List, the official record of persons registered as status Indians under the *Indian Act* and maintained by Indigenous and Northern Affairs Canada or the British Columbia First Nations Health authority (Decker et al., 2015, 2016; Marrett & Chaudhry, 2003; McGahan et al., 2017; Nishri et al., 2015). This is the most efficient way to extract data on registered Indians in Canada, however, the registry does not track location of status Indians and whether they are in their home reserve when a cancer diagnosis is made. Further, access to the registry is limited to INAC employees responsible for the registry, or Band employees given authority to act on behalf of the Indian Registrar (Government of Canada, 2018).

In our approach, we recognized that while it is true that the CCR does not include ethnic identifiers, and the data that we were given access to did not include patient names or street addresses, we were still able to get to the data at the First Nation level in order to assess the incidence of cancer for PLFN. This paper presents the approach we took to conduct the study that gave PLFN data on

cancer for the first time, considering that the INAC representative on the JEHMC did not facilitate access to link the CCR to the Indian Registry List.

To assist the NWG, which included members sitting on the JEHMC, to determine whether their concerns were warranted, we set out to access data to determine if the empirical evidence supported the anecdotal evidence of cancer prevalence in PLFN. Moreover, the approach we took in our study demonstrates what can be accomplished when a community advocates for its' own health, despite governmental oversight, and mobilizes to engage researchers to get their questions answered. What follows is the approach that was taken in order to do so.

### **Methods**

We accessed the 2013 CCR through the Atlantic Research Data Centre (ARDC), a member of the Canadian Research Data Centre Network (CRDCN), a partnership between 38 universities and Statistics Canada whereby each university can provide a secure laboratory setting for researchers to access confidential census, surveys, and administrative data (Canadian Research Data Centre Network, n.d.). Researchers wishing to access any of the Research Data Centres across Canada will submit a proposal to Statistics Canada. Once approved, the researcher will proceed through a federal government security clearance, sign a contract with Statistics Canada for a specific research study, take an Oath or Affirmation of Office and Secrecy, and then will be deemed an employee of Statistics Canada for the duration of the contract (Statistics Canada, 2020). A research data analyst in the centre controls the data output that is released only to the contracted researcher to ensure confidentiality is not breached. In these secure locations, detailed individual/household/business responses to surveys (microdata) is available, depending

on the survey, and this level of data is significantly more detailed than publicly available aggregate data and public use microdata files (Statistics Canada, 2019).

The CCR is a patient-oriented administrative database that the Canadian Council of Cancer Registries maintains to provide data on cancer diagnoses since 1992, and to help track patients who have been diagnosed with neoplasms, or tumours (Statistics Canada, 2017b). Administered through Statistics Canada, the CCR links to each provincial and territorial CCR which tracks individual cancer patient data (Statistics Canada, 2017a). The CCR reports place of residence at diagnosis for patients (Statistics Canada, 2017c). The address is coded using the standard geographical classification (SGC), an official classification used by Statistics Canada for all addresses throughout Canada (Statistics Canada, 2017c). Each province is broken down using the SGC system into census geographic divisions, further subdivided into census geographic subdivisions. These subdivisions are defined as municipalities, or the equivalent, such as an Indian reserve or settlement (Statistics Canada, 2011).

Taking the First Nation profiles maintained by INAC, we extracted the names of each of the thirteen Nova Scotia First Nations, and each of their respective reserves, settlements, and villages (Indigenous and Northern Affairs Canada, 2019). For example, PLFN is comprised of five reserves, settlements, or villages: Boat Harbour West 37, Fisher's Grant 24, Fisher's Grant 24G, Franklin Manor No. 22 (co-owned with Paq'tnkek First Nation), and Merigomish Harbour 31 (Indigenous and Northern Affairs Canada, 2019). Of the five, only two have residents, Fisher's Grant 24 and Merigomish Harbour 31, both being assigned their own census subdivision codes. We were then able to extract data for each subdivision code. To access the data for all thirteen Nova Scotia

First Nations, we did the same for each of the other twelve Nova Scotia First Nations.

Each cancer patient is given a unique number that is used throughout their registration in the CCR (Statistics Canada, 2017b). The CCR file provided through the ARDC removes the name and street address of the patient to ensure privacy. We were able to extract gender, age, SGC including census, and census subdivision, year of diagnosis, and histology for each patient record, at the PLFN, Pictou County, Nova Scotia First Nation, provincial, and national levels. The histological description of a neoplasm is coded according to the World Health Organization International Classification of Diseases for Oncology, Third Edition (ICD-O-3) (Statistics Canada, 2017b).

We have grouped human cancers sites using the International Agency for Research on Cancer (IARC) classification system, which groups human cancer sites according to digestive organ cancers, respiratory organ cancers, breast and female genitalia cancers, male genital organ cancers, urinary tract cancers (Fritz et al., 2000), cancers that were present in PLFN. Other cancer sites listed in the IARC classification system, such as lip, oral cavity and pharynx cancers, skins cancers, or thyroid and other endocrine gland cancers, were grouped into the category of 'All other cancers', as they did not occur in PLFN, or were at an incidence rate in PLFN that could not be released for use in this study for confidentiality reasons. Gender and age are not reported to protect the confidentiality of individuals in PLFN.

### **Relationship**

The NWG is comprised of a collective of women from PLFN who approached the first author, a Mi'kmaq woman from a neighboring First Nation, who had just earned a master's degree in Resource and Environmental Management at Dalhousie University in the spring of 2010

(Lewis et al., 2016). The first author invited the fourth author, a community-based participatory researcher (CBPR) with years of experience working with other Indigenous communities on environment and health studies, to meet with the NWG to explore the possibility of a research partnership (Lewis et al., 2016). This research formed part of a multi-year CBPR project, co-led by the second author, who at the time was the President of the NWG, and the fourth author (for further details on the research partnership that ensured research was pertinent to and respectful of PLFN needs, see Castleden et al., 2017; Lewis et al., 2016, 2020; Pictou Landing Native Women's Group et al., 2016). The research received both Dalhousie University Health Sciences Research Ethics Board and the Mi'kmaq Ethics Watch approval. The latter is the Mi'kmaw Ethics

Committee appointed by the Sante' Mawio'mi (Grand Council) in 1999 to establish principles and protocols to protect the integrity and cultural knowledge of the Mi'kmaq and ensures Mi'kmaq control and ownership of the data collected.

### Results

The data presented in Table 1 has been taken from the 2013 CCR and compares the proportion of cancer diagnoses for the period 1992-2013 at the PLFN, Pictou County, Nova Scotia First Nation, provincial, and national levels, using the International Agency for Research on Cancer (IARC) classification system, as mentioned above. As noted in every broad category, PLFN experiences the highest rates of cancer, with the exception of breast and female genital organ cancers. Compared to all thirteen

**Table 1**

***Comparative Cancer Rates by Cancer Site for PLFN (1992-2013)***

Cancer category	PLFN %	Nova Scotia First Nations %	Pictou County %	Nova Scotia %	Canada %
Digestive organs	18	9	7	7	6
Respiratory organs	27	17	15	14	13
Breast and female genital organs	9	12	11	12	10
Male genital organs	18	10	14	13	13
Urinary tract	18	9	7	7	6
All other cancers (1)	10	43	46	47	52

1) Statistics Canada does not permit the release of data that could potentially disclose the identity of respondents to surveys, therefore, the category 'All other cancers' includes the cancers that could not be disclosed, or did not occur in PLFN, but were reported for Nova Scotia First Nations, Pictou County, province, and national levels.

Source: CCR, 2013.

Cancer Diagnosis: Canada *N* = 3,097,870; NS *N* = 112,480; Pictou County *N* = 6,195; Nova Scotia First Nation *N* = 625; PLFN *N* = 55

*Note.* Adapted from

<https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3207>

Nova Scotia First Nations, with the exception of breast and female genital organ cancers, the incidence rate is eight to ten percent higher in PLFN. For digestive organ, respiratory organ, and urinary tract cancers the rates are twelve to fourteen percent higher in PLFN compared to Nova Scotia First Nations, Pictou County, provincial, and national rates. Tobias et al. (2013) note that where cancer rates in Indigenous populations were historically lower, they are now converging with the rates found in non-Indigenous populations in Canada today. This may be so for breast and female genital organ cancers and male genital organ cancers in the populations at the county, province, and national levels, where the rates tend to be converging with the rates seen in PLFN.

As we see in Table 1, digestive organ cancer rates occur at twice the rate in PLFN (18%) compared to the combined rate for all First Nations in Nova Scotia (9%), and almost triple, or triple, the rate for residents of Pictou County excluding PLFN (7%), Nova Scotia (7%), and Canada (6%). Respiratory organ cancers are 10% higher in PLFN (27%) than that for all First Nations in Nova Scotia (17%), and almost double, or double, that of Pictou County (15%), Nova Scotia (14%), and Canada (13%). Male genital organ cancer is highest in PLFN (18%), almost double that of all First Nations in Nova Scotia (10%) but is only four to five percent higher than the rates of Pictou County (14%), Nova Scotia (13%), and Canada (13%). Lastly, urinary tract cancers are at least double or more in PLFN (18%) than the rate for all First Nations in Nova Scotia (9%), Pictou County (7%), Nova Scotia (7%), and Canada (6%). Female breast and genital organ cancers, however, are 3% lower in PLFN than compared to the rate for all Nova Scotia First Nations (12%) and Nova Scotians (12%), 2% lower than the Pictou

County (11%) rate, and 1% lower than the national (10%) rate. This is an unexpected finding since the NWG were certain that they were experiencing highest rates of cancer amongst their female community members (Pictou Landing Native Women's Group, 2011).

### **Limitations**

There are several limitations to this study. Although this study analyzes data coming from PLFN for the first time, it is only capturing the data of those who were living on-reserve at the time of initial diagnosis. This does not capture those who may have lived on-reserve most of their lives but lived off-reserve for a period of time prior to diagnosis, or those who may have returned to PLFN since their diagnosis. This study is also limited by the availability of the CCR data in the ARDC at the time of data collection, which at the time was only available to 2013. Finally, unless a community has a relationship with a researcher who can be granted access to an RDC, the data is not accessible for their use.

### **Discussion and Conclusions**

The significance of the study is that for the first time NWG were able to demonstrate that empirical evidence supported their anecdotal evidence of cancer prevalence in PLFN. The data confirmed that in every broad category where cancer diagnosis was present for PLFN, PLFN experiences the highest rates of cancer, with the unexpected finding of the lower prevalence of breast and female genital organ cancers compared to cancers specific to men. The authors (with the exception of the fifth author) presented the data to the members of the NWG first, who then instructed us to present the findings to the elected Chief and Council.

The Chief and Council instructed us to present our findings to the PLFN community as a whole. The community unanimously supported that data from 2013 to current needs to be collected. Since we have completed the research, the Canadian Research Data Centre Network (CRDCN) (n.d.) announced in May 2019 that the CCR data is now available up to 2016.

As noted earlier, and as a follow up to this initial study, data from the CCR must be linked to the Indian Registry List in order to give PLFN as thorough a record as possible of all registered members of the community, to determine cancer incidence of those who, at one time or another, may have lived in the community and have moved away. Using the SGCs gives only a partial picture. The JEHMC is mandated to establish and implement programs that would be “reasonably required to monitor the health of the band members” (Joint Environmental and Health Monitoring Committee, 1996, p. 1). The Indian Registry List already exists and sits within Indigenous Services Canada (formerly INAC). Access to this list would enable researchers to link the identity of registered PLFN band members to those in the CCR.

Statistics Canada data is available and accessible to government (Canadian Research Data Centre Network, n.d.). Had the JEHMC adequately fulfilled its mandate, the research data that we were able to provide to the community, although not a complete picture of cancer incidence amongst registered community members, could have been achieved two decades ago, long before this study was conducted. Environmental health regulatory bodies like the JEHMC need to address health concerns voiced by First Nation and other Indigenous communities, especially serious concerns like cancer when data is readily available to make an assessment. The community believed there to be concern and our study

validated them. These findings signal that more in-depth cancer studies are warranted. The PLFN can now decide what next steps it needs to take in their research efforts and health priorities.

This study demonstrates that if Indigenous Peoples believe that governmental regulatory agencies are not fulfilling their mandates, they can still acquire the data they need, even if the data tells only a portion of the story. It is empirical evidence that may change a narrative, by supporting Indigenous efforts for healthy equity and justice. As more and more Indigenous scholars are trained in the quantitative skills to work with data that is stored in government-controlled repositories, Indigenous Peoples can start to utilize the data in the ways that directly benefit community health and wellness. Sadly, this is the shocking reality of how Indigenous Peoples, the first peoples of Canada, are treated like ‘second class citizens’ (Allan & Smylie, 2015). If, as the United Nations Special Rapporteur on the Rights of Indigenous Peoples notes, Indigenous Peoples around the world lack access to reliable data to understand “how they are faring”, this is directly related to the “weakness of governments” to implement decisions that would enable them to do so (Kukutai & Taylor, 2016, p. xxi).

We hope that government-controlled narratives like the one endured by PLFN are challenged. In doing so, environmental health justice for Indigenous communities can be achieved. We close by stating that Indigenous Peoples must advocate for easier access to data held by government, like that of the CCR, especially where regulatory bodies like the JEHMC are ostensibly unable to do so. The NWG have always been guided by the desire that what happened to their community should never happen to another Indigenous community again. While the results of our analysis show disturbing high rates of cancer,

which would be scary for any community, if there is some benefit from the work that we have undertaken together to demonstrate how to access and use existing government data, then the NWG wants their story to be told.

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