Black Lung Incidence Study

Navajo Nation Research Brief

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Prepared by:	**Summit Consulting, LLC** 777 6th Street NW, Suite 520 | Washington, DC 20001 DUNS: 134631675 | Taxpayer ID: 95-4816438 CAGE Code: 3GZS9 | Unique ID: FNYSF7X4ELS5 http://www.summitllc.us/

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Table of contents

List of figures

List of tables

EXECUTIVE SUMMARY

Background. The Federal Mine Safety and Health Act of 1977 chartered the Mine Safety and Health Administration (MSHA), whose mission is to "prevent death, illness, and injury from mining and promote safe and healthful workspaces for U.S. miners" (29 U.S.C. § 557a; 30 CFR § 72.1; 30 CFR § 72.510). To support this mission, Summit Consulting (Summit) conducted the Black Lung Incidence Study to examine black lung incidence in the United States, exploring both cases and deaths.[1] The study included a literature review[2] and quantitative analysis of publicly available data to build MSHA's understanding of this topic. Within this scope, the study examined whether black lung incidence is higher among specific subpopulations of interest, including miners, mining communities, and residents of Appalachia. A fourth subpopulation of interest was the Navajo Nation.

This research brief focuses on findings from Summit's literature review and data analysis related to the Navajo Nation. To supplement these findings, Summit interviewed subject matter experts Dr. Robert Finkelman from the University of Texas at Dallas in the Department of Geosciences; Dr. Cecile Rose and Dr. Lauren Zell-Baran from the Miners Clinic of Colorado; and Dr. Akshay Sood, Bobbi Gore, and Xin Shore from the Miners' Colfax Medical Center. These interviews informed considerations for future research as MSHA continues to investigate this topic.

Key findings. This research brief describes the following key findings:

- There is a public health burden in the Navajo Nation related to residential coal use and coal mining, both of which have historically been important to the Navajo economy.
- Underreporting of black lung cases and deaths in the Navajo Nation may result from lack of trust in and access to health care and lack of trust in both researchers and the federal government.
- There are six U.S. counties that partially reside within Navajo Nation borders. Zero cases and just 10 deaths were reported in these counties during the respective data collection periods (1970-2014 and 1999-2020). These results may be a function of underreporting in the Navajo Nation. Data suppression might also affect these results.
- Statistical tests to compare Navajo Nation counties to other counties in the United States are inconclusive due to current data limitations.
- According to statistical models designed to estimate black lung prevalence in the Navajo Nation, estimated black lung prevalence is higher than reported in five of six counties.

Conclusions and next steps. This report highlights the need for additional research focused on the health impacts of coal use and coal mining in the Navajo Nation. As plans for future research are made, MSHA should consider the following recommendations:

1. **Align research with the needs of the Diné (the Navajo Nation population).** MSHA should consider research efforts that will result in the greatest tangible benefit for the Diné, thereby increasing buy-in. This could mean expanding the scope of the research to include both black lung disease and comorbidities, such as lung cancer, asthma, or diabetes. Another option could be offering health care screenings or black lung benefits application assistance to research participants.

[1] Please see the Black Lung Incidence Study Final Report for more information.
[2] Please see the Black Lung Incidence Literature Review for more information.

2. **Partner with the Diné.** Future research efforts should be in direct collaboration with members of the Navajo Nation to create trust, mitigate cultural misunderstandings, and add credibility to the research.
3. **Identify advocates.** When engaging with the Navajo Nation community, MSHA should consider partnering with individuals from the Navajo Technical University, United Mine Workers of America, Health Resources and Services Administration Black Lung Clinics Program grantees, and other organizations who can provide important context and guidance to researchers while advocating for the interests of the community and miners.
4. **Avoid redundancy.** Rather than collecting new data, MSHA should consider partnering with organizations trusted by the Diné that already have extensive black lung disease databases. These partnerships will lessen the burden of the research effort while adding validity to the results.

1 INTRODUCTION

The Federal Mine Safety and Health Act of 1977 chartered the Mine Safety and Health Administration (MSHA), whose mission is to "prevent death, illness, and injury from mining and promote safe and healthful workspaces for U.S. miners" (29 U.S.C. § 557a; 30 CFR § 72.1; 30 CFR § 72.510). To support this mission, Summit Consulting (Summit) conducted the Black Lung Incidence Study to examine black lung incidence in the United States, exploring both cases and deaths.[3] Within this scope, the study examined whether black lung incidence is higher among specific subpopulations of interest, including miners, mining communities, and residents of Appalachia. A fourth subpopulation of interest was the Navajo Nation, located in northeastern Arizona, northwestern New Mexico, and southeastern Utah (Navajo Nation, accessed September 29, 2023).

This study included a literature review[4] to build MSHA's understanding of the topic by systematically reviewing the current state of knowledge in this field and by identifying existing research and opportunities for future research. The literature review included a specific focus on coal mining and coal use in the Navajo Nation. The relevant sources from the literature review that are cited by this brief are included in Appendix A.

Concurrent with the literature review, Summit conducted a dataset scan and quantitative analysis to define key parameters and metrics of interest, conduct descriptive data analysis, and estimate black lung cases and deaths. This quantitative analysis included a focus on U.S. counties that partially reside within Navajo Nation borders.

While the literature review, dataset scan, and quantitative analysis found publications and data focused on black lung disease among the general population and Appalachian populations, there were few available sources of information on the health effects of coal among Navajo Nation populations (the Diné). This gap highlights a need for black lung disease research in the Navajo Nation, both in terms of how coal mining affects the Diné and how burning coal for home heating contributes to respiratory ailments.

This research brief focuses on findings from Summit's literature review and data analysis related to the Navajo Nation. To supplement these findings, Summit interviewed subject matter experts (SMEs) Dr. Robert Finkelman from the University of Texas at Dallas in the Department of Geosciences; Dr. Cecile Rose and Dr. Lauren Zell-Baran from the Miners Clinic of Colorado; and Dr. Akshay Sood, Bobbi Gore, and Xin Shore from the Miners' Colfax Medical Center. These interviews inform considerations for future research as MSHA continues to investigate this topic.

The rest of this brief summarizes findings from the literature review and quantitative analysis and describes SME-informed considerations for future research.

[3] Please see the Black Lung Incidence Study Final Report for more information.
[4] Please see the Black Lung Incidence Literature Review for more information.

2 FINDINGS

2.1 Defining "black lung"

There is a wide variety of respiratory diseases associated with exposure to coal dust through mining activities and residential coal use. Historically, high rates of pneumoconiosis have occurred in mining settings with dust exposure (Perret et al. 2017; Patra, Gautam, and Kumar 2016; Ross and Murray 2004). The narrowest interpretation of black lung disease is coal workers' pneumoconiosis (CWP), a lung disease caused by chronic inhalation of coal dust for which there is no cure (Paul, Adeyemi, and Arif 2022; Cecil 2021; Finkelman, Wolfe, and Hendryx 2021; Arif et al. 2020; Zosky et al. 2016; Laney and Weissman 2014; Lockwood 2012, 52, 125-6; Huang et al. 2006; Royal 2019). However, use of this term varies across government publications. For example, a definition from an archived MSHA website titled *End Black Lung: Act Now* (accessed January 24, 2023) defines black lung disease as CWP, emphysema, silicosis, and bronchitis.

The black lung definition used in the Black Lung Incidence Study stemmed from insights gathered during the literature review coupled with publicly available data. Consequently, this definition includes a broader range of illnesses beyond CWP. These illnesses include CWP, silicosis, and other pneumoconioses (see Table 4 in Section 2.3). A more thorough explanation of why Summit chose this expanded definition is provided in Section 2.3.

2.2 Literature review on black lung disease in the Navajo Nation

Summit conducted a literature review to assess the current state of research on black lung disease.[5] One area of focus within that literature review was black lung incidence due to coal mining or residential coal use within the Navajo Nation. In conducting this literature review, Summit followed a rigorous methodology and documentation process. Our methodology included (1) developing key search terms that correspond to the evaluation's research questions (see Table 1 below for a list of these search terms), (2) identifying inclusion and exclusion criteria, (3) conducting the initial literature search, (4) reviewing the literature for relevant information and synthesizing findings to focus on the topics of interest, and (5) completing additional literature searches as needed. Summit also acquired relevant sources from Dr. Robert Finkelman. These sources were analyzed and included in this review where relevant.

Table 1: List of search terms

- **Appalachia** (Appalachian)
- **Coal mining communities**
- **Household cooking** (searched in combination with "coal")
- **Black lung** (pneumoconiosis, coal workers' pneumoconiosis, emphysema, silicosis, bronchitis, respiratory illness, respiratory disease, lung cancer)
- **Coal workers' pneumoconiosis definition** (coal workers' pneumoconiosis medical codes)
- **Indoor air pollution**
- **Black lung definition** (black lung medical diagnosis codes)
- **Home coal burning** (residential coal burning, residential coal combustion)

[5] Please see the Black Lung Incidence Literature Review for more information.

- **Navajo Nation**

Note: Searches were conducted via Google Scholar using combinations of these terms. For example, Summit searched for "Navajo Nation" and "home coal burning," rather than simply searching "Navajo Nation." All terms, including variations shown in parentheses, were used verbatim.

The inclusion and exclusion criteria that further focused the search are in Table 2. The inclusion criteria are requirements that must be met for a source to be considered for analysis. The exclusion criteria are characteristics that lead to the omission of a source for analysis.

Table 2: Inclusion and exclusion criteria for literature review search

Inclusion criteria	Exclusion criteria
• Source is relevant to one of the following: ○ Black lung disease resulting from residential coal burning ○ Black lung disease resulting from a coal-related occupation ○ Contributes to black lung disease definition or medical code discussion	• Source is older than 20 years (2002 or earlier); this exclusion criterion did not apply to federal legislation

In comparison to the published literature on black lung disease among coal miners, the available information on black lung disease in the Navajo Nation is extremely limited, representing a gap in the available evidence.[6] This highlights the need for further research on black lung disease (and other respiratory illnesses associated with coal exposure) within the Navajo Nation. However, this gap in published literature is not evidence against the impact of black lung disease in this population. Li et al. (2018) noted that "while the health effects of indoor air pollution in urban environments has received great attention, the same cannot be said for the rural Native American communities where residents are directly exposed to pollutants from solid fuel combustion." Similarly, they noted that although the number of studies examining the health impacts of solid fuel use on Navajo residents is limited, the studies that are available "have consistently found an association between respiratory disease burdens and the use of wood and coal in several Navajo communities" (Li et al. 2018; Bunnell et al. 2010). Despite the relatively limited amount of published evidence, the studies that are available indicate high levels of residential coal use in the Navajo Nation and high public health burden among this population related to coal use and coal mining (Li et al. 2018; Bunnell et al. 2010).

2.2.1 Coal mining

Coal mining has historically been important to the Navajo economy (Finkelman and Simoni n.d.; Rekow 2019). The Black Mesa Coal Field, located largely in the Navajo Nation, is the principal coal-bearing region in Arizona (Finkelman and Simoni n.d.). Rekow (2019) describes the Navajo economy as "dependent on fossil fuel" with more than half of the Nation's annual revenue coming from coal mining

[6] It is worth noting that our search for relevant literature often turned up papers on uranium mining within the Navajo Nation. Uranium mining resulting in radon exposure can lead to respiratory illnesses similar to black lung disease. While the topic of uranium mining is out of scope for this project, it may be of potential interest for future research, given it may be a factor for higher rates of respiratory illness among former uranium miners in the Navajo Nation (there are no longer active uranium mines in the Navajo Nation) (Dr. Robert Finkelman, personal communication with author, January 4, 2023).

and thousands of Navajo Nation residents relying on coal mines for employment.[7] As with coal miners in other parts of the country, this is associated with a higher incidence of black lung disease and other respiratory diseases among Navajo coal miners. As Patel explains, "the Navajo Nation continues to suffer from the abusive policies of coal companies. Their already decreasing population has suffered from multiple diseases related to mining, such as black lung, asthma, and cancer" (Patel 2015).

2.2.2 Outdoor air pollution

Coal-related air pollution also affects Navajo Nation populations. For example, coal-fired power plants near Shiprock, New Mexico (a town in the Navajo Nation) often produce "noticeable amounts of smog" (Bunnell et al. 2010; Finkelman and Simoni n.d.). Thermal atmospheric inversions trap the smog low to the ground along the San Juan Basin, especially during colder months (Bunnell et al. 2010; Finkelman and Simoni n.d.). Because they were built before the legislation's effective date, these power plants are exempt from U.S. Environmental Protection Agency (EPA) regulation under the 1990 American Clean Air Act (Bunnell et al. 2010). One study examining hospital records from April 1997 to December 2002 among Navajo residents seen at the Northern Navajo Medical Center Indian Health Service (IHS) Hospital found that out of all 37 communities in the IHS's Shiprock Service Area, the town of Shiprock ranked in the top 10 for all seven of the diseases and conditions[8] analyzed for the study (Bunnell et al. 2010). The overall conclusion of the study was that residents of Shiprock and nearby towns are at greater risk for respiratory disease than residents of Navajo Nation communities not subject to thermal inversions (Bunnell et al. 2010).

2.2.3 Residential coal burning

It is well documented that many homes in the Navajo Nation continue to use solid fuels such as wood and coal for cooking and heating (Li et al. 2018; Champion et al. 2017; Finkelman and Bunnell 2003; Finkelman and Simoni n.d.). Coal is commonly used in Navajo Nation homes due to its low cost and wide availability; in some cases, residents receive coal for free from nearby mines or can purchase coal inexpensively at local flea markets (Li et al. 2018; Champion et al. 2017; Bunnell et al. 2010; Bunnell and Garcia 2006; Finkelman and Simoni n.d.).

The adverse effect of indoor coal burning in residential settings is notable: the 2019 Global Burden of Disease Study ranked household solid fuels such as coal, charcoal, and wood in the top 10 risk factors for global deaths, years of life lost, and disability-adjusted life years ("Household air pollution from solid fuels" 2020). Similarly, a 2010 report from the World Health Organization's International Agency for Research on Cancer concluded that emissions from indoor coal burning are carcinogenic (World Health Organization 2010). Available literature highlights that indoor air pollution from solid fuel use is associated not only with lung cancer but also with acute respiratory infections, chronic obstructive pulmonary disease (COPD), and other immune system impairments (Hosgood et al. 2011; Zhang and Smith 2007). Rural and poor areas of the United States, which burn solid fuel in the home, are at risk of similar negative health outcomes (Rogalsky et al. 2014). A 2014 study found concentrated solid fuel use in the Four Corners region (New Mexico, Arizona, Utah, and Colorado), which overlaps with the Navajo Nation (Rogalsky et al. 2014). Although most of the solid fuel examined by this study was wood (94%),

[7] While the San Juan Mine and the coal-powered San Juan Generating Station recently shut down in 2022 (Moses 2022; Robinson-Avila 2022), the APS Four Corners power plant continues to operate, albeit at a reduced rate (Randazzo 2021).

[8] The diseases and conditions analyzed by Bunnell et al. (2010) are asthma, bronchitis, COPD, coughing, pneumonia, upper respiratory tract infection, and wheezing.

the rest was coke[9] or coal (6%). The burning of these materials is likely to expose households to "health effects similar to those elsewhere in the world who use coal as their primary household energy source" (Rogalsky et al. 2014). Additionally, a 2018 study examining the cellular effects of Particulate Matter 2.5 ($PM_{2.5}$)[10] emitted from coal and wood commonly burned in Navajo Nation homes found that this $PM_{2.5}$ exposure led to adverse cellular responses comparable to those caused by vehicle emissions (Li et al. 2018).

There are several factors that may exacerbate exposure to fine particulates from coal burning in Navajo Nation homes, such as residents closing controller dampers on coal stoves (to avoid heat loss), stoves in disrepair, and stoves that "were not designed to operate at the higher temperatures at which coal burns" (Bunnell et al. 2010). Bunnell et al. (2010) conducted Particulate Matter 2.5 ($PM_{2.5}$) monitoring with 18 of 137 Navajo Nation households participating in a survey on home heating methods and noted observable cracks on coal stoves and "evidence of soot, sometimes quite heavy" on surfaces within the home, both signs of higher levels of $PM_{2.5}$ exposure from coal burning. The authors noted that the average and maximum 24-hour $PM_{2.5}$ concentrations inside these homes were 36 $\mu g/m^3$ and 109 $\mu g/m^3$, respectively, and that both these measurements exceeded the EPA's 24-hour standard of 35 $\mu g/m^3$ for ambient $PM_{2.5}$ (Bunnell et al. 2010). Based on the evidence that residential coal burning for cooking and heating creates indoor air pollution (Li et al. 2018; Champion et al. 2017; Bunnell et al. 2010; Finkelman and Bunnell 2003; Finkelman and Simoni n.d.), and that indoor air pollution is associated with adverse health effects ("Household air pollution from solid fuels" 2020; World Health Organization 2010; Hosgood et al. 2011; Zhang and Smith 2007; Rogalsky et al. 2014), it is not unreasonable to suggest that the same respiratory illnesses discussed above are also present among the Diné.

Taken together, coal mining, coal-related outdoor air pollution, and residential coal burning lead to a high public health burden in the Navajo Nation. As Li et al. (2018) notes, higher rates of exposure to $PM_{2.5}$ due to residential coal use "may be major contributing factors to public health burdens observed in the Navajo Nation, such as the higher death rates due to cardiovascular and respiratory illness compared to the rest of the US." The literature shows that Navajo people suffer "high levels of respiratory disease," despite low rates of cigarette smoking (Bunnell and Garcia 2006). When compared with the general U.S. population, the Navajo Nation and other Native Americans "suffer disproportionately from respiratory morbidity" (Finkelman and Simoni n.d.).

2.3 Quantitative analysis of black lung disease data

To learn more about the prevalence of black lung disease in the Navajo Nation, Summit conducted a quantitative analysis on aggregated public health data. The full methodology for the quantitative analysis can be found in the Black Lung Incidence Study Final Report.[11] Although we were able to find publicly available data (as described below), data limitations in the form of data suppression and underreporting[12] make it unclear whether the results in this section capture the whole picture of black

[9] Coke is a solid fuel derived from coal (EIA, accessed November 27, 2023).
[10] Particulate Matter 2.5 ($PM_{2.5}$) consists of fine, inhalable, airborne particles that are 2.5 micrometers or smaller (EPA 2023).
[11] Please see the Black Lung Incidence Study Final Report for more information on the methodology for the quantitative analysis.
[12] Data suppression is defined as the practice of redacting sensitive information to keep personal details such as medical history private. Data underreporting, on the other hand, refers to data that reports fewer counts than is true or accurate. For example, data underreporting occurs when fewer than the total number of people who have a disease receive or report a diagnosis for that disease.

lung incidence in the Navajo Nation. More information on data suppression and underreporting can be found in Section 2.4.

Summit analyzed data at the U.S. county level. Given that the Navajo Nation is its own governing entity and does not directly align with U.S. county lines, Summit opted to define Navajo Nation counties according to the six U.S. counties that partially reside within Navajo Nation borders. These six counties are:

1. Apache County, AZ
2. Coconino County, AZ
3. Navajo County, AZ
4. McKinley County, NM
5. San Juan County, NM
6. San Juan County, UT

Summit searched government databases, reports, and data sources from regulatory agencies to access aggregated public health data across time in the United States. Table 3 summarizes the databases from which Summit derived data for analysis.

Table 3: Quantitative analysis data sources

Title	Description	Study Period	Relevant Data
Centers for Disease Control and Prevention Wide-ranging ONline Data for Epidemiologic Research (CDC WONDER)	Aggregated health statistics including acquired immunodeficiency syndrome, cancer, sexually transmitted diseases, and morbidity and mortality	1999*–2020^	Total black lung deaths by International Classification of Disease-9 (ICD-9)/ICD-10 diagnosis
CDC Enhanced Coal Workers' Health Surveillance Program (ECWHSP)	Coal mining medical monitoring database sponsored by the CDC National Institute for Occupational Safety and Health (NIOSH)	1970*–2014^	Total black lung cases, black lung severity, mine type
U.S. Census American Community Survey, 1-year estimates	Annual demographics survey that includes information such as population, number of total households, and proportion of homes using coal for heating or cooking	2014; 2020; 2021^	County name, state, Federal Information Processing System code, population, total deaths, total households, households using coal or coke as fuel
U.S. Census County Business Patterns	Annual report providing labor statistics by industry (North American Industry Classification System (NAICS) or Standard Industrial Classification (SIC) codes[13])	1986*; 2020^	Total mining employees

[13] The research team reviewed NAICS codes and SIC codes to classify coal-mining business patterns. Coal mining NAICS codes are 2121, 212111, 212112, and 212113. SIC codes are 1211, 1213, 122, 1221, 1222, 123, 1231, 124, and 1241.

Title	Description	Study Period	Relevant Data
U.S. Energy Information Administration	Annual statistical report that analyzes and projects energy production and usage including coal	1983*; 2020	Coal mining regions, coal mine production
MSHA Mines Data Set	Panel dataset of all coal mines under MSHA jurisdiction as well as active status	1970*–2020	Number of coal mines, mine type (underground or surface), coal type, production hours, mine activity status, MSHA district

*Indicates the earliest available data.
^Indicates the most currently available data at the time of collection.

First, the team needed to identify how black lung disease is defined within the data. CDC NIOSH's Enhanced Coal Workers' Surveillance Program (ECWHSP), for example, defines and collects black lung data among active and former miners according to a strict diagnosis of CWP from the International Classification of Disease (ICD-9 code 500, ICD-10 J60). This dataset further classifies each black lung incidence according to its severity, ranging from 1 (least severe) to 3 as well as progressive massive fibrosis (PMF, the most severe), according to the International Labour Organization (ILO 2011).

CDC's WONDER database tracks all deaths according to relevant diagnosis code. Table 4 identifies the relevant black lung disease diagnostic codes from the International Classification of Diseases (ICD) classification system (CMS 2022).[14] This list, informed by the results of the literature review, includes multiple illnesses associated with coal dust exposure beyond CWP. With the exception of the final row, all ICD codes in Table 4 require exposure for diagnosis; for example, ICD-10 CM code J62.8 requires pneumoconiosis to be directly attributable to silica exposure. There may be instances where a healthcare professional is unable to make a causal connection to talc dust, silica, or other dust due to lack of medical records or awareness of a patient's occupational history (Kurth and Casey 2020). In this situation, the healthcare professional may use other ICD codes related to respiratory and cardiovascular diagnoses, but not specifically associated with talc dust, silica, or other dust; this can result in a misclassification of disease (Kurth and Casey 2020). Including diagnoses beyond CWP enables a broader understanding of black lung prevalence according to the definition used in the Black Lung Incidence Study, which aims to capture black lung instances due to both mining and non-mining activities.

Table 4: Black lung disease diagnostic codes

Diagnosis Description*	ICD-9 CM† code	ICD-10 CM‡ code
Coal Workers' Pneumoconiosis (CWP)	500	J60
Asbestosis (Pneumoconiosis due to asbestos and other mineral fibers)	501	J61
Pneumoconiosis due to dust containing silica§	-	J62

[14] The universal use of ICD-10 codes was mandated in 2015 (CMS 2021), but the preceding ICD-9 codes may also be relevant in studies of historical black lung disease prevalence. Not all ICD-10 codes for lung diseases in the range between J60 and J70 were relevant for analysis; those outside the range of acceptable diagnoses based on the literature were excluded from this study. For example, cannabinosis (J66.2), is a disease stemming from routine exposure to cannabinoids (i.e., marijuana use), which is not relevant to the purpose of the Black Lung Incidence Study.

Diagnosis Description*	ICD-9 CM† code	ICD-10 CM‡ code
Pneumoconiosis due to other dust containing silica	502	J62.8
Berylliosis, pneumoconiosis due to other inorganic dust	503	J63.2
Pneumonopathy due to inhalation of other dust	504	-
Pneumoconiosis, unspecified	505	J64

*Sources: CMS 2022, Kurth and Casey 2020
†International Classification of Diseases (ICD) Clinical Modification (CM) is a diagnostic system used to code and classify medical diagnoses.
‡The universal use of ICD-10 codes was mandated in 2015 (CMS 2021), but the preceding ICD-9 codes may also be relevant in studies of historical black lung disease prevalence.
§Also known as silicosis.

We organized our quantitative approach into three phases. Summit:

1. developed descriptive statistics to quantify black lung cases or deaths reported in the data;
2. conducted statistical hypothesis testing to determine whether black lung disease is more prevalent in the Navajo Nation than other parts of the United States; and
3. estimated black lung cases and death rates through a series of statistical models.

These three steps are described in the sections below.

2.3.1 Descriptive statistics

In order to contextualize the likelihood of black lung disease in a particular county, the research team assessed the factors associated with black lung disease in each county, namely the number of coal mines, production level (in short tons), number of coal miners that live in the county, and their relative exposure to coal dust (in hours). Each attribute, except average exposure time, was derived from sources in Table 3 above and was collected at a discrete point in time.[15] The average exposure time is an average across time between 1970 and 2020.

Table 5 below presents each Navajo Nation county's association with coal dust across these four metrics, plus a description of the percentage of the county's population that identifies as American Indian or Alaska Native. This percentage is illustrative, given it includes members of populations not limited to the Navajo Nation.

Table 5: Population and coal dust attributes across discrete points in time in Navajo Nation counties

County	Apache, AZ	Coconino, AZ	Navajo, AZ	McKinley, NM	San Juan, NM	San Juan, UT
American Indian/Alaska Native population (2021)	72.7%	25.1%	42.6%	73.1%	37.7%	72.7%
Total mines (1983)	0	0	2	2	5	0
Total mines (2020)	0	0	0	1	2	0

[15] More information on the data collection periods for these attributes can be found in the Black Lung Incidence Study Final Report.

County	Apache, AZ	Coconino, AZ	Navajo, AZ	McKinley, NM	San Juan, NM	San Juan, UT
Coal production, x1000 short tons (1983)	0	0	11,404	5,242	14,516	0
Coal production, x1000 short tons (2020)	0	0	0	4,555	5,695	0
Number of coal miners (1986)	0	0	0	0	0	0
Number of coal miners (2020)	0	0	0	0	711 (1%)	0
Average weekly dust exposure, hours	0	0	0	0	0.47	0
Households utilizing coke/coal for fuel (2021)	10 (0%)	3 (0%)	17 (0%)	28 (0%)	323 (1%)	5 (0%)

Sources: U.S. Energy Information Administration (1983, 2020); U.S. Census County Business Patterns (1986, 2020); MSHA Mines Data Set (1970-2020); U.S Census American Community Survey (2021). Notes: "American Indian/Alaska Native population" includes both Navajo Nation members and members of other Native American tribes, such as the Hopi Tribe. "Number of coal miners" and "Households utilizing coke/coal for fuel" rows present the total count of each metric as well as the share of each respective population in parentheses, where applicable. Counties with inactive mines will present a non-zero count for the number of total mines but will present zero coal miners and zero average weekly dust exposure hours.

Summit used this context to inform a preliminary view of black lung prevalence, specifically how many cases or deaths exist within the data. Given that each metric – black lung cases and deaths – is defined and collected differently, Summit analyzed black lung cases and deaths independently.

Summit's analysis included a series of descriptive statistics (e.g., means, medians, minimums, maximums) of black lung cases and deaths. Table 6 shows the cumulative reported black lung cases (reported by NIOSH's ECWHSP) and deaths (reported in CDC's WONDER database) in each of the six Navajo Nation counties across time. Given the coal attributes information for each county in the table above and knowing that the ECWHSP and WONDER databases each suppress county-level results when there are fewer than 10 confirmed cases/deaths for privacy reasons (CDC 2022a; CDC 2022b; Quick 2019), it is unclear whether there are truly zero cases/deaths in these counties as shown in the table or if this is a sign of data suppression. Additional details about data suppression can be found in Section 2.4.

Table 6: Reported black lung cases and deaths in Navajo Nation counties

County	# Reported Cases (1970-2014)	# Reported Deaths (1999-2020)
Apache, AZ	0	0
Coconino, AZ	0	0
Navajo, AZ	0	0
McKinley, NM	0	0
San Juan, NM	0	10
San Juan, UT	0	0

Sources: Cumulative black lung cases reported by ECWHSP during 1970–2014. Cumulative black lung deaths reported by CDC WONDER database during 1999–2020. Note: If the total number of diagnosed cases in a county is less than 10, the total is suppressed by ECWHSP and reported as zero rather than the actual total. Similarly, CDC

WONDER suppresses the actual total number of diagnosed deaths (i.e., CDC WONDER reports that the county has zero deaths instead of the actual total) if the total number of diagnosed deaths in the county is less than 10.

Beyond maintaining data privacy through data suppression, reported cases and deaths are potentially reflective of underreporting in the Navajo Nation. For example, Navajo Nation tribe members that have contracted or that are dying from black lung disease that do not visit a doctor for diagnosis or treatment of the disease are not reported in these measurements. Additional details on underreporting are discussed later in Section 2.4.

2.3.2 Statistical inference

After completing the summary statistics phase and gaining a fundamental understanding of the data, Summit conducted a series of statistical hypothesis tests to compare subpopulations within the data. One such test was to compare black lung cases and deaths within the Navajo Nation to other counties in the United States. The team tested Navajo Nation counties versus non-Navajo Nation counties for statistically significant differences in black lung cases and deaths in terms of both counts and rates (i.e., cases/deaths per 1,000 residents). Summit used a hypothesis test of equality, namely the average prevalence is equal between Navajo Nation counties and other U.S. counties. Given the normal distribution of the dataset, we performed two-tailed t-tests against the null hypotheses at 95% confidence that the average number of cases/deaths is equal between those two populations. These tests factor in the difference in sample size between the Navajo Nation counties and other counties (6 and 3,130, respectively). Table 7 below shows the results of the tests, keeping in mind that data suppression and underreporting may play a significant role in whether or not these subpopulations are conclusively different from one another.

Table 7: Two-tailed t-test comparing the difference in black lung counts and rates at 95% confidence, Navajo Nation versus other counties

	Navajo Nation	Other Counties	*p* - value	Statistically Significant?
Sample Size	6	3,130	-	-
Avg cases / county	0.00	4.34	0.78	No
Avg cases per 1,000 / county	0.00	0.11	0.80	No
Avg Deaths / county	1.67	3.44	0.80	No
Avg Deaths per 1,000 / county	0.01	0.04	0.85	No

Sources: Center for Disease Control and Prevention (CDC) ECWHSP 1970–2014, CDC WONDER database 1999–2020, and U.S. Census Bureau American Community Survey (ACS) 1-year estimates. Notes: Counties with 9 or fewer black lung cases or deaths are suppressed and reported as 0. As of 2020, there are 3,143 counties according to the U.S. Census Bureau. However, 7 counties either had completely missing data or merged with other counties to generate statistics. Merged counties occur in Alaska only. The total number of counties studied in this evaluation excluded those 7 counties, leaving 3,136 total counties. The "Other Counties" sample size of 3,130 is equal to the 3,136 total counties minus the 6 Navajo Nation counties.

The null hypothesis of equality could not be rejected for any of the four tests. In other words, there is insufficient evidence to conclude that black lung cases and deaths are statistically different (neither higher nor lower) from the average non-Navajo Nation county.

2.3.3 Estimating prevalence

As discussed later in Section 2.4, there is reason to believe that some areas, particularly in and around the Navajo Nation, tend to underreport black lung cases and deaths. However, we can use statistical models to estimate the number of black lung cases and deaths for each county in the Navajo Nation, thereby comparing the reported prevalence of black lung disease to what it may be using data from the rest of the United States. To accomplish this, Summit began by generating correlation matrixes for a series of factors (independent variables) associated with black lung – including the number of coal mines in a county, number of coal employees, exposure to coal mine dust, and use of coal residentially (such as heating or cooking) – to understand their correlation with black lung cases and deaths.[16] The team built on this information by designing a series of least absolute shrinkage and selection operator (LASSO) models to estimate each county's prevalence of black lung cases and deaths (the dependent variables) based on these independent variables. More information on the methodology and reasoning employed in this analysis can be found in Appendix C of the Black Lung Incidence Study Final Report.[17]

Table 8 compares the reported number of black lung cases and deaths to Summit's estimated results in the Navajo Nation. In almost every case, the LASSO models estimated more cases (except for Navajo, AZ and San Juan, UT, which remain at zero) and more deaths (except for San Juan, UT, which remains at zero) than were reported.[18]

Table 8: Navajo Nation, black lung disease reported vs. estimated results

County	# Reported Cases (1970-2014)	# Estimated Cases	# Reported Deaths (1999-2020)	# Estimated Deaths
Apache, AZ	0	1	0	2
Coconino, AZ	0	1	0	4
Navajo, AZ	0	0	0	3
McKinley, NM	0	30	0	20
San Juan, NM	0	22	10	22
San Juan, UT	0	0	0	0

Sources: Cumulative black lung cases reported by ECWHSP during 1970–2014. Cumulative black lung deaths reported by CDC WONDER database during 1999–2020. Estimated cases and deaths are LASSO model estimates.

Keeping in mind that counties with 10 or fewer cases/deaths are not reported for privacy purposes, the estimated values for these counties estimate reported black lung disease prevalence in these counties, not the true prevalence of the disease in these counties. While these results are only considered estimates based on a select set of publicly available data that contain the limitations described in the next section, they may help future researchers and policy makers better understand the disconnect

[16] The full list of independent variables is population (in 2014 and 2020); coal dust exposure per worker (hours); number of surface coal mines (in 1983 and 2020); number of underground coal mines (in 1983 and 2020); number of coal mining employees (in 1986 and 2020); surface coal production, x1000 short tons (in 1983 and 2020); underground coal production, x1000 short tons (in 1983 and 2020); and percent of households with residential coal use.

[17] Please see the Black Lung Incidence Study Final Report for more information on the methodology for the quantitative analysis.

[18] Given the different data collection periods and varied definitions for black lung disease by ECWHSP and WONDER, it is possible to have more black lung deaths than live cases.

between the prevalence of black lung disease in areas of the Navajo Nation and what is reported in the data.

2.4 Limitations

This section describes factors that potentially limit the availability of information and data on black lung disease among the Diné. As a result, these factors potentially affect the results of the quantitative analysis presented in this research brief.

Data Suppression. Black lung case data are collected by ECWHSP. For counties with fewer than 10 confirmed black lung cases, ECWHSP reports the county as having zero cases. This is intended to protect individuals' privacy in accordance with numerous health policies (CDC 2022a; Quick 2019). CDC WONDER suppresses black lung death data in a similar manner (i.e., suppressing any county with less than 10 deaths to zero) (CDC 2022b; Quick 2019). This practice makes it impossible to identify counties with less than 10 black lung cases/deaths, making the data more difficult to interpret. Note that suppression applies to the number of *total* black lung cases across the county regardless of disease severity. For example, consider a county with 100 total black lung cases, 99 of which are not severe, and one which is severe. In this county, all 100 cases will be reported, including the single, severe case. When counts of black lung cases or deaths are suppressed (in this case, replaced with zeroes), estimates of black lung disease prevalence are biased toward zero. Using these artificial "zeroes" for counties with suppressed results will have a downstream effect on the accuracy of any subsequent statistical model—the model will also pull county estimates closer to zero than if precise statistics were reported in the raw data.

Underreporting. It is possible that the public health burden of coal in the Navajo Nation is not fully documented, given the underreporting of health problems due to healthcare access constraints. In the Navajo Nation, the Navajo Area Indian Health Service—the region's primary health care provider—serves over 244,000 American Indians but only has 222 beds across five hospitals, representing 0.91 hospital beds per 1,000 people (Arambula Solomon et al. 2022). In comparison, the American Hospital Association estimated there were 920,531 hospital beds across the United States in 2022, representing 2.76 beds per 1,000 people (AHA 2022; U.S. Census Bureau 2022). Looking at Native American populations more broadly, many Native Americans live in areas lacking healthcare providers, requiring them to travel long distances to access healthcare (Arambula Solomon et al. 2022; Whitney 2017). Additionally, lack of health insurance is also common in Native American communities (Arambula Solomon et al. 2022; Whitney 2017). Lack of trust may be another reason for the underreporting of health problems, as several studies have cited lower levels of trust in healthcare providers among Native Americans compared to other populations (Guadagnolo et al. 2009; Hunt, Gaba, and Lavizzo-Mourey 2005). In agreement with these findings from the Black Lung Incidence Literature Review, the SMEs interviewed to inform this research brief confirmed that healthcare access and lack of trust in healthcare providers, researchers, and government organizations are challenges faced by the Diné. These factors are discussed in more detail in Section 3.1.1. The underreporting of black lung cases and deaths creates data that underrepresents the actual prevalence of black lung disease. Because these data are missing from the datasets, the statistical models that are applied to the datasets have reduced accuracy and reduced statistical power. The results of these models are likely biased toward underestimating the true prevalence of black lung disease.

3 CONSIDERATIONS FOR FUTURE RESEARCH

Given limited academic research on black lung disease in the Navajo Nation and potential undercounting in publicly available counts of black lung cases and deaths within Navajo Nation counties, this topic would benefit from future research. To inform recommendations for potential next steps, Summit conducted three interviews with SMEs who have worked closely with the Navajo Nation. These interviews were informally structured to solicit descriptions of the SMEs' expertise, experience, and recommendations based on their background. Summit developed an interview guide with questions designed to help direct the content and flow of the interviews, but the interviewers were not limited to discussing only those questions. Questions on the interview guide included a focus on the availability of Navajo Nation health data and recommendations to inform for future studies of black lung disease in the Navajo Nation. Figure 1 describes the participants in each interview (note that Interviews 2 and 3 were group interviews). Each of these SMEs has expertise in black lung disease research and experience conducting research with the Navajo Nation or Navajo Nation coal miners. The information and recommendations presented in the rest of this section come from the interviews conducted with these SMEs, unless otherwise cited.

Figure 1: Breakdown of SME interview groups

Interview #1	Interview #2	Interview #3
➢ **Dr. Robert Finkelman.** Research Professor at the University of Texas at Dallas in the Department of Geosciences. Conducted research in Navajo Nation while with the U.S. Geological Survey.	➢ **Dr. Cecile Rose.** Medical Director of the Miners Clinic of Colorado and Co-Director of the Black Lung Data and Resource Center, which serve miners, including Navajo Nation coal miners. ➢ **Dr. Lauren Zell-Baran.** Epidemiologist and spirometry technician at the Miners Clinic who performs database development, management, and recruitment for Black Lung Data and Resource Center.	➢ **Dr. Akshay Sood.** Medical Director of the Miners' Colfax Medical Center's (MCMC's) black lung outreach program and the Miners Wellness TeleECHO Program. MCMC serves Navajo Nation communities in New Mexico. ➢ **Bobbi Gore.** Program manager for the Black Lung Program at MCMC. ➢ **Xin Shore.** Senior statistician who manages MCMC's database for coal-related analysis.

3.1.1 Data and research challenges

All three interview groups confirmed that the available information on black lung disease in the Navajo Nation is limited. What data is available might still underrepresent the public health burden of coal in the Navajo Nation. These data limitations are associated with several key challenges faced by Navajo Nation populations, primarily healthcare access challenges and lack of trust in both healthcare providers and researchers.

Healthcare access challenges. One SME noted there is often a high "hassle factor" for many Native Americans as they attempt to access healthcare: in New Mexico, it might take six or seven hours of travel to see a physician for black lung screening (Interview 3). Not only is this travel time-consuming, but it can be expensive (Interview 3). SMEs noted that healthcare access challenges may lead to fewer recorded incidences of black lung disease (Interview 3).

Lack of trust in healthcare providers and researchers. Dr. Sood noted that some miners go to multiple health care providers to receive X-rays because they distrust the accuracy of diagnoses, and that they might not be willing to participate in government-sponsored screenings. Additionally, the SMEs noted that Native Americans may distrust researchers and government organizations because these organizations often show up, conduct low impact "helicopter research," and then leave without making a commitment to use their work to help the community (Interview 1, Interview 2, Interview 3). This distrust could result in underreporting, which could then impact the completeness of datasets such as CDC WONDER and NIOSH's ECWHSP.

3.1.2 Cultural considerations for future research

When identifying cultural considerations to inform future research efforts, all SMEs agreed on the importance of understanding and respecting Navajo Nation culture when conducting research.

Obtaining Navajo Nation approval. Researchers should be aware that receiving Institutional Review Board (IRB) approval for studies through the Navajo Nation Human Research Review Board can take more time (at least a year) and have additional complexities than expected from other IRBs (Interview 1, Interview 3). These complexities include needing to make multiple trips to the Navajo Nation Agency Councils to obtain approving resolutions and meeting with Navajo stakeholders such as executives at Navajo Area IHS to receive support letters. As a result, Dr. Sood recommended that research should have dedicated funding and resources for IRB experts in Native American research (Interview 3). Additionally, researchers should respect that the Diné value patience in decision-making and will take time to counsel together before finalizing a decision (Interview 1). Throughout any study, researchers should also partner with Navajo Nation stakeholders and experts in communication with Native American communities to ensure research purposes and findings are issued to the public in appropriate, respectful ways (Interview 1, Interview 3).

Building trust. As mentioned in the previous section, the SMEs noted that many Native American communities often mistrust researchers because of a history of academics showing up, conducting their research, and leaving without making a long-term commitment to share their results or aid the community (Interview 1, Interview 2, Interview 3). To build trust, researchers should focus on making a commitment to the community. For example, the Miners Clinic of Colorado and other the Health Resources and Services Administration (HRSA) Black Lung Clinics Program (BLCP) grantees have shown this commitment by providing regular high-quality screening over time, linking the Diné to local healthcare providers for management of abnormalities identified during screening, and providing assistance to the Diné as they apply for black lung benefits (Interview 2). Studying comorbidities (such as lung cancer, asthma, or diabetes) is another way researchers can help the community (Interview 2, Interview 3). Researchers will build trust by prioritizing the ultimate purpose of this research: helping people with black lung disease (Interview 2).

Addressing language barriers. Because the Diné have their own language, there are also potential language barrier issues that might arise during primary data collection. Researchers should consider teaming with language translators in the community to ensure data collected through verbal or written questionnaires or other instruments is complete and accurate (Interview 3).

Cultural competency training. To understand these cultural considerations and more, future researchers should consider undergoing cultural competency training in preparation for research in American Indian/Alaska Native (AI/AN) communities. This training will help researchers understand the

population and conduct their research in a way that is respectful. It could also reduce avoidable challenges for both researchers and the population (Interview 2).

3.1.3 Potential data sources for future research

Although information and data on black lung disease in the Navajo Nation are likely limited, there are a few available data sources that potential researchers could consider using.

As discussed in the quantitative analysis sections, Summit found and analyzed data from several sources, including CDC WONDER and NIOSH's ECWHSP, which capture black lung disease incidence, severity, and deaths. However, the usefulness of these datasets might be limited due to data suppression and underreporting constraints, as described in Section 2.4. SMEs noted that HRSA has data that is not publicly available that could contribute to MSHA's understanding of trends in black lung disease (Interview 2). HRSA collects data from grantee organizations such as the Miners Clinic of Colorado, the Black Lung Data and Research Center, and Canyonlands Healthcare (Interview 2). However, WONDER, ECWHSP, and HRSA data are limited because race and ethnicity data are not collected, so analysis of data specific to AI/AN or Navajo Nation cannot be performed.

Rather than building a database from the ground up, MSHA could consider partnering with researchers currently building their own databases. For example, organizations like the Miners Clinic of Colorado and the MCMC have databases informed by chest X-rays, B readings,[19] spirometry testing,[20] and questionnaires. These databases both track demographics, though at the AI/AN level rather than at the tribal affiliation level, so data specific to the Diné likely cannot be parsed out (Interview 2, Interview 3).

By using existing data rather than collecting new data, SMEs highlighted that MSHA would mitigate the challenges of establishing trust and preventing redundancy in data collection (Interview 2, Interview 3).

3.1.4 Next steps for future research

Should MSHA decide to conduct future research on black lung incidence with Navajo Nation populations, the following recommendations should be considered.

Partner with the Navajo Nation. Dr. Sood suggested that MSHA involve the Diné in the initial stages of research project development to both increase trust between researchers and the Diné and to ensure that the research effort will have a long-term impact on the community. Particularly, partnering with the Diné when developing research questions is crucial (Interview 3). SMEs also suggested that MSHA consider expanding this research to include a focus on comorbidities such as lung cancer, asthma, or diabetes to increase the benefit of the research effort for the Navajo Nation and other AI/AN communities (Interview 2, Interview3). By ensuring future research efforts are meeting the needs of those communities, MSHA could increase the level of buy-in and willingness to participate from those communities.

Partner with researchers who have built trust with the Diné. All SMEs recommended that future researchers consider partnering with individuals or organizations that already have strong relationships with the Diné. These partners could include members of the Navajo Nation both on and off Navajo

[19] B readings are examinations of radiographs "for the presence, profusion, and type of lung parenchymal abnormalities" (Blackley, Halldin, and Laney 2018).
[20] Spirometry testing is a common breathing test that measures lung capacity and the ease and speed at which an individual can blow air out of their lungs (American Lung Association 2023).

reservations, SMEs, long-established researchers, professionals at the Navajo Technical University, trusted medical practitioners, the United Mine Workers of America, HRSA BLCP grantees, or Indian Health Services. Collaboration with these groups could provide context for research results, increase the level of trust between researchers and the population, ensure the interests of the Diné are protected, break down potential language barriers, help avoid cultural misunderstandings, and add validity to the research (Interview 1, Interview 2, Interview 3). Additionally, researchers should consider partnering with organizations in New Mexico, Utah, and Colorado that are funded by the National Institutes of Health's Clinical and Translational Science Awards Program so that translational science can make meaningful differences in Navajo communities (Interview 3).

Consider whether a new primary data collection effort is warranted. Given the identified challenges in conducting research with the Navajo Nation population and the history of "helicopter research," which provides little or no positive impact to this population (Interview 3), MSHA may consider whether a new research project that involves primary data collection is the best course of action. As an alternative, MSHA may consider partnering with researchers and existing organizations, such as HRSA BLCP grantees, that have built trust within this community, that already have extensive databases, and whose projects are designed to benefit the Diné (Interview 2).

4 CONCLUSION

The key findings from this research brief are summarized below:

- There is a public health burden in the Navajo Nation related to residential coal use and coal mining, both of which have historically been important to the Navajo economy.
- Underreporting of black lung cases and deaths in the Navajo Nation may result from lack of trust in and access to health care and lack of trust in both researchers and the federal government.
- There are six U.S. counties that partially reside within Navajo Nation borders. Zero cases and just 10 deaths were reported in these counties during the respective data collection periods (1970-2014 and 1999-2020). These results may be a function of underreporting in the Navajo Nation. Data suppression might also affect these results.
- Statistical tests to compare Navajo Nation counties to other counties in the United States are inconclusive due to current data limitations.
- According to statistical models designed to estimate black lung prevalence in the Navajo Nation, estimated black lung prevalence is higher than reported in five of six counties.

Given evidence that the Diné may experience a disproportionate negative impact from coal compared to the rest of the United States, MSHA could consider future research to address the lack of public health data available for analysis. Our SMEs offered several considerations and suggestions for next steps:

1. **Align research with the needs of the Diné.** MSHA should consider research efforts that will result in the greatest tangible benefit for the Diné, thereby increasing buy-in. This could mean expanding the scope of the research to include both black lung disease and comorbidities, such as lung cancer, asthma, or diabetes. Another option could be offering health care screenings or black lung benefits application assistance to research participants.
2. **Partner with the Diné.** Future research efforts should be in direct collaboration with members of the Navajo Nation to create trust, mitigate cultural misunderstandings, and add credibility to the research.
3. **Identify advocates.** When engaging with the Navajo Nation community, MSHA should consider partnering with individuals from the Navajo Technical University, United Mine Workers of America, HRSA BLCP grantees, and other organizations who can provide important context and guidance to researchers while advocating for the interests of the community and miners.
4. **Avoid redundancy.** Rather than collecting new data, MSHA should consider partnering with organizations trusted by the Diné that already have extensive black lung disease databases. These partnerships will lessen the burden of the research effort while adding validity to the results.

The information from this research brief can support MSHA's efforts to shed light on the effects of black lung disease in the Navajo Nation.

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Table A-1: Links to quantitative data sources for coal usage and black lung prevalence statistics

Title	Link
Center for Disease Control and Prevention (CDC) Wide-ranging ONline Data for Epidemiologic Research (WONDER) [1999–2020]	https://wonder.cdc.gov/controller/datarequest/D76
CDC Enhanced Coal Workers' Health Surveillance Program (ECWHSP) [1970–2014]	https://www.cdc.gov/niosh/data/default.html
U.S. Census American Community Survey (ACS), 1-year estimates [2014, 2020, 2021]	https://www.census.gov/programs-surveys/acs/data.html
U.S. Census County Business Patterns (CBP) [1986, 2020]	https://www.census.gov/programs-surveys/cbp/data/datasets.html
U.S. Energy Information Administration (EIA) [1983, 2020]	https://www.eia.gov/coal/annual/
Mine Safety and Health Administration (MSHA) Mines Data Set [1970–2020]	https://arlweb.msha.gov/OpenGovernmentData/OGIMSHA.asp