Improving the Quality of Cancer Incidence Data for American Indians in Michigan Using Tribal Linkages

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BACKGROUND

National studies have shown cancer incidence and mortality for American Indians to be understated due to racial misclassification in medical charts. The Michigan Cancer Surveillance Program links with data from two sources to address this problem. Cases in the state registry are annually linked to Indian Health Service (IHS) records. In addition, linkages are done with tribal rosters of several Michigan tribes.

Michigan has linked the statewide registry to the rosters from five of Michigan's 12 federally recognized tribes. The rosters from the five linked tribes represent over 80 percent of the enrolled tribal member population from all Michigan tribes.

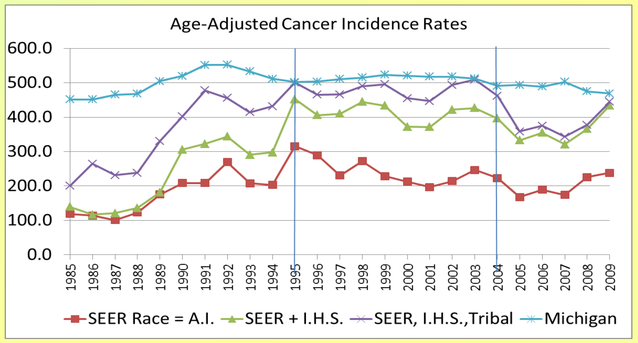
METHODS

Conducting linkages to tribal rosters has been accomplished with the collaborative support of the Intertribal Council of Michigan and the logistical and funding support of the Centers for Disease Control and Prevention. The linkages are conducted with participating tribes under the terms of an agreement that assures the confidentiality of the tribal roster and tribe specific cancer incidence data. Each tribe is provided with a de-identified database of the tribes cancer experience for analysis by the tribe while the state registry retains the information needed to update the racial classification of linked patients within the state registry.

Linkages are accomplished by traveling to each tribe bringing a prepared registry database ready for linking in a zipped and encrypted file. The tribes roster file is provided and prepared for linking on an external hard drive attached to an encrypted laptop computer. File preparation and linkage follows the protocols developed for linking to the Indian Health Service files, with linkage accomplished using LinkPlus software. Upon completion of the link, output files are prepared and then all files input to the link and any working files generated during the link are scrubbed from the external hard drive.

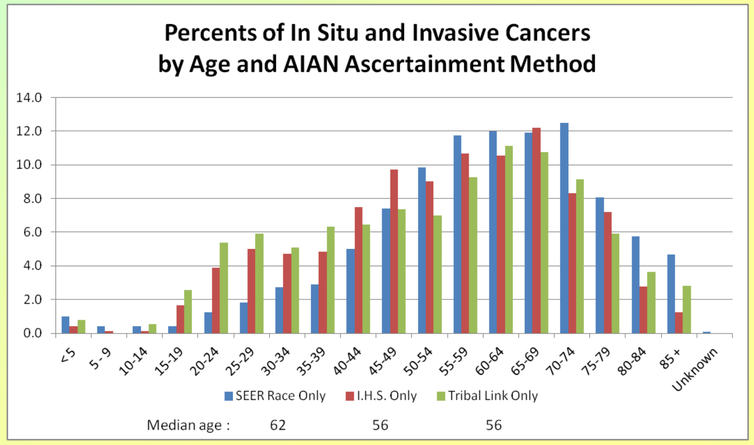
RESULTS

To date, the Michigan registry has been linked to rosters of Michigan tribes and the IHS, increasing the number of known American Indian cases in the statewide registry by over 100 percent. The IHS link contributes 2/3 of these newly identified cases, with the tribal roster links uniquely contributing the remaining 1/3 of the misclassified cases.



The graph above shows the progressive increase in incidence as each improvement in the data is considered. The tribal data combined with IHS identified cases double the resulting age-adjusted incidence rates. Because of the timing of the tribal links and the characteristics of the tribal rosters, the time period 1995 through 2004 represents the time period where ascertainment of the AI/AN population is most complete.

The characteristics of cases identified by the successive methods used have distinctive demographic characteristics. As can be seen in the chart to the left, the age distribution of cases ascertained through the IHS link and by the tribal link are much younger than reported cases.



The improved data enable calculation of AI/AN cancer incidence rates that can be more meaningfully compared to rates for other subpopulations. The table below shows how the leading cancer types vary for white and AI/AN males and females.

Leading Primary Sites by Race and Sex
Michigan Residents, 1995 - 2004

White Male			
Rank	Site	Number	Rate
1	Prostate	69214	183.8
2	Lung	36270	97.4
3	Colon	16537	46.0
4	Bladder	16500	45.7
5	Non-Hodgkin	9434	25.0
6	Melanoma	9127	23.7
7	Rectum	7494	20.0
8	Leukemia	6877	18.7
9	Kidney	6771	17.6
10	Oral	6313	16.3

American Indian Male			
Rank	Site	Number	Rate
1	Prostate	187	125.1
2	Lung	174	119.5
3	Colon	74	45.6
4	Rectum	42	25.3
5	Bladder	40	35.6
5	Oral	37	19.5
7	Kidney	33	17.1
8	Non-Hodgkin	30	15.8
9	Liver	26	15.7
	Leukemia	26	14.6

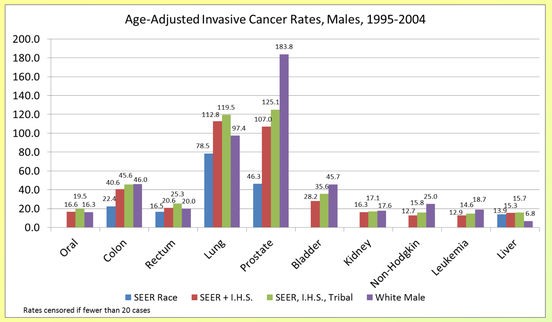
White Female			
Rank	Site	Number	Rate
1	Breast	62405	135.5
2	Lung	28413	59.6
3	Colon	17558	35.2
4	Corpus Uteri	12573	27.2
5	Non-Hodgkin	8864	18.6
6	Ovary	7825	17.0
7	Melanoma	7393	16.8
8	Rectum	6101	12.7
9	Bladder	5446	11.1
10	Leukemia	5358	11.3

American Indian Female			
Rank	Site	Number	Rate
1	Breast	236	95.9
2	Lung	176	84.8
3	Colon	68	35.1
4	Corpus Uteri	44	17.1
5	Ovary	28	11.8
6	Kidney	26	10.9
7	Cervix Uteri	25	9.5
8	Non-Hodgkin	24	9.0
9	Rectum	23	11.9
10	Leukemia	18	*
	Melanoma	18	*

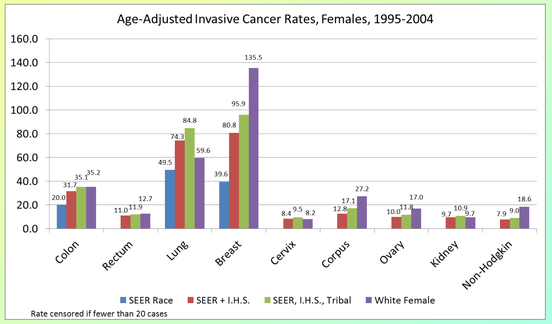
* Rate is considered statistically unreliable.

The progressive improvement in cancer incidence ascertainment for American Indians is shown in the charts below for males and females. These data indicate that the degree of improvement in AI/AN ascertainment completeness also varies by cancer type.

The improved data reveal higher rates of lung cancer in males. The tribal link results also reveal higher rates for oral and rectal cancers in AIAN males while the colon cancer rate draws up to the comparative white male rates. AI/AN prostate cancer rates increased to 2.7 times the unimproved rate but remained well below the white male rate.



Age-adjusted incidence rates for AI/AN females rose to levels comparable to white female rates for colon, rectum, cervix and kidney and climbed well above the white female rate for lung cancer after improvement. Breast cancer rates more than doubled but remained well below the rate for white females.



IMPLICATIONS AND FUTURE DIRECTIONS

Results of such efforts will undoubtedly vary by state and region but, in Michigan, registry links to tribal rosters add to the completeness of AI/AN status and contribute significantly to efforts at understanding the cancer risk of this population.

Working to link to more rosters of Michigan's 12 federally recognized tribes, with periodic relinks, this work will provide further clarity on disparities in cancer incidence and mortality among Michigan's American Indians. At the same time, continuing to provide tribal leaders with tribe specific data on cancer risk is also important.

These results suggest that a reliable method for adjusting AI/AN cancer incidence data can be developed based on these results to permit more timely availability of data on trends in the statewide AI/AN cancer experience.

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