Using Data Linkage to Identify First Nations Manitobans

Technical, Ethical, and Political Issues

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ABSTRACT

Background: The Manitoba Health Registry does not fully identify First Nations Manitobans, impacting the ability to adequately describe their health status and use of health services using this data source alone. This paper describes the processes in producing a valid database for use in a population-based report by the Manitoba Centre for Health Policy (MCHP).

Methods: The Indian Registry's Status Verification System (SVS) file is a national database containing a complete list of Registered First Nations eligible for benefits through the Indian Act. Through negotiations with the Assembly of Manitoba Chiefs' Health Information Research Committee, Indian and Northern Affairs Canada, FNIHB, Manitoba Health, and MCHP, a linkage of the SVS files and Manitoba Health's Registry was accomplished. Of the 116,177 SVS records and 5,803 deceased records, 97,635 individuals linked to the Manitoba Health Registry.

Results: There was a 99% match on gender, 70% match on surname, 94% match on given name, and 96% match on birth year. The total represents a 20% decrease in records from the Indian Registry. The decrease was greater for females, older people and those from southern areas.

Conclusion: The linkage resulted in a 20% increase over Manitoba Health data alone. Our inability to link all of the records may be due to several factors. Individuals with a Manitoba Band affiliation living outside of the province could not be linked to the Manitoba Health Registry. First Nations living in Manitoba but affiliated with a non-Manitoba Band would not have been in the file obtained. Finally, births, deaths and surname change after marriage may be under-reported to the Indian Registry. This linkage enabled MCHP to provide a more accurate picture of First Nations health status and use of health care services than otherwise would have been available. Ongoing linkages with Manitoba Health data, as well as similar linkages elsewhere in Canada, are encouraged.

MeSH terms: Indians, North American; health services research; medical records; medical record linkage; Manitoba; Canada

La traduction du résumé se trouve à la fin de l'article.

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The full report "The Health and Health Care Use of Registered First Nations People Living in Manitoba: A Population-Based Study" on which this article is based is available from the Manitoba Centre for Health Policy at the above address or on-line at: http://www.umanitoba.ca/centres/mchp/reports.htm
Acknowledgements of Sources of Support: This work was supported as part of a project on First Nations health in Manitoba, one of several projects undertaken each year by the Manitoba Centre for Health Policy under contract to Manitoba Health. The results and conclusions are those of the authors and no official endorsement by Manitoba Health was intended or should be inferred. Dr. Martens is also supported by a Community Alliances for Health Research Program grant from the Canadian Institutes of Health Research (CIHR), as well as a CIHR New Investigator's Award. The authors are indebted to Health Information Services, Manitoba Health, First Nations and Inuit Health Branch, Indian and Northern Affairs Canada and the Office of Vital Statistics in the Agency of Consumer and Corporate Affairs for the provision of data. Thanks to the Health Information Research Committee of the Assembly of Manitoba Chiefs, who acted as the Working Group (1999-2002) for The First Nations Report from which this paper was derived.

First Nations and Aboriginal Canadians have been shown to suffer more from various health problems than the general population.[1-6] Higher premature mortality rates and lower life expectancies have also been found among the First Nations population of Canada.[7] However, there are concerns with the quality of data identifying people as First Nations, both in Canada and the United States. In the United States, Indian Health Services data are commonly used in First Nations health research. However, data from Indian Health Services are limited to those who use their clinics,[8,9] cover only on-reserve American Indians,[10] and include only 33 of the 50 states.[11] Indian Health Services data have been estimated to cover approximately 25% of the American Indian population of the United States.[11] In Canada, many studies examine small samples of individual First Nations communities[12] or groups of communities.[13] Others rely on self-reports of First Nations status from the Canada Census.[14] However, Census data significantly undercount First Nations Canadians.[15] One of the reasons for this undercounting is that some First Nations communities refuse to participate in the Canada Census; in 2001, a total of 30 communities declined to participate in the Census.[14]

Context

The Manitoba Centre for Health Policy (MCHP) maintains the Population Health Research Data Repository of all residents of Manitoba who receive universal health insurance coverage. This information is anonymous, with no names and addresses, but contains demographic information (age, sex, region of residence) and an encrypted identification number for purposes of cross-linkage. Other files contained in the Repository (including vital statistics, hospital, medical claims, nursing home, and home care data) use the same number to track use of services. The research repository documents almost every health care contact for the Manitoba population, making it possible to describe the health status or health care use of all residents of a geographical region, whether that be a Tribal Council area, a Regional Health Authority area, or the entire province. The health status of residents of different geographical areas, as well as their use of health care resources (such as hospi-

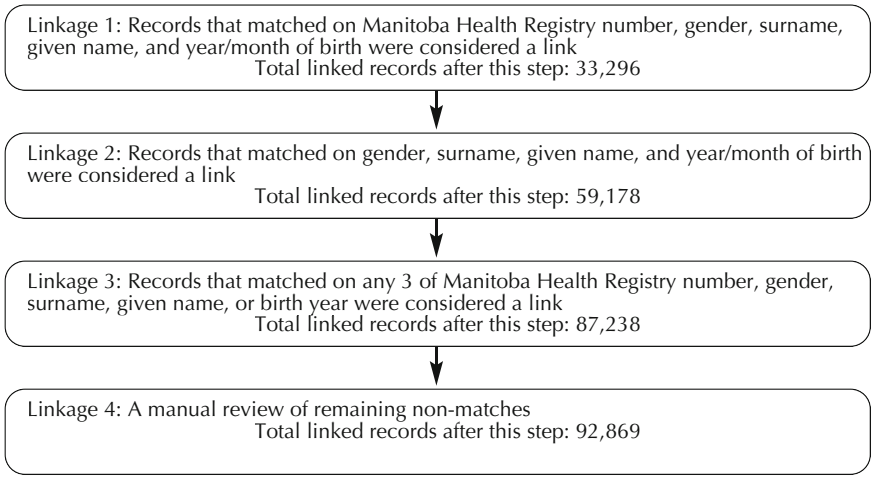

Figure 1. The linkage process (active file)

tals, physicians and preventive services), can also be compared. In 1999, MCHP began work on a report on the health of First Nations Manitobans using data in the Research Repository. The goal was to produce an accurate picture of health status and health services use of the entire Registered First Nations population of the province, with all other Manitobans as a comparison group.

Data from Health Canada's Medical Services Branch (First Nations and Inuit Health Branch (FNIHB)) – considered to be a more complete record of First Nations Canadians than the Census[15] – have been used for health research in two other provinces. FNIHB Ontario includes approximately 63,000 First Nations on reserve in Ontario. They have developed a Health Information System database, which allows First Nations communities, Tribal Councils, and Health Authorities to quickly obtain health reports on their residents.[16] The database, however, is strictly for use by First Nations groups, and the data are owned exclusively by the Ontario Aboriginal Health Authority.[16] In British Columbia, a contract between FNIHB and the province's Vital Statistics Agency established an annual reporting system of birth and death statistics for the First Nations population in British Columbia.[17] The reporting system uses the Status Verification File to identify First Nations residents and has resulted in a doubling of the annual reported deaths in the British Columbia First Nations population.[17] However, the Status Verification File cannot be used for any purpose other than the vital statistics reporting system. Both of these databases took a significant amount of time to create: the British Columbia reporting system took a year and a half to obtain approvals and set up the system;[17] the Ontario system took over two years.[16]

Administrative data have been used in the past to examine First Nations health in Manitoba. Young et al. used Manitoba Health data to determine First Nations status in a study of cervical cancer incidence.[6] However, Manitoba Health undercounts Registered First Nations living in Manitoba (65,526 in 1999 vs. 101,407 counted by FNIHB for the same year). To ensure validity of the comparison, MCHP wished to obtain a more accurate count of Registered First Nations in Manitoba.

Data source: The Indian Registry

The Indian Registry is a national database which contains a complete list of Registered First Nations eligible for benefits under FNIHB's Non-Insured Health Benefits Program. We requested a linkage with the Manitoba files, containing all Registered First Nations having Band membership with a Manitoba First Nation community. The Indian Registry, begun in 1951, includes approximately 700,000 individuals for all of Canada and is maintained by Indian and Northern Affairs Canada (INAC). FNIHB maintains the Status Verification System (SVS) files, which are based on the Indian Registry file. The SVS files include all individuals from the Indian Registry, along with additional individuals (such as Inuit) and some additional variables.

METHODS

Initially, permission was sought from FNIHB for the Status Verification files, which are based on the Indian Registry. However, as the Indian Registry files are maintained by INAC, permission needed to be sought from that department directly. Permission was obtained from the Assembly of Manitoba Chiefs' (AMC) Chiefs Health Committee and the AMC Health Information Research Committee (HIRC), INAC, FNIHB Manitoba, and Manitoba Health to proceed with a linkage of the Status Verification System (SVS) file of Manitoba Band members with the Manitoba Health administrative data. The principal researcher of the report, P.J. Martens, obtained permission through INAC's Access to Information and Privacy Coordinator, through a "Request For Personal Information by Research Body or Researcher for Research or Statistical Purposes", from Section 8(2)(j) under the federal Privacy Act. Once permissions had been obtained, INAC sent SVS files from 1994 to 1999 to FNIHB, who sent the files to Manitoba Health. After the linkage of the SVS file and the Manitoba Health Registry was complete, Manitoba Health then stripped the files of identifiers and sent the anonymized files to MCHP. These contained only an encrypted identification number. The files are strictly for use within this report, unless further permission is obtained from all stakeholders (MCHP, Manitoba Health, AMC, INAC, FNIHB).

The Manitoba SVS file which was sent to Manitoba Health by FNIHB included 116,177 unique records. Once duplicate records were removed, 106,949 remained. The approximately 10,000 duplicate records were usually files for the same individuals with different names or Department of Indian Affairs and Northern Development (DIAND) numbers.

Only 47% of the records in the SVS file contained a Manitoba Health Registry number. In order to match the individual records to the correct Registry numbers, the SVS file was linked with Manitoba Health data in four passes. The first pass used deterministic linkage and linked on Registry number, gender, surname, given name, and year/month of birth. Manitoba Health had linked to 33,296 individuals at the end of

this pass. The second pass was again a deterministic linkage, with Registry number left out of the link. At the end of this pass, there were 59,178 total linked individuals. The third pass was a probabilistic linkage using LinkPro© (1991-2003 InfoSoft Inc., 22 Sand Lily Drive, Winnipeg, MB, Canada, All Rights Reserved).[18] Probabilistic linkage gives more numerical weight to stronger and rarer identifiers. Weights are added among identifiers, and the total weight indicates the probability that the records are a match.[19] Records that linked on at least three of Registry number, gender, surname, given name, or birth year were considered a match. Soundex matching, a linkage method which accounts for variations in names that sound alike, was used on surname. At the end of this pass, there were 87,238 links. The final pass was also a probabilistic linkage, and included a manual review of unlinked records with high weights. The final number of linked records sent to MCHP was 92,869 (see Figure 1).

After obtaining the linked file at MCHP, we noticed that the mortality rates were far lower than the mortality rates calculated using unlinked Manitoba Health data. A closer examination of the linked file revealed that almost no deceased individuals were included. Although deceased individuals are never removed from the Indian Registry, in the SVS they are removed and archived into a separate file. FNIHB had sent Manitoba Health only the active SVS file. A second file containing 5,803 deceased individuals was subsequently obtained directly from INAC and linked separately. The first pass matched records based on given name, surname, and year/month of birth, resulting in an initial link of 1,350 records. The second pass matched records on Registry number and gender, increasing the total to 4,333. Further linkage to an earlier Registry file based on the same criteria, in addition to manual linkage, brought the total number of records to 4,766 (see Figure 2). Combining the active file with the deceased file gives us our final total of 97,635 individuals for the years 1994 to 1999 inclusive.

RESULTS

The active file showed a 99% match on gender, a 70% match on surname, a 94% match on given name, and a 96% match on birth year. There was a remarkably high 45% match on Health Number, considering that only 47% of the records sent to Manitoba Health contained a Health Number. Our number of 97,635 represents a 20% decrease in records from the Indian Registry data that Manitoba Health received from FNIHB. The decrease was greater for female than male (probably due to under-reporting of surname change after marriage), as well as for older people (possibly due to under-reporting of death) and those from southern Tribal Councils (possibly a more mobile population than those in the northern Tribal Councils, with a greater number of First Nations registered with Manitoba Bands no longer living in Manitoba). The largest addition to known Registered First Nations was among off-reserve urban residents.

Table I presents the completeness of various data sources for Registered First Nations Manitobans. These numbers are for all Registered First Nations Manitobans, both on reserve and off reserve, in 1999. The first row is the FNIHB data. The second row is Manitoba Health data. The final row is MCHP data linked with the Indian Registry file. The unlinked Manitoba Health data have the lowest count at just under 70,000, less than three quarters of FNIHB's count of over 100,000. The link with the Indian Registry increased that number to over 87,000 for 1999, which is much closer to FNIHB's total. The total number of linked records over the 5-year period was 97,635. But in any given year, the number will be lower due to mortality and migration over the five years.

Tables II to IV compare unlinked Manitoba Health data with the linked file by age group and region. The data from each file is presented for each group, followed by the difference between the two files, both directly and proportionally using a ratio of linked to unlinked. An age comparison is presented in Table II. Most age groups gained approximately 25%

TABLE I

Comparisons of Linked, Unlinked, and FNIHB Data, 1999

Data Source	RFN Population Count
Medical Services Branch (FNIHB)	101,407
Manitoba Health (Unlinked)	69,526
MCHP Linked	87,328

TABLE II

Age Comparisons of Linked vs. Unlinked Data, 1999

Age	Manitoba Health (Unlinked)	MCHP Linked	Difference	Ratio of Linked to Unlinked
0-14	27,766	33,657	5,891	1.21
15-24	12,502	15,786	3,284	1.26
25-34	11,064	14,224	3,160	1.29
35-44	8,480	11,190	2,710	1.32
45-54	4,762	6,321	1,559	1.33
55-64	2,706	3,444	738	1.27
65-74	1,440	1,797	357	1.25
75-79	412	461	49	1.12
80-84	217	254	37	1.17
84-89	113	128	15	1.13
90+	64	66	2	1.03

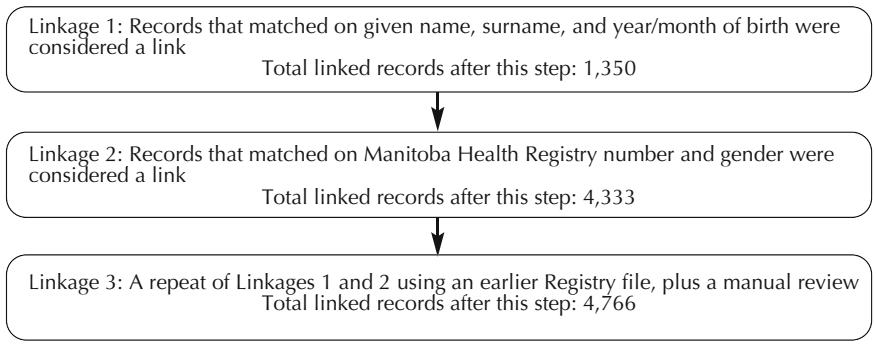

Figure 2. The linkage process (deceased file)

TABLE III

Regional Health Authority Comparisons of Linked vs. Unlinked Data, 1999

RHA	Manitoba Health	MCHP Linked	Difference	Ratio
Central	5,155	5,959	804	1.16
North Eastman	5,745	6,527	782	1.14
South Eastman	190	307	117	1.62
Interlake	6,361	7,977	1,616	1.25
Nor-Man	5,141	7,144	2,003	1.39
Parkland	3,367	4,976	1,609	1.48
Burntwood	24,456	26,956	2,500	1.10
Churchill	149	258	109	1.73
Brandon	1,602	2,233	631	1.39
Marquette	2,715	3,111	396	1.15
South Westman	495	488	-7	0.99
Winnipeg	14,150	21,392	7,242	1.51

more individuals. The greatest increase was among those age 35 to 54, with approximately one third more people added. Those aged 75 to 89 dropped substantially, and there was minimal increase in the number of individuals age 90 or older.

Linked and unlinked data are compared by Regional Health Authorities (RHAs) of Manitoba in Table III. These are geographical areas for purposes of provincial health administration, but not for on-reserve First Nations communities. Churchill and South Eastman had the greatest increase in proportion of individuals, although both RHAs have small numbers of Registered First Nations. The urban centre of Winnipeg also had a large increase; an additional 50% was added to their Registered First Nation population. There does not appear to be a geographical pattern to the proportional increases.

Table IV presents a comparison between linked and unlinked data by Tribal Council. (See http://www.umanitoba.ca/centres/mchp/fnts/maps.html for maps of Manitoba's RHAs and Tribal Councils.) Only on-reserve Registered First Nations are included in Tribal Council groupings. Our count of off-reserve Registered First Nations increased by almost 50%, while the majority of Tribal Council numbers changed little. Again, there is no apparent geographical pattern to the changes, although the western Tribal Councils of Swampy Cree and West Region had much larger increases than any of the other Tribal Councils.

DISCUSSION

There are a number of possible reasons why we could not link all of the Indian Registry file's records. First, some individuals with a Manitoba Band affiliation may be living outside of the province. While the Indian Registry file we used included all Manitoba Band members regardless of province of residence, the Manitoba Health Registry does not include non-Manitoba residents. Second, some individuals who died prior to 1994 may not have been removed from the Indian Registry file. We did not go back further than 1993 to find records of death. Finally, some of the records may not have had enough information to permit a reliable link.

Our number may have been lower than INAC estimates for several reasons. The Indian Registry file did not include Manitoba residents with a non-Manitoba Band affiliation, who would be counted in INAC's number. Births and deaths may also be under-reported to the Indian Registry. A limited number of individuals in Canada are responsible for notification and updating the Registry – most at First Nations communities, with a small core staff at INAC. Thus, it is likely that differences exist between when births and deaths are recorded and when they are updated in the Registry. Finally, surname changes after marriage may be under-reported, leading to records unlinkable to the Manitoba Health Registry.

AMC-HIRC have raised concerns about the existence of linked 1994-99 data regarding its use in other projects without consulting all stakeholders involved. We have guarded against this possibility by keeping the linked information "under lock and key". It was strictly for use within this report and cannot be used for any purpose without permission from AMC, INAC, FNIHB, Manitoba Health, and MCHP. There is discussion underway regarding defining the process of accessing already-linked 1994-99 data and the possibility of future ongoing linkages of the SVS files with the Manitoba Health Registry. Ongoing linkages would enable the continued production of high-quality information regarding the health status and health services use of First Nations Manitobans. However, these must take into consideration the concerns of all stakeholders in the process, while maintaining strict privacy and confidentiality safeguards.

This linkage resulted in the identification of a substantial number of First Nations Manitobans who had not been counted by the Manitoba Health Registry, enabling MCHP to provide a more accurate picture of First Nations health status and use of health care services. Because First Nations Canadians suffer from poorer health status than the rest of the population, it is of critical importance that information produced about First Nations health be of the highest quality possible. Future SVS linkages, both in Manitoba and elsewhere in Canada, will help to ensure the quality of data on First Nations health.

TABLE IV

Regional (On-Reserve Tribal Council) Comparisons of Linked vs. Unlinked Data, 1999

Tribal Council	Manitoba Health	MCHP Linked	Difference	Ratio	FNIHB Data
Dakota Ojibway Tribal Council	4,835	5,283	448	1.09	7,908
Island Lake Tribal Council	5,831	5,792	-39	0.99	7,170
Interlake Reserves Tribal Council	3,422	3,883	461	1.13	7,187
Keewatin Tribal Council	6,578	7,093	515	1.08	8,598
West Region Tribal Council	2,107	2,765	658	1.31	3,739
Swampy Cree Tribal Council	4,512	6,340	1,828	1.41	8,199
Southeast Resource Development Council	3,260	3,798	538	1.17	6,722
Independent - North	8,190	9,356	1,166	1.14	10,699
Independent - South	2,914	3,331	417	1.14	6,605
Off-Reserve	26,801	38,541	11,740	1.44	34,580

REFERENCES

1. Anand SS, Yusuf S, Jacobs R, Davis AD, Yi Q, Gerstein H, et al. Risk factors, atherosclerosis, and cardiovascular disease among Aboriginal people in Canada: The Study of Health Assessment and Risk Evaluation in Aboriginal Peoples (SHARE-AP). *Lancet* 2001;358(9288):1147-53.
2. Blackmer J, Marshall SC. A comparison of traumatic brain injury in the Saskatchewan Native North American and non-Native North American populations. *Brain Injury* 1999;13(8):627-35.
3. Health Canada. *A Second Diagnostic on the Health of First Nations and Inuit People in Canada*. Ottawa: 1999.
4. Martens PJ, Bond R, Jebamani LS, Burchill CA, Roos NP, Derksen SA, et al. *The Health and Health Care Use of Registered First Nations People Living in Manitoba: A Population-Based Study*. Winnipeg: Manitoba Centre for Health Policy, 2002.
5. Young TK. Prevalence and correlates of hypertension in a subarctic Indian population. *Prev Med* 1991;20(4):474-85.
6. Young TK, Reading J, Elias B, O'Neil JD. Type 2 diabetes mellitus in Canada's First Nations: Status of an epidemic in progress. *CMAJ* 2000;163(5):561-66.
7. MacMillan HL, MacMillan AB, Offord DR, Dingle JL. Aboriginal health. *CMAJ* 1996;155(11):1569-78.
8. Negoita S, Swamp L, Kelley B, Carpenter DO. Chronic diseases surveillance of St. Regis Mohawk Health Service patients. *J Public Health Management Practice* 2001;7(1):84-91.
9. Partin MR, Rith-Najarian SJ, Slater JS, Korn JE, Cobb NC, Soler JT. Improving cancer incidence estimates for American Indians in Minnesota. *Am J Public Health* 1999;89(11):1673-77.
10. Sugarman JR, Holliday M, Ross A, Castorina J, Hui Y. Improving American Indian cancer data in the Washington State Cancer Registry using linkages with the Indian Health Service and Tribal records. *Cancer* 1996;78(7):1564-68.
11. Burhansstipanov L. Native American data limitations and home care. *Alaska Med* 1995;37(4):133-38.
12. Harris SB, Glazier R, Eng K, McMurray L. Disease patterns among Canadian aboriginal children. *Can Fam Phys* 1998;44:1869-77.
13. Martin JD, Yidegiligne HM. Diabetes mellitus in the First Nations population of British Columbia, Canada. *Int J Circumpolar Health* 1998;57(Suppl 1):335-39.
14. Wilson K, Rosenberg MW. Exploring the determinants of health for First Nations peoples in Canada: Can existing frameworks accommodate traditional activities? *Soc Sci Med* 2002;55(11):2017-31.
15. Wright RE. Using Census data to examine Aboriginal issues: A methodological note. *Can J Native Studies* 1993;13(2):291-307.
16. Johnson RJ. The potential for Ontario Region's health information system to facilitate case management, program planning, and evaluation and to promote enhanced First Nations; control of health services. *Int J Circumpolar Health* 1998;57(Suppl 1):671-74.
17. Martin JD, Uh SH. A Vital Statistics system for determining births and mortality in the First Nations population of British Columbia, Canada. *Int J Circumpolar Health* 2002;61(2):92-97.
18. Wajda A, Roos LL, Layefsky M, Singleton JA. Record linkage strategies: Part II. Portable software and deterministic matching. *Meth Inform Med* 1991;30(3):210-14.
19. Roos LL, Wajda A, Nicol JP. The art and science of record linkage: Methods that work with few identifiers. *Comp Biology Med* 1986;16(1):45-57.

RESUMÉ

Contexte : Le registre de Santé Manitoba n'identifie pas parfaitement les Manitobains membres des Premières nations, ce qui réduit la possibilité de décrire convenablement leur état de santé et leur utilisation des services de santé à l'aide de ce seul registre. Notre étude décrit la marche à suivre pour créer une base de données valide dont le Centre d'élaboration et d'évaluation de la politique des soins de santé du Manitoba (MCHP) se servirait pour produire un rapport représentatif.

Méthode : Le Système de vérification du statut (SVS) du Registre des Indiens est une base de données nationale qui renferme la liste complète des membres inscrits des Premières nations admissibles aux prestations en vertu de la Loi sur les Indiens. À la faveur de négociations avec le comité de l'Assembly of Manitoba Chiefs chargé de la recherche sur l'information sanitaire, du ministère des Affaires indiennes et du Nord canadien, de la Direction générale de la santé des Premières nations et des Inuits (DGSPNI), de Santé Manitoba et du MCHP, les fichiers du SVS ont été reliés au registre de Santé Manitoba. Sur les 116 177 dossiers du SVS et les 5 803 dossiers des inscrits décédés, nous avons pu relier 97 635 dossiers au registre de Santé Manitoba.

Résultats : La concordance obtenue était de 99 % pour le sexe, de 70 % pour le nom de famille, de 94 % pour le prénom et de 96 % pour l'année de naissance. Cela représente au total une baisse de 20 % par rapport au nombre de dossiers dans le Registre des Indiens. Cette baisse était supérieure pour les femmes, les personnes âgées et les résidents des régions du Sud.

Conclusion : Ce maillage a représenté une hausse de 20 % par rapport aux seules données de Santé Manitoba. L'impossibilité d'apparier tous les dossiers s'explique par plusieurs facteurs. Tout d'abord, les personnes affiliées à une bande manitobaine mais vivant hors de la province n'ont pas pu être reliées au registre de Santé Manitoba. Les membres des Premières nations vivant au Manitoba mais affiliés à une bande non manitobaine n'apparaissaient pas non plus dans le fichier obtenu. Enfin, les naissances, les décès et les changements de noms après le mariage pourraient être sous-déclarés dans le Registre des Indiens. Notre maillage a néanmoins permis au MCHP de dessiner un portrait plus exact de l'état de santé des Premières nations et de leur utilisation des services de santé que ce qui aurait été disponible autrement. Il serait bon d'apparier en permanence les données du Registre des Indiens avec celles de Santé Manitoba et d'autres bases de données semblables ailleurs au Canada.