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## **Health Reports**

## Cancer in First Nations people in Ontario, Canada: Incidence and mortality, 1991 to 2010

by Sehar Jamal, Carmen Jones, Jennifer Walker, Maegan Mazereeuw, Amanda J. Sheppard, David Henry, and Loraine D. Marrett

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## **Cancer in First Nations people in Ontario, Canada: Incidence and mortality, 1991 to 2010**

by Sehar Jamal, Carmen Jones, Jennifer Walker, Maegan Mazereeuw, Amanda J. Sheppard, David Henry, and Loraine D. Marrett

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### ABSTRACT

### Background

This study aims to measure cancer incidence and mortality rates of Registered First Nations people in Ontario and compare them with those of other people in Ontario from 1991 to 2010.

### Data and methods

The federal Indian Register, the Ontario Cancer Registry and the Registered Persons Database were linked to develop a cohort of First Nations people diagnosed with cancer in Ontario. Sex-and site-specific age-standardized cancer incidence and mortality rates, and selected trends over time, were calculated. Rate ratios (RRs) were used to compare rates in First Nations peoples with those of other people in Ontario.

### Results

The First Nations cohort comprised 194,392 people, with 6,859 cancer diagnoses. First Nations people had higher rates for certain cancers than others in Ontario: lung (males RR 1.19; females RR 1.47), colorectal (males RR 1.36; females RR 1.34) and kidney (males RR1.95; females RR 2.23). While lung cancer rates rose in First Nations females (annual percent change [APC] +2.67), they fell at a similar rate (APC -2.28) in males. Cervical cancer rates fell (APC -9.53) and approached the rate among other females in Ontario. Kidney cancer rates increased in First Nations people.

### Interpretation

First Nations people in Ontario have higher incidence and mortality for certain cancers compared with other people in Ontario. However, the declines in cervical cancer rates in First Nations females and lung cancer rates in First Nations males illustrate the likely impact of Pap test uptake and smoking cessation programs. Community-led efforts to develop culturally appropriate prevention and screening programs are essential to further reduce cancer rates in First Nations people.

### Keywords

First Nations, cancer, Indigenous

### AUTHORS

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### Acknowledgements

### Analytic contributions

The authors would like to acknowledge the foundational role of their esteemed colleague, Diane Nishi, in this project. In particular, the work benefited from her analytic expertise, her constant vigilance regarding flaws in logic and data quality, and her always insightful recommendations for improvement. Abigail Amartey also played a pivotal role in the initial development of the study cohort. Nelson Chong was responsible for the complex record linkage process.

### Leadership contributions

Alethea Kewayosh and Tracey Antone brought organizational leadership and insight to the project while maintaining loyalty to the populations they serve.

The Chiefs of Ontario Health (Cancer Care Ontario), Health Canada (First Nations and Inuit Health), Indigenous Services Canada (formely Indian-and-Northern Affairs Canada), and ICES collaborated on this endeavour for over a decade.

### Disclaimers

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### What is already known on this subject?

- Prior to 1991, Registered First Nations people had lower cancer rates compared with the general population; however, rates for certain cancers (e.g., lung, colorectal) were rising more quickly over time than for other people in Ontario.
- Follow-up studies found lower rates of cancer survival among First Nations people compared with other people, particularly for colorectal, female breast, male lung and prostate cancers.
- Given the rising rates of certain cancers (e.g., lung, colorectal), updating cancer burden statistics in this population is important for providing more targeted prevention measures and programs.

### What does this study add?

- From 1991 to 2010, First Nations people had higher incidence and mortality rates for several cancers (e.g., lung, colorectal and kidney) compared with other people in Ontario.
- While cervical cancer incidence was rising in First Nations females prior to 1991, findings from this study indicate a decrease over time, with convergence with the incidence rates of the general population.
- This study presents important data for culturally appropriate cancer-control planning and priority-setting; however, data regarding cancer screening and follow-ups among First Nations in Ontario are needed to help inform health policies and programs.

There are three distinct Indigenous groups in Canada: First Nations, Inuit and Métis (FNIM).<sup>1</sup> They have unique histories, languages, cultural practices and beliefs. First Nations comprise the largest of these groups, with over 230,000 people residing in Ontario (about 2% of the provincial population and about 24% of the national First Nations population).<sup>2</sup> Many First Nations people face significant barriers to achieving good health, stemming in part from colonialism, racism and social exclusion.<sup>3</sup> As a result, many experience poorer health compared with the general population (e.g., lower life expectancy, higher avoidable mortality).<sup>4</sup> Other factors may also contribute to poorer health outcomes, including geographic challenges that limit accessibility to health services, affordable food and education.<sup>3</sup>

Cancer is among the leading causes of death in First Nations people.<sup>5</sup> However, a lack of Indigenous identifiers in health administrative databases, including cancer registries, has limited the measurement of health outcomes of First Nations people and the required conducting of special studies. Through record linkage, recently accumulated evidence has demonstrated differing patterns of cancer incidence in Indigenous populations compared with non-Indigenous populations. In Canada, it has been shown that First Nations people have a higher incidence of colon and rectum, kidney, cervix, and liver cancers, and a lower incidence of prostate, breast, bladder, uterus and brain cancers, as well as non-Hodgkin lymphoma, leukemia and melanoma.<sup>6-8</sup>

In Ontario, Canada's most populous province, available data were very out of date; coverage was only as recent as 1991.<sup>7</sup> These data showed rising cancer incidence rates in First Nations people in Ontario, especially for lung and colorectal cancers.<sup>7</sup> The purpose of this study is to present updated cancer burden information for First Nations people living in Ontario and to

look at trends over time, particularly in cancer rates that are targeted by screening programs (cervical, breast, colorectal) or public health interventions (smoking).

### Data and methods

As mandated by the Ontario First Nations Chiefs in Assembly in 2009, three organizations (Chiefs of Ontario, ICES and Ontario Health (Cancer Care Ontario)) collaborated on the development of a strategy to estimate cancer burden in First Nations people in Ontario. Chiefs of Ontario is the secretariat for the 133 First Nations communities in Ontario and led the effort in gaining access to the federal Indian Register (IR). ICES is an independent data research organization in Ontario that holds, maintains and uses the IR under authority from Chiefs of Ontario. Ontario Health (Cancer Care Ontario) is the government's cancer advisor and was responsible for analyzing and interpreting the cancer data.

The project strategy involved linking multiple databases to create a First Nations cohort, along with developing data governance and sharing agreements that detailed how the organizations would collaborate to manage data under the First Nations data-sovereignty principles of ownership, control, access and possession (OCAP®).<sup>9,10</sup> The Cancer Surveillance Working Group was formed to guide project development and implementation. Results were initially delivered to First Nations communities in Ontario using a knowledge translation and exchange framework with support from a First Nations Knowledge Translation Specialist.

### **Cohort creation**

The Cancer Surveillance Working Group submitted an application to Indigenous Services Canada requesting access to the IR for the years 1991 to 2010 ("study period"). The IR is the official record of all "status Indians" ("Indians" are now referred to as First Nations people) who meet defined eligibility criteria under the federal *Indian Act.*<sup>11</sup>A copy of the file with selected IR variables was sent to ICES, a prescribed entity under the *Personal Health Information Protection Act* of Ontario that is legally able to receive and link files with individual identifying information. ICES acted as data custodian on behalf of the First Nations in Ontario for the purpose of this project.<sup>12</sup> ICES created a cohort of Registered First Nations people (aged

Table 1

0 to 99) living in Ontario ("First Nations cohort") by linking the IR file with the Ontario Registered Persons Database (RPDB); the latter includes all Ontario residents entitled to publicly funded health care since 1991.<sup>12</sup> Ontario residents must have their health cards updated every five years; the RPDB includes specific years of health coverage and, therefore, assumed residence in the province. The linkage was performed using a combination of deterministic and probabilistic methods.<sup>12</sup> The First Nations cohort thus included all First Nations people in the IR (irrespective of the location of their band) who were also in Ontario's RPDB (and therefore assumed to be Ontario residents) for at least one year between 1991 and 2010. These datasets were linked using unique encoded identifiers and

Age-standardized incidence rate per 100,000 and rate ratios in First Nations people and other people in
Ontario, 1991 to 2010

	Number	Age-standar	dized		95% confidence	95% confidence
	(First Nations)	First Nations	Other	Rate ratio	interval (lower)	interval (upper)
Males						
All sites combined	3,152	324.1	336.7	0.96	0.93	1.00
0 to 14 years	48	11.5	17.7	0.65 <sup>‡</sup>	0.48	0.87
15 to 29 years	85	20.9	35.1	0.60 ‡	0.48	0.74
30 to 49 years	434	107.2	131.4	0.82 *	0.74	0.90
50 to 64 years	1,226	892.6	870.7	1.03	0.97	1.09
65 to 74 years	853	2,228.6	2,303.1	0.97	0.90	1.04
75 years and older	506	3,104.6	3,128.8	0.99	0.91	1.08
Prostate	636	72.5	90.6	0.80 ‡	0.74	0.87
50 to 64 years	250	186.6	253.5	0.74 <sup>‡</sup>	0.65	0.84
65 to 74 years	251	656.0	781.9	0.84 ‡	0.74	0.95
75 years and older	121	725.7	839.7	0.86	0.71	1.04
Colorectal	532	56.4	41.3	1.36 ‡	1.25	1.49
Younger than 50 years	64	4.9	4.3	1.12	0.86	1.44
50 to 64 years	229	166.9	110.3	1.51 <sup>‡</sup>	1.32	1.73
65 to 74 years	145	378.9	293.4	1.29 <sup>‡</sup>	1.09	1.52
75 years and older	94	591.1	441.8	1.34 <sup>‡</sup>	1.07	1.65
Lung	522	57.0	47.7	1.19 <sup>‡</sup>	1.09	1.30
Younger than 50 years	46	3.6	3.2	1.12	0.84	1.45
50 to 64 years	207	154.9	123.8	1.25 ‡	1.08	1.44
65 to 74 years	175	457.2	380.6	1.20 *	1.03	1.39
75 years and older	94	557.7	503.6	1.11 <sup>‡</sup>	0.89	1.36
Kidney	210	19.3	9.9	1.95 <sup>‡</sup>	1.68	2.25
30 to 49 years	49	12.3	6.8	1.81 <sup>‡</sup>	1.33	2.41
50 to 64 years	105	73.1	30.4	2.41 <sup>‡</sup>	1.96	2.93
65 to 74 years	32	83.5	53.4	1.57 <sup>‡</sup>	1.07	2.21
75 years and older	18	108.4	64.9	1.67	0.98	2.68
Non-Hodgkin lymphoma	121	11.5	15.0	0.76 ‡	0.63	0.92
Oral cavity and pharynx	116	11.2	10.9	1.03	0.85	1.25
Leukemia	86	8.0	12.9	0.62 ‡	0.49	0.77
Stomach	84	8.4	8.0	1.05	0.83	1.31
Liver	71	7.2	4.6	1.57 <sup>‡</sup>	1.22	1.99
Bladder	67	7.2	15.1	0.47 *	0.36	0.61
Pancreas	61	6.3	6.8	0.92	0.70	1.19
Esophagus	59	5.9	4.7	1.24	0.93	1.61
Testis	58	3.6	4.8	0.76	0.57	1.00
Myeloma	51	5.2	4.5	1.15	0.84	1.52
Brain	48	3.5	7.2	0.49 <sup>‡</sup>	0.35	0.66
Larynx	42	4.2	4.1	1.04	0.74	1.41
Melanoma of the skin	31	2.6	11.7	0.22 ‡	0.15	0 32

<sup>+</sup> statistically significant result (95% confidence interval excludes 1)

<sup>++</sup> Incidence rate for all ages combined for lung cancer in females is for ages 30 to 99 years.

Notes: Rates were calculated for age, sex and type combinations with 30 or more cases in First Nations people, age-standardized to the World Standard Population. Incidence rate for all ages combined include ages 0 to 99 years, unless otherwise specified.

Sources: Ontario Cancer Registry. Indian Registry System.

#### Table 1

Age-standardized incidence rate per 100,000 and rate ratios in First Nations people and other people in Ontario, 1991 to 2010 (continued)

		Age-standar	dized			
	Number_	incidence r	ate		95% confidence	95% confidence
	(First Nations)	<b>First Nations</b>	Other	Rate ratio	interval (lower)	interval (upper)
Females						
All sites combined	3,707	290.8	276.1	1.05 <sup>‡</sup>	1.02	1.09
0 to 14 years	42	10.3	15.7	0.66 ‡	0.47	0.89
15 to 29 years	100	27.1	41.1	0.66 ‡	0.54	0.80
30 to 49 years	962	237.5	237.1	1.00	0.94	1.07
50 to 64 years	1,331	823.8	768.3	1.07 <sup>‡</sup>	1.01	1.13
65 to 74 years	799	1,589.2	1,359.7	1.17 <sup>‡</sup>	1.09	1.25
75 years and older	473	1,861.4	1,810.0	1.03	0.94	1.13
Breast	919	69.6	81.0	0.86 ‡	0.80	0.92
30 to 49 years	328	81.5	89.7	0.91	0.81	1.01
50 to 64 years	358	218.2	261.4	0.83 <sup>‡</sup>	0.75	0.93
65 to 74 years	161	320.4	352.6	0.91	0.77	1.06
75 years and older	65	260.5	358.5	0.73 <sup>‡</sup>	0.56	0.93
Lung <sup>††</sup>	537	45.6	30.9	1.47 <sup>‡</sup>	1.35	1.61
30 to 49 years	57	14.6	10.9	1.34 <sup>‡</sup>	1.01	1.74
50 to 64 years	216	137.0	92.1	1.49 <sup>‡</sup>	1.29	1.70
65 to 74 years	178	354.6	225.0	1.58 <sup>‡</sup>	1.35	1.83
75 years and older	86	328.8	248.6	1.32 <sup>‡</sup>	1.06	1.64
Colorectal	465	38.2	28.4	1.34 <sup>‡</sup>	1.22	1.47
Younger than 50 years	77	5.9	4.0	1.48 <sup>‡</sup>	1.16	1.86
50 to 64 years	174	107.7	72.9	1.48 <sup>‡</sup>	1.26	1.72
65 to 74 years	124	246.8	183.6	1.34 <sup>‡</sup>	1.12	1.60
75 years and older	90	355.3	327.9	1.08	0.87	1.34
Cervix	169	11.1	6.9	1.61 <sup>‡</sup>	1.37	1.88
30 to 49 years	99	23.1	14.6	1.54 <sup>‡</sup>	1.28	1.93
50 to 64 years	30	17.8	13.4	1.33	0.89	1.91
65 to 74 years	15	29.7	14.1	2.10 <sup>‡</sup>	1.17	3.48
75 years and older	8	31.5	13.2	2.39 <sup>‡</sup>	1.02	4.76
Kidney	161	12.6	5.7	2.23 <sup>‡</sup>	1.89	2.62
Younger than 50 years	45	3.4	1.7	1.94 <sup>‡</sup>	1.41	2.62
50 to 64 years	63	38.2	15.8	2.41 <sup>‡</sup>	1.84	3.10
65 to 74 years	38	75.8	29.8	2.54 <sup>‡</sup>	1.79	3.50
75 years and older	15	59.4	36.0	1.65	0.92	2.73
Uterus	148	11.4	15.5	0.73 <sup>‡</sup>	0.62	0.87
Ovary	140	11.1	11.4	0.97	0.82	1.15
Non-Hodgkin lymphoma	139	10.9	10.9	0.99	0.83	1.18
Thyroid	97	6.5	14.1	0.46 ‡	0.37	0.57
Leukemia	92	7.2	8.2	0.89	0.71	1.09
Pancreas	78	6.5	5.4	1.20	0.94	1.50
Oral cavity and pharynx	68	5.2	4.5	1.16	0.90	1.48
Myeloma	67	5.4	3.1	1.75 <sup>‡</sup>	1.35	2.23
Stomach	65	5.2	3.7	1.42 <sup>‡</sup>	1.09	1.82
Brain	56	4.1	5.4	0.75 <sup>‡</sup>	0.56	0.98
Melanoma of the skin	48	3.4	9.7	0.35 <sup>‡</sup>	0.25	0.46
Bladder	35	2.9	4.0	0.73	0.50	1.01
Liver	32	2.8	1.4	1.95 <sup>‡</sup>	1.32	2.76
Gallbladder	31	2.6	0.9	2.70 <sup>‡</sup>	1.82	3.86
Vulva	31	2.3	1.4	1.58 <sup>‡</sup>	1.06	2.27

<sup>+</sup> statistically significant result (95% confidence interval excludes 1)

<sup>++</sup> Incidence rate for all ages combined for lung cancer in females is for ages 30 to 99.

Notes: Rates were calculated for age, sex and type combinations with 30 or more cases in First Nations people, age-standardized to the World

Standard Population. Incidence rate for all ages combined include ages 0 to 99 years, unless otherwise specified.

Sources: Ontario Cancer Registry, Indian Registry System.

analyzed at ICES. Analysis was also done at Ontario Health (Cancer Care Ontario).

#### Cancer cases and deaths

The Ontario Cancer Registry (OCR) includes information on all diagnoses of invasive cancer in Ontario residents since 1964, excluding non-melanoma skin cancers.<sup>13</sup> Cancers were

classified according to the International Classification of Diseases for Oncology, Third Edition.<sup>14</sup> Vital status and cause of death were available in the OCR. Deaths were classified according to the International Classification of Diseases, 10<sup>th</sup> Revision.<sup>15</sup> The First Nations cohort was linked with the OCR using a combination of deterministic and probabilistic methods. Cohort members who matched with the OCR were First Nations

people with cancer or dying from cancer; all other people diagnosed with or dying from cancer (i.e., non-Registered First

Nations, other Indigenous and non-Indigenous people) over the same time period were classified as "other people in Ontario".

#### Table 2

Age-standardized mortality rate per 100,000 and rate ratio in First Nations people and other people in Ontario, 1991
to 2010, most common cancer causes of death

Number         rate         95% confidence         95% confidence           (First Nations)         First Nations         Other         Rate ratio         interval (oper)           Males
(First Nations)         First Nations)         Other         Rate ratio         interval (lower)         interval (lower)           Males
Males         1         1         1         1         1         1         1         1           All sites combined         1,444         157.7         145.5         1.08 <sup>±</sup> 1.03         1.14           Younger than 30 years         27         3.1         4.2         0.74         0.48         1.08           30 to 49 years         143         36.1         35.6         1.01         0.85         1.20           50 to 64 years         495         368.6         308.0         1.20 <sup>±</sup> 1.09         1.31           65 to 74 years         442         1,155.2         1,001.9         1.15 <sup>±</sup> 1.05         1.27           75 years and older         337         2,081.1         2,222.4         0.94         0.84         1.04           Prostate <sup>11</sup> 131         16.3         13.8         1.18         0.96         1.40           50 to 64 years         17         13.7         11.4         1.20         0.70         1.93           65 to 74 years         44         115.1         84.4         1.36         0.99         1.33           Colorectal <sup>++</sup> 218         24.1         18.2         1.33         1.15         1.52
All sites combined         1,444         157.7         145.5         1.08 <sup>±</sup> 1.03         1.14           Younger than 30 years         27         3.1         4.2         0.74         0.48         1.08           30 to 49 years         143         36.1         35.6         1.01         0.85         1.20           50 to 64 years         495         368.6         308.0         1.20 <sup>±</sup> 1.09         1.31           65 to 74 years         442         1.155.2         1.001.9         1.15 <sup>±</sup> 1.05         1.27           75 years and older         337         2.081.1         2.222.4         0.94         0.84         1.04           Postate <sup>1+</sup> 131         16.3         13.8         1.18         0.98         1.40           50 to 64 years         17         13.7         14.4         1.20         0.70         1.93           65 to 74 years         44         115.1         84.4         1.36         0.99         1.83           Colorectal <sup>#1</sup> 218         24.1         18.2         1.33 <sup>±</sup> 1.15         1.52           30 to 49 years         69         180.5         12.61         1.43 <sup>±</sup> 1.11         1.81
Younger than 30 years         27         3.1         4.2         0.74         0.48         1.08           30 to 49 years         143         36.1         35.6         1.01         0.85         1.20           50 to 64 years         495         368.6         308.0         1.20*         1.09         1.31           65 to 74 years         442         1,155.2         1,001.9         1.15*         1.05         1.27           75 years and older         337         2,081.1         2,222.4         0.94         0.84         1.04           Prostate**         131         16.3         13.8         1.18         0.98         1.40           50 to 64 years         17         13.7         11.4         1.20         0.70         1.93           65 to 74 years         44         115.1         84.4         1.36         0.99         1.83           75 years and older         70         438.6         403.1         1.09         0.84         1.38           Colorectal**         218         24.1         18.2         1.33*         1.11         1.81           20 to 49 years         20         4.9         4.0         1.23         0.74         1.90           1
30 to 49 years         143         36.1         35.6         1.01         0.85         1.20           50 to 64 years         495         368.6         308.0         1.20 t         1.09         1.31           65 to 74 years         442         1.155.2         1,001.9         1.15 t         1.05         1.27           75 years and older         337         2,081.1         2,222.4         0.94         0.84         1.04           Prostate <sup>t+1</sup> 131         16.3         13.8         1.18         0.98         1.40           S0 to 64 years         17         13.7         11.4         1.20         0.70         1.93           65 to 74 years         44         115.1         84.4         1.36         0.99         1.83           75 years and older         70         438.6         403.1         1.09         0.84         1.38           Colorectal <sup>it</sup> 218         24.1         18.2         1.33         1.15         1.52           30 to 49 years         20         4.9         4.0         1.23         0.74         1.90           65 to 74 years         69         180.5         126.1         1.43 t         1.11         1.81
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Prostate <sup>+++</sup> 131         16.3         13.4         1.8         0.98         1.40           So to 64 years         17         13.7         11.4         1.20         0.70         1.93           65 to 74 years         44         115.1         84.4         1.36         0.99         1.83           75 years and older         70         438.6         403.1         1.09         0.84         1.38           Colorectal <sup>++</sup> 218         24.1         18.2         1.33 <sup>+</sup> 1.15         1.52           30 to 49 years         20         4.9         4.0         1.23         0.74         1.90           50 to 64 years         82         61.3         38.3         1.60 <sup>+</sup> 1.27         2.00           65 to 74 years         69         180.5         126.1         1.43 <sup>+</sup> 1.11         1.81           75 years and older         47         297.6         292.8         1.02         0.74         1.36           Lung <sup>+++</sup> 405         45.1         40.3         1.12 <sup>+</sup> 1.01         1.24           30 to 49 years         31         8.1         6.6         1.24         0.84         1.76           50 to 64 year
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Solito 4-9 years         20         4.3         4.0         1.23         0.74         1.30           50 to 64 years         82         61.3         38.3         1.60 <sup>‡</sup> 1.27         2.00           65 to 74 years         69         180.5         126.1         1.43 <sup>‡</sup> 1.11         1.81           75 years and older         47         297.6         292.8         1.02         0.74         1.36           Lung <sup>‡+</sup> 405         45.1         40.3         1.12 <sup>‡</sup> 1.01         1.24           30 to 49 years         31         8.1         6.6         1.24         0.84         1.76           50 to 64 years         148         111.3         94.5         1.18         0.99         1.39           65 to 74 years         148         386.7         322.5         1.20 <sup>‡</sup> 1.01         1.41           75 years and older         78         464.6         515.7         0.90         0.71         1.13           Kidney         61         6.5         3.5         1.88 <sup>‡</sup> 1.42         2.42           Females
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Lung <sup>#†</sup> 395 33.9 23.3 1.46 <sup>‡</sup> 1.32 1.61
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Colorectal <sup>##</sup> 169 14.2 11.5 1.23 <sup>#</sup> 1.05 1.44
30 to 49 years 17 4.3 3.4 1.24 0.72 1.99
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Cervix <sup>#†</sup> 70 5.2 1.8 2.90 <sup>‡</sup> 2.24 3.68
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<sup>+</sup> statistically significant result (95% confidence interval excludes 1)

<sup>††</sup> Mortality rate for all ages combined includes ages 50 to 99 years.

<sup>##</sup> Mortality rate for all ages combined includes ages 30 to 99 years.

Notes: Rates were calculated for age, sex and type combinations with 30 or more cases in First Nations people, age-standardized to the World Standard Population.

Cancer mortality for all ages combined include ages 0 to 99 years, unless otherwise specified.

Sources: Ontario Cancer Registry, Indian Registry System.

#### Figure 1

Time trends in age-standardized cancer incidence rates for lung cancer in First Nations people and other people in Ontario, 1991 to 2010



1a - Lung, males

1b - Lung, females

New cases per 100,000 females per year



Incidence for First Nations people
 Trend for First Nations people
 Incidence for other people in Ontario

Notes: APC = Annual percent change. The APC for lung cancer in First Nations males is -2.28; First Nations females is 2.67; for other males in Ontario is -2.33; and other females in Ontario is 1.22. From 1999 to 2010, the APC for lung cancer with other females in Ontario is -0.24. Sources: Ontario Cancer Registry, Indian Registry System.

### Statistical analysis

Person-years at risk for First Nations people were calculated from the first year that an individual appeared in the First Nations cohort file to the last year they were determined to be an Ontario resident, the year of cancer diagnosis, the year of death, or the end of the follow-up period (December 31, 2010), whichever was earliest. Annual population estimates for First

<sup>&</sup>lt;sup>‡</sup> statistical significance (p < 0.05)

#### Figure 2

Time trends in age-standardized cancer incidence rates for colorectal cancer in First Nations people and other people in Ontario, 1991 to 2010



New cases per 100,000 females per year

2b - Colorectal, females



<sup>+</sup> statistical significance (p < 0.05)

Notes: APC = Annual percent change. The APC for colorectal cancer in First Nations males is 0.38; First Nations females is 0.35; for other males in Ontario, from 1991 to 2007, is 0.07 and from 2008 to 2010 is -6.18; for other females in Ontario is -0.45.

Sources: Ontario Cancer Registry, Indian Registry System.

Nations people in Ontario were created from the First Nations cohort, based on specific years of provincial residence imputed from the RPDB. Person-years for other people in Ontario were calculated using Statistics Canada censuses from 2001, 2006 and 2011; intercensal estimates; and Ontario Ministry of Finance projections (Fall 2014). Annual population estimates for "other people in Ontario" were formed by subtracting the number of people in the First Nations cohort from annual population estimates for all of Ontario. Population sizes were estimated by age and sex, as well as calendar year.

Sex- and site-specific cancer incidence and mortality rates were calculated as the respective number of cases and deaths per 100,000 person-years, age-standardized to the World Standard Population.<sup>16</sup> Cancer types were grouped according to the

Surveillance, Epidemiology, and End Results Program site recode.<sup>17</sup> Rates are presented for age, sex and cancer combinations with 30 or more cases or deaths. The three most common cancer types for each sex were further stratified by age. Estimates for First Nations people and other people in Ontario were compared using the ratio of age-standardized rates, for which 95% confidence intervals (CIs) were calculated.<sup>18</sup> Rates between the two populations were considered to differ

significantly if rate ratio (RR) CIs excluded 1. These analyses were performed using SEER\*Stat software (version 8.3.2).

Incidence rates for the six most common cancer types in each sex were also estimated by year of diagnosis. For cervical and kidney cancers, incidence rates are presented in groups of two and three years, respectively, because of small numbers. Trend lines were produced, and annual percent change (APC)

#### Figure 3









 $^{\dagger}$  statistical significance (p < 0.05)

Notes: APC = Annual percent change. The APC for breast cancer in First Nations female is -0.09; for other females in Ontario is 1.19. For cervical cancer, the APC for First Nations females is -9.53; for other females in Ontario is -4.40 and between 2006 to 2010 is -4.46. Sources: Ontario Cancer Registry, Indian Registry System.

#### Figure 4

#### New cases per 100.000 males per year 120 100 APC = -3.39APC=2.15 0 80 0 0 0 0 60 0 0 0 0 0 APC=-0.05 40 20 0 1990 1995 2000 2005 2010 Year Incidence for First Nations people Trend for First Nations people Incidence for other people in Ontario Trend for other people in Ontario 0

#### Time trends in age-standardized cancer incidence rates for prostate cancer in First Nations males and other males in Ontario, 1991 to 2010

<sup>+</sup> statistical significance (p < 0.05)

Notes: APC = Annual percent change. The APC for prostate cancer in First Nations males is -0.05; for other males in Ontario is 2.15 and, from 2006 to 2010, is -3.39. Sources: Ontario Cancer Registry, Indian Registry System.

estimates and 95% CIs were calculated using Joinpoint software (version 4.2). The model recommended by Joinpoint was used, with a maximum of three joinpoints.

### Results

The First Nations cohort comprised 194,392 individuals, among whom 6,859 cancers were diagnosed during 3.1 million personyears of follow-up between 1991 and 2010. Of other people in Ontario, 1,069,446 cases of cancer were diagnosed during more than 246 million person-years at risk. The First Nations cohort was younger than other people in Ontario. Only 15% of First Nations people were older than 50, compared with over 25% of other people in Ontario. Table 1 shows the number of new cancer cases, age-standardized incidence rate (ASIR) and RR by cancer type and sex.

Cancer incidence for all sites combined was significantly higher for First Nations females compared with other females in Ontario (RR=1.05, 95% CI: 1.02 to 1.09), although incidence was significantly lower for females younger than 30; it was significantly higher for those aged 50 to 64 and 65 to 74 (Table 1). The all-sites ASIR for First Nations males was similar to that of other males in Ontario, although it was significantly lower for age groups younger than 50.

The most commonly occurring cancers in First Nations males were prostate, colorectal, lung and kidney cancers. In First Nations females, the most common were breast, lung, colorectal, cervix and kidney cancers. First Nations males and females had significantly higher incidence of colorectal, lung, kidney and liver cancers compared with other people in Ontario. First Nations females also had significantly higher incidence of cervical cancer, myeloma, stomach, gallbladder and vulvar cancers. First Nations males had significantly lower incidence of prostate, bladder and brain cancers, as well as non-Hodgkin lymphoma, leukemia and melanoma of the skin. First Nations females had significantly lower incidence of breast, uterus, thyroid and brain cancers, as well as melanoma of the skin.

Colorectal and lung cancer rates were significantly higher in First Nations males 50 or older compared with other males of the same age group in Ontario. Among First Nations females, colorectal cancer was significantly higher in all age groups younger than 75, and lung cancer was significantly higher in all age groups, compared with other Ontario females in those respective age groups. Kidney cancer RRs were significantly higher in First Nations males and females in all age groups younger than 75 compared with other males and females in Ontario younger than 75. Cervical cancer rates were significantly higher for all age groups in First Nations females, excluding those aged 50 to 64, compared with other females in Ontario.

Figures 1 to 5 illustrate fitted time trends for incidence rates of the most common cancers from 1991 to 2010. Rates increased significantly for lung cancer in First Nations females (p < 0.05), compared with other females in Ontario, whose rates remained relatively stable, thereby diverging over time. Lung cancer rates

for other females in Ontario.

Kidney cancer rates in First Nations females notably increased

over time compared with other females in Ontario (APC 17.43;

APC 4.13). First Nations males had higher rates than other

males in Ontario but exhibited a declining rate until 2003 (APC

-9.64), after which rates rose rapidly compared with males in

Ontario, potentially because of small numbers (APC 38.39;

APC 3.26). Cervical cancer incidence in First Nations females decreased significantly (APC -9.53), converging with the rate

decreased in both First Nations and other males in Ontario. Colorectal cancer rates in First Nations females and males remained higher than for other people in Ontario, with no significant upward or downward trends. Although breast cancer incidence was lower in First Nations females, rates increased steadily and approached those of other females in Ontario (APC 1.19; APC -0.09). Prostate cancer rates were stable in First Nations males; other males in Ontario experienced increasing rates until 2006.

#### Figure 5







5b - Kidney, females

<sup>+</sup> statistical significance (p < 0.05)

Notes: APC = Annual percent change. The APC for kidney cancer for First Nations males is -9.64 and from 2006 to 2010 is -38.39; for First Nations females is 17.43; for other males in Ontario is 3.26; for other females in Ontario is 4.13 Sources: Ontario Cancer Registry, Indian Registry System.

Mortality rates for all sites combined were significantly higher among First Nations people (especially in females and older age groups) compared with other people in Ontario (males: RR=1.08, CI: 1.03 to 1.14; and females RR=1.23, CI=1.16 to 1.29) (Table 2). Mortality rates were significantly elevated for lung and colorectal cancer in First Nations males and females aged 30 or older, and in all ages for kidney cancers, compared with other people in Ontario. Deaths from cervical cancer (30 years or older) were almost three times higher in First Nations females cwompared with other females in Ontario.

### Discussion

For several cancer types, incidence and mortality rates were higher in First Nations people compared with other people in Ontario. Similar findings have been reported for Indigenous populations in other parts of Canada (British Columbia, Alberta, Quebec) and the United States, Australia and New Zealand.<sup>6,8,19,20</sup> Rising incidence rates of kidney cancers in First Nations males and females, and lung cancer rates in First Nations females, were observed. Rates of lung cancer incidence among First Nations males declined over time. Encouragingly, a fall in cervical cancer incidence was also documented, resulting in a rate close to that of other Ontario females by the end of the study period. These positive trends may be a result of measures taken to reduce smoking and encourage cervical screening in First Nations communities.<sup>21</sup>

The incidence for all cancers combined was similar in First Nations males compared with other males in Ontario. However, rates of all cancers were higher in First Nations females compared with other females in Ontario. This finding, as well as the observation of higher cancer mortality rates, highlights the particular vulnerabilities of First Nations females.

Lung cancer was the most common cancer in First Nations people in Ontario, affecting 1,059 First Nations people between 1991 and 2010; incidence was significantly elevated in both sexes and across most age groups. Higher incidence of lung cancer was also found in the Indigenous populations in New Zealand, the United States (Alaska) and Queensland compared with the respective general populations.<sup>19</sup> However, lung cancer incidence was lower among First Nations people in British Columbia and Alberta compared with non-First Nations people.<sup>6,19</sup> In this study, lung cancer incidence declined among First Nations males (paralleling the trend of other Ontario males) but increased in First Nations females. Higher lung cancer rates in First Nations people may be expected in the future, given the current high prevalence of smoking in First Nations youth compared with non-Aboriginal youth.<sup>21</sup> Smoking cessation and prevention programs remain crucial to prevent or reduce commercial tobacco consumption among Indigenous youth in Ontario. The Indigenous Cancer Care Unit (ICCU) within Ontario Health (Cancer Care Ontario) has developed an Indigenous Tobacco Program to collaborate with communities for the purpose of enhancing knowledge and building capacity

through culturally sensitive approaches to address commercial tobacco cessation and prevention.

Colorectal cancer incidence was substantially higher among First Nations people than other people in Ontario. Higher colorectal cancer incidence has also been observed in First Nations people in other regions of Canada.<sup>6,19</sup> By contrast, colorectal cancer incidence was lower in Indigenous populations in New Zealand and Australia, although mortality was significantly higher and survival was poorer.<sup>22,23</sup> Specific to the findings of this study was that the risk of colorectal cancer in younger age groups (younger than 50 years) was higher in First Nations people, but only statistically significant in females. In Ontario, colorectal cancer screening guidelines suggest screening every two years for adults aged 50 to 74 who are at average risk.<sup>24</sup> However, the higher level of risk and earlier age of onset in First Nations people suggest that screening guidelines may need to be reconsidered for this population. This has been done for African Americans and Alaska Natives through organizations in the United States.<sup>25,26</sup> More research on the apparently younger age of diagnosis for colorectal cancer is needed in Indigenous populations.<sup>27</sup> First Nations have a higher prevalence of obesity and a lower consumption of fruits and vegetables compared with non-Aboriginal Indigenous people-strong risk factors for colorectal cancer.<sup>21</sup> In self-reported surveys of age-eligible First Nations people, 39% of females and 53% of males were underscreened for colorectal cancer.21

Historically, and as observed in this study, cervical cancer incidence has been significantly higher in First Nations females than in the non-Indigenous population.<sup>7</sup> However, from 1991 to 2010, incidence has decreased and converged with that of the Ontario population. Higher cervical cancer incidence has also been observed in Indigenous populations in other Canadian jurisdictions, as well as in New Zealand, Australia and parts of the United States (Alaska).<sup>6,19</sup> Based on self-reported data, First Nations women and non-Aboriginal women had similar Pap test uptake in more recent years,<sup>21</sup> which may have contributed to the strong downward trend of cervical cancer incidence in First Nations females and its convergence with that of other females in Ontario.

Breast cancer incidence has historically been lower among First Nations women in Canada, although it has increased since the 1980s.<sup>7,8</sup> Lower breast cancer incidence has also been observed in most Indigenous populations outside Canada, except in Alaska Natives in the United States and Maori females in New Zealand.<sup>19</sup> While breast cancer incidence was lower in First Nations people in Ontario from 1991 to 2010, it has increased over time and approaches that of other females in Ontario. This increase may be related to changes in risk factors such as diet and physical activity levels, or initiatives to improve screening (e.g., mobile screening bus or coach that made mammography more accessible). More research on understanding the increase in breast cancer among First Nations females is important to reverse its rise.

Kidney cancer was the fifth most common cancer affecting First Nations people. By contrast, it was the 12th most common cancer in other people in Ontario; however, it increased over time in both populations. High rates of kidney cancer have also been reported in Alaska Natives, who are more likely to be diagnosed with late-stage disease compared with White people.<sup>28</sup> Higher kidney cancer incidence was also observed in First Nations females in British Columbia.<sup>6</sup> Some partial explanations for increased kidney cancer incidence may include improved diagnostic imaging and higher prevalence of risk factors, including cigarette smoking, obesity, diabetes and hypertension. In the United States, over 40% of renal cell carcinomas are attributed to overweight and obesity.<sup>28</sup> Followup research is urgently needed, especially because of the steep increasing trend among First Nations people relative to other people in Ontario.

Overall cancer mortality was significantly higher in First Nations people compared with other people in Ontario; higher mortality from lung, colorectal, cervical and kidney cancers contributed to this. Previous studies of a similar yet older cohort from 1968 to 1991, as well as national cohorts in Canada, indicated survival was worse for First Nations people for many cancer types.<sup>29,30</sup> This was possibly explained by a higher prevalence of comorbidity and later-stage diagnosis.<sup>31</sup> Poorer access to medical care may lead to later presentation and impaired response to treatment.

The higher incidence and mortality of certain cancers may be due to the higher prevalence of some behavioural risk factors (e.g., cigarette smoking, obesity, lower fruit and vegetable consumption) in First Nations people in Ontario.<sup>21,32-34</sup> These differences in risk factors are rooted in the determinants of Indigenous peoples' health, which also include historical trauma, marginalization and poor access to the healthcare system.<sup>3</sup> Equitable access to a conducively built environment, affordable healthy foods, and a culturally safe and respectful health system are important in addressing the differences in the cancer experience and risk of First Nations people compared with others in Ontario. Indigenous Navigators support First Nations people and other Indigenous groups in Ontario make their way through the cancer system, providing access to Indigenous healers and well-being resources, as well as participating in medical appointments.<sup>35</sup>

Policies and programs must take a holistic approach to modifying the economic, physical and social environments that influence health-related behaviours.<sup>4</sup> Recommendations for such policies in Ontario have been made through extensive outreach and engagement with First Nations communities.<sup>36</sup>

### Strengths and limitations

The work involved close collaboration between the Chiefs of Ontario, Ontario Health (Cancer Care Ontario) and ICES. The work was led by First Nations and conducted according to First Nations OCAP® principles.<sup>10</sup> The First Nations Cohort included information about all Registered First Nations people

in Ontario who were linked to the RPDB (a database that identifies Ontarians who have accessed health care). Subsequent linkage to a population-based cancer registry (OCR) provided details regarding cancer diagnoses between 1991 and 2010. This enabled estimation of incidence for over 15 cancer types, with relatively stable estimates of incidence over a 20-year time period, including trends for more common cancers. Data linkage was completed by experienced staff using both deterministic and probabilistic methods.<sup>12</sup> This study has demonstrated that through partnership there is an opportunity to continue First Nations cancer surveillance using high-quality data to help inform cancer programs and funding for First Nations in Ontario.

Generalizability is limited to First Nations people who are registered under the *Indian Act*; according to the 2016 Census, at least 36% of self-identified First Nations people in Ontario are not registered.<sup>37</sup> Diversity among First Nations people across different communities in Ontario is not reflected in the results of this study.

### **Conclusions and impact**

Overall, colorectal and kidney cancer incidence and mortality in First Nations people were notably higher than those of other people in Ontario. Conversely, lung cancer incidence in First Nations males and cervical cancer incidence in First Nations females have been declining. The declines in incidence demonstrate the success of efforts to enhance prevention policies (e.g., smoking cessation) and programs (e.g., cancer screening) in First Nations communities. Developing culturally relevant programs in collaboration with First Nations communities may be a successful way to reduce the prevalence of risk factors and improve screening. The ICCU at Ontario Health has developed policy recommendations to reduce population-level exposure to four key risk factors (tobacco, alcohol, diet and physical activity), to build capacity for chronic disease prevention and to work toward health equity.<sup>36</sup> The education and prevention programs, research, and policy changes supported by the ICCU have been developed through strong partnerships among First Nations communities and organizations. Continued partnerships are needed to leverage First Nations health data to measure the entire cancer journey, including cancer screening and follow-up, to further understand and inform decisions.

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