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# Land Acknowledgment

Public Health Ontario (PHO) acknowledges that we are on the traditional territory of many nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples and is now home to many diverse First Nations, Inuit and Métis peoples. PHO also acknowledges that Toronto is covered by Treaty 13 signed with the Mississaugas of the Credit, and the Williams Treaties signed with multiple Mississaugas and Chippewa bands.

# **Evidence to Inform Policy Options for the Elimination of Hepatitis C Virus in First Nations Populations in Ontario**

Presenters: Lyndia Jones, Andrew Mendlowitz, Evelynne Hill April 27, 2021





• Have an understanding of the health and economic impacts of HCV in First Nations populations in Ontario

• Discuss how HCV elimination efforts can be tailored differently to the experience and needs of First Nations individuals in Ontario

• Explain how this evidence supports Canada's recommendations for what is needed to achieve HCV elimination by 2030

# **Key Findings**

1) Rates of diagnosed cases of Hepatitis C (HCV) infection in Status First Nations populations in Ontario are high and have increased annually since 2006

2) Rates of HCV testing in Status First Nations populations have also increased over time

3) Healthcare costs associated with HCV infection are high among Status First Nations individuals

# The impact of HCV on Indigenous populations in Canada

- An estimated 220,000 to 246,000 Canadians are living with hepatitis C viral (HCV) infection<sup>1</sup>
  - 44% are unaware of their diagnosis
  - Without treatment, over 41% of those infected may develop liver cirrhosis<sup>2</sup>
- The rate of HCV infection among Indigenous people in Canada has been estimated to be five times higher than the rest of the population<sup>3</sup>
- Among First Nations populations the epidemic has been associated with:
  - Younger age of infection
  - Higher rate of newly diagnosed infection

<sup>1.</sup> Trubnikov M, Yan P, Archibald C. Hepatitis C: estimated prevalence of Hepatitis C Virus infection in Canada, 2011. Canada Communicable Disease Report. 2014 Dec 18;40(19):429.

<sup>2.</sup> Thein HH, Yi Q, Dore GJ, Krahn MD. Estimation of stage-specific fibrosis progression rates in chronic hepatitis C virus infection: a meta-analysis and meta-regression. Hepatology. 2008 Aug;48(2):418-31.

<sup>3.</sup> Fayed ST, King A, King M, Macklin C, Demeria J, Rabbitskin N, Healy B, Gonzales S. In the eyes of Indigenous people in Canada: exposing the underlying colonial etiology of hepatitis C and the imperative for trauma-informed care. Canadian Liver Journal. 2018 Oct;1(3):115-29.

## **Understanding Determinants of Indigenous Health and Wellbeing**

- Distal determinants consist of colonization, racism and social exclusion<sup>1</sup>
  - Risk factors such as injection drug use, linked to trauma caused by colonial stress<sup>2</sup>
  - A ripple effect of trauma and unresolved grief is manifestations of substance abuse
- Intermediate determinants represent environmental origins
  - Link between individuals and community health
  - Impact access to treatment



Image from: McConkey SR. The Indigenous Determinants of Health as Predictors for Diabetes and Unmet Health Needs Among Urban Indigenous People: A Respondent-Driven Sampling Study in Toronto, Ontario.

1. Reading CL, Wien F. Health inequalities and social determinants of Aboriginal peoples' health. Prince George, BC: National Collaborating Centre for Aboriginal Health; 2009 Mar 26.

2. Fayed ST, King A, King M, Macklin C, Demeria J, Rabbitskin N, Healy B, Gonzales S. In the eyes of Indigenous people in Canada: exposing the underlying colonial etiology of hepatitis C and the imperative for trauma-informed care. Canadian Liver Journal. 2018 Oct;1(3):115-29.

# **Canada's commitment to First Nations people in the Blueprint**

## **Priority Population**

Facing barriers to care and a disproportionate impact of infection

### Surveillance

**Representation needed** in reporting and monitoring of infection

### Resources

Inform culturally safe approaches and programming



## Stigma

Image from: The Canadian Network on Hepatitis C Blueprint Writing Committee and Working Groups. Blueprint to inform hepatitis C elimination efforts in Canada. Montreal, QC: Available at: canhepc.ca/sites/default/files/media/documents/blueprint hov 2019 05.pdf

Committee calls to action



- Although a few studies have analyzed the impact of HCV on certain First Nations populations in Ontario:
  - Estimates have been limited in their scope
  - Lack of province-wide evidence
  - Practices in culturally safe handling of the epidemic remain unclear

A reference point is needed to inform the necessary health response for HCV elimination



## Performing First Nations health research using Ontario administrative data

- ICES houses Ontario healthcare administrative data
  - Health claims and utilization data (physician visits, hospitalizations, etc)
- Under the governance of the Chiefs of Ontario (COO), ICES received the Indian Register from Indigenous Services Canada
  - Reviewed for OCAP compliance and permission was obtained from both the COO and GCT3
- Linked to records of HCV testing from Public Health Ontario (PHO)



**Research Goal:** To work in partnership with First Nations organizations to provide evidence that can inform policy options for HCV elimination efforts in First Nations populations in Canada

## **Objectives:**

**1.** Examine trends in the testing and diagnosis of HCV among First Nations individuals in Ontario

2. Estimate the economic impact of infection among First Nations people in Ontario

# Working in partnership with First Nations organizations to incorporate cultural understandings and perspectives

- First Nations involvement ensured that cultural understandings and perspectives were incorporated throughout this work
- Ontario First Nations HIV/AIDS Education Circle (OFNHAEC) was advisory group and partner on this study
  - Involved in supporting and educating First Nations communities in dealing with challenges of HCV
- Partnership built on approaches stemming from principles of:
  - Anti-colonial approaches to research
  - Reciprocity and relational accountability
  - First Nations data sovereignty



# **Timeline of First Nations involvement throughout the research**

![](_page_13_Figure_1.jpeg)

# What are the trends in the testing and diagnosis of HCV among First Nations populations in Ontario?

# Hepatitis C virus infection in First Nations populations in Ontario: A province-wide descriptive analysis

- Existing studies on the impact of HCV on First Nations people have been region-specific and limited in scope
- To guide the creation of HCV policy and monitor progress towards elimination, comprehensive evidence describing the extent of infection among First Nations populations is first needed
- The *Blueprint* recognizes that HCV-relevant data must be disaggregated to reflect the impact of infection on different populations in Canada

Mendlowitz AB, Bremner KE, Walker JD, Wong WWL, Feld JJ, Sander B, Jones L, Isaranuwatchai W, Krahn M. Hepatitis C virus infection in First Nations populations in Ontario from 2006 to 2014: A population-based retrospective cohort analysis. CMAJOpen (Accepted for Publication)

# **Study Design**

Component	Description
Population	<ul> <li>Status First Nations population in Ontario (record in the Indian Register)</li> </ul>
Intervention	<ul> <li>Earliest record of a HCV test and/or diagnosis in PHO records</li> </ul>
Comparator	<ul> <li>First Nations individuals without a test record for HCV infection</li> <li>First Nations individuals tested for HCV</li> <li>First Nations individuals diagnosed with HCV</li> </ul>
Time	<ul> <li>January 1, 2006 to the end of linked PHO data (December 31, 2014)</li> </ul>
Outcomes	<ul> <li>Characteristics of those tested, diagnosed and with no test record</li> <li>Annual point prevalence and incidence of tested and diagnosed individuals</li> </ul>

# **Testing has increased**

![](_page_16_Figure_1.jpeg)

# Larger increase among those who reside within First Nations communities

![](_page_17_Figure_1.jpeg)

## **Diagnoses have increased**

![](_page_18_Figure_1.jpeg)

# Larger increase among those who reside within First Nations communities

![](_page_19_Figure_1.jpeg)

# Regions with the highest rates of HCV testing have the highest rates of diagnosed infection

### Prevalence of Ever Tested (2014)

![](_page_20_Figure_2.jpeg)

#### Incidence of First Test (2006 to 2014)

![](_page_20_Figure_4.jpeg)

#### **Prevalence of Diagnosed Infection (2014)**

![](_page_20_Figure_6.jpeg)

![](_page_20_Figure_7.jpeg)

## **Summary of Descriptive Findings**

#### **Characteristics**

- Most individuals were younger than 40 years of age
- Majority of those tested were female, more males were diagnosed

#### **Higher Rates**

- National rate of reported diagnosis of HCV is 0.5%<sup>1</sup>
- In 2014, we saw a prevalence of diagnosed infection of 2% among Status First Nations individuals

### **Success of Testing**

• Parallel increases in testing and diagnoses of infection

### **Use with Caution**

• Rates only paint part of the picture due to the asymptomatic nature of infection

# What are the healthcare costs associated with HCV infection among First Nations populations in Ontario?

# Healthcare costs associated with hepatitis C virus infection in the First Nations populations in Ontario

- HCV infection places economic strain on the healthcare system, driven by expensive antiviral drugs and treatment of advanced liver disease
- Despite this, no studies of HCV costs in Indigenous people have been published
- Estimates of First Nations-specific costs of care associated with HCV infection are essential to planning and evaluating effective and culturally-safe approaches to mitigating infection

Mendlowitz AB, Bremner KE, Walker JD, Wong WWL, Feld JJ, Sander B, Jones L, Isaranuwatchai W, Krahn M. Healthcare costs associated with hepatitis C virus infection in the First Nations populations in Ontario. CMAJOpen (Accepted for Publication).

# **Study Design**

Component	Description
Population	<ul> <li>Status First Nations population in Ontario with a record in the Indian Register</li> </ul>
Intervention	<ul> <li>Earliest record of a HCV test in PHO records from 2004 to 2014</li> </ul>
Comparator	<ul> <li>First Nations population with either a negative or no test record for HCV infection</li> </ul>
Time	<ul> <li>January 1, 2004 to December 31, 2017</li> </ul>
Outcomes	<ul> <li>Provincial total and net healthcare costs per 30 days in 2018 Canadian dollars by resource category</li> </ul>

To measure costs, HCV was divided into four phases that consider the natural history and care trajectory of the disease

![](_page_24_Figure_1.jpeg)

• Individuals with HCV were matched to up to two similar individuals without HCV to estimate the costs due to infection (net costs)

## Inpatient care accounted for the majority of healthcare costs among cases

![](_page_25_Figure_1.jpeg)

Inpatient care accounted 30-50% of total healthcare costs for pre-diagnosis, initial and late care phases, and 60-70% of total costs in the terminal phase

## **Costs of HCV infection increased with disease progression**

Net Total Costs

# Net total costs per 30 days greatly increased when liver disease developed

![](_page_26_Figure_3.jpeg)

## Costs differed by community residence, especially in terminal phase

- Net total costs were higher in the initial, late and terminal phases for those who resided outside of First Nations communities
- Net costs differed the most in terminal phase between those who resided within versus outside of First Nations communities

![](_page_27_Figure_3.jpeg)

Net Total Costs by Community Residence

## Female net costs were higher than males, except in terminal phase

![](_page_28_Figure_1.jpeg)

- In the pre-diagnosis, initial, and late phases, female cases exhibited higher net total costs of care than male cases
- Only in terminal phase did males exhibit higher net total costs than females

# **Summary of Cost Findings**

### **High Costs of Infection**

• Annual costs were nearly 1.5 times the average Canadian healthcare cost and higher than BC estimates of the cost of HCV infection

### **Costs differed by Community Status**

 End-of-life care within communities may be associated with family support rather than services delivered in hospital or hospice settings<sup>1</sup>

### **Costs differed by Sex**

- First Nations Women may be more likely to have a family physician and seek healthcare services<sup>2</sup>
- Women may be more likely to choose traditional medicine and community supports for end of life care<sup>3</sup>

#### **Provincial healthcare expenditures**

• ICES databases do not capture out-of-province or federally funded healthcare services

<sup>1.</sup> Russell B, Fred DE, Brown C. Culturally safe end-of-life care for First Nations persons living on reserve. Rural and remote health. 2018;18(3):287.

<sup>2.</sup> Verde M, Li HZ, George P. Are native men and women accessing the health care facilities? Findings from a small native reserve. The Canadian Journal of Native Studies. 2003;23(1):113–33.

<sup>3.</sup> OFNHAEC Project Update Meeting, 2020 July 6 (Unpublished).

# **Key Findings**

- 1) Rates of diagnosed cases of HCV infection in Status First Nations populations in Ontario are high and have increased annually since 2006
  - Found a prevalence of 2% among First Nations people which is higher than national measures (0.5%)
- 2) Rates of HCV testing in Status First Nations populations have also increased over time
  - Testing strategies and approaches in First Nations populations are successful, especially within First Nations communities
  - Successful partnerships between First Nations communities and their LHINs to formulate accessible and culturally appropriate healthcare services, especially in mental health and addiction
- 3) Healthcare costs associated with HCV infection are high among Status First Nations individuals
  - Costs were nearly 1.5 times the average Canadian healthcare cost and higher than BC estimates of the cost of HCV infection
  - Costs of late and terminal phases forecast the economic impact if HCV infection remains untreated or diagnosed late

## Lessons Learned Through Partnership

## Ways of Knowing

- Understand the journey with HCV among First Nations individuals
- Helped understand which administrative data parameters should not be used

## **Relationship Building**

 Brought awareness to processes in engaging First Nations partners when using administrative health data

![](_page_31_Picture_6.jpeg)

## **Co-learning**

 Experiences have built capacity for both researchers and partners

## **Fostering Trust**

- Establishing trust with the organizations that govern access to the Indian Register
- Built research network that has surpassed this thesis work

# **Moving towards HCV elimination**

![](_page_32_Picture_1.jpeg)

## Surveillance

 Monitor progress towards elimination of infection

![](_page_32_Figure_4.jpeg)

## **Elimination Efforts**

- Create a case for investment in HCV prevention and treatment efforts
- Efforts will need to be strengthfocused and tailored to the experience of First Nations individuals

## Empowerment

 Inform OFNHAEC programming, community leaders and decision-makers

# Acknowledgements

#### **First Nations Partner:**

• Ontario First Nations HIV/AIDs Education Circle

#### **Funding Sources:**

- Canadian Institute of Health Research Project Grant
- Canadian Network on Hepatitis C (CanHepC) Doctoral Fellowship

#### Research Team:

- Principal Investigators: Dr. Murray Krahn, Dr. Jennifer Walker
- Co-Investigators: Andrew Mendlowitz, Dr. Beate Sander, Dr. Michelle Murti, Dr. Vanessa Allen, Dr. Wanrudee Isaranuwatchai, Dr. Jordan Feld, Dr. William Wong, Dr. Nicholas Mitsakakis
- **Collaborators:** Lyndia Jones, Thomas Wong, , Gwen Medicine, Irene Peters

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![](_page_33_Picture_11.jpeg)

![](_page_33_Picture_12.jpeg)

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Thank You

Supplement

# **Demographic Characteristics**

Characteristic	Individuals tested for HCV infection (at earliest testing date)	Individuals diagnosed with HCV Infection (at earliest date of positive test result)	No test record in PHO (at midpoint – July 1, 2010)
Cohort Size, N	20,481	2,423	135,185
Age in years			
Mean ± SD	34.2 ± 15.6	36.2 ± 12.3	29.9 ± 20.8
Median (IQR)	31 (22-44)	35 (27-45)	27 (12-46)
Age group, years, N (%)			
<25	6,776 (33.1%)	451 (18.6%)	63,570 (47.0%)
25-29	2,902 (14.2%)	378 (15.6%)	8,829 (6.5%)
30-34	2,209 (10.8%)	324 (13.4%)	8,356 (6.2%)
35-39	1,849 (9.0%)	290 (12.0%)	8,638 (6.4%)
40-44	1,666 (8.1%)	323 (13.3%)	9,012 (6.7%)
45-49	1,466 (7.2%)	284 (11.7%)	9,572 (7.1%)
50-54	1,201 (5.9%)	184 (7.6%)	8,091 (6.0%)
55+	2,412 (11.8%)	189 (7.8%)	19,117 (14.1%)
Sex, N (%)			
Male	9,247 (45.1%)	1,282 (52.9%)	69,808 (51.6%)
Female	11,234 (54.9%)	1,141 (47.1%)	65,377 (48.4%)
Birth Cohort, N (%)			
Before 1945	899 (4.4%)	16 (0.7%)	7,858 (5.8%)
1945 to 1964	3,958 (19.3%)	628 (25.9%)	27,981 (20.7%)
1965 to 1975	3,836 (18.7%)	630 (26.0%)	19,496 (14.4%)
1975+	11,788 (57.6%)	1,149 (47.4%)	79,850 (59.1%)
Community Population Size, N (%)			
1,500,000+	1,308 (6.4%)	239 (9.9%)	11,092 (8.2%)
500,000 to 1,499,999	837 (4.1%)	144 (5.9%)	8,699 (6.4%)
100,000 to 499,999	5,397 (26.4%)	1,058 (43.7%)	36,998 (27.4%)
10,000 to 99,999	2,019 (9.9%)	327 (13.5%)	17,524 (13.0%)
<10,000	10,546 (51.5%)	633 (26.1%)	59,712 (44.2%)
Missing/Unknown	374 (1.8%)	22 (0.9%)	1,160 (0.9%)

# **Demographic Characteristics (Continued)**

Characteristic	Individuals tested for HCV infection (at earliest testing date)	Individuals diagnosed with HCV Infection	No test record in PHO (at midpoint – July 1, 2010)	
First Nations Community Status, N (%)				
Within Community	7,523 (36.7%)	453 (18.7%)	45,748 (33.8%)	
Outside of Community	12,773 (62.4%)	1,934 (79.8%)	87,009 (64.4%)	
Out of Province*	75 (0.4%)	13 (0.5%)	1,682 (1.2%)	
Missing/Unknown	110 (0.5%)	23 (0.9%)	746 (0.6%)	
Comorbidities				
ADG Score, mean $\pm$ SD	6.7 ± 4.0	7.8 ± 4.2	4.8 ± 3.2	
ADG Score, median (IQR)	6 (4-9)	7 (5-11)	4 (2-7)	
Number of ADG Categories, N (%)				
Non-User/Missing	1,874 (9.1%)	146 (6.0%)	27,421 (20.3%)	
0 to 3	4,625 (22.6%)	392 (16.2%)	45,091 (33.4%)	
4 to 7	6,906 (33.7%)	771 (31.8%)	42,542 (31.5%)	
8 to 10	3,743 (18.3%)	514 (21.2%)	13,419 (9.9%)	
11+	3,333 (16.3%)	600 (24.8%)	6,712 (5.0%)	
Mental health conditions, N (%)				
Anxiety disorders	7,207 (35.2%)	775 (32.0%)	37,263 (27.6%)	
Deliberate Self Harm	3,012 (14.7%)	661 (27.3%)	5,283 (3.9%)	
Bipolar mood disorder	318 (1.6%)	91 (3.8%)	602 (0.4%)	
Depression mood disorder	4,042 (19.7%)	540 (22.3%)	15,193 (11.2%)	
Other mood disorders	202 (1.0%)	24 (1.0%)	364 (0.3%)	
Personality disorder	390 (1.9%)	83 (3.4%)	702 (0.5%)	
Schizophrenia spectrum and other psychotic disorders	985 (4.8%)	196 (8.1%)	2,113 (1.6%)	
Substance-related and addictive disorders	10,094 (49.3%)	1,974 (81.5%)	20,090 (14.9%)	
Trauma/stressor-related disorders	3,807 (18.6%)	501 (20.7%)	13,217 (9.8%)	
Disease-specific flags, N (%)				
HIV record	189 (0.9%)	98 (4.0%)	122 (0.1%)	
HIV prior to HCV diagnosis	-	37 (1.5%)	-	
HBV record	107 (0.5%)	65 (2.7%)	50 (0.0%)	
HBV prior to HCV diagnosis	-	25 (1.0%)	-	

# **Sex-Specific Testing Rates**

![](_page_39_Figure_1.jpeg)

## **Sex-Specific Diagnosis Rates**

![](_page_40_Figure_1.jpeg)

🔶 Overall 🔺 Reside Within First Nations Communities 🛛 💷 Reside Outside of First Nations Communities

# Mean costs of cases and controls per 30 days

	Phase of Care, mean cost per 30 days (% of total)								
	Pre-diagnosis	Pre-diagnosis, \$ (% of total)		Initial, \$ (% of total)		Late, \$ (% of total)		Terminal, \$ (% of total)	
Resource Category	Cases	Matched Controls	Cases	Matched Controls	Cases	Matched Controls	Cases	Matched Controls	
Outpatient Visits	62 (9.7%)	31 (10.8%)	89 (10.2%)	70 (14.1%)	227 (8.1%)	240 (23.7%)	667 (7.5%)	738 (9.2%)	
Physician Services	130 (20.3%)	76 (26.5%)	168 (19.2%)	110 (22.1%)	405 (14.5%)	151 (14.8%)	1056 (11.9%)	875 (10.9%)	
Emergency Room Visits	77 (12.0%)	27 (9.3%)	55 (6.3%)	40 (8.0%)	173 (6.2%)	57 (5.6%)	249 (2.8%)	271 (3.4%)	
Same Day Surgery	8 (1.3%)	9 (3.1%)	9 (1.0%)	10 (2.0%)	33 (1.2%)	16 (1.6%)	17 (0.2%)	31 (0.4%)	
Inpatient Care	252 (39.6%)	103 (35.5%)	325 (37.2%)	172 (34.7%)	1307 (46.9%)	332 (32.7%)	5929 (66.6%)	5261 (65.3%)	
Outpatient Prescription	33 (5.2%)	18 (6.3%)	150 (17.1%)	47 (9.5%)	405 (14.5%)	105 (10.4%)	215 (2.4%)	201 (2.5%)	
Lab Claims	28 (4.4%)	11 (3.7%)	17 (1.9%)	9 (1.9%)	21 (0.8%)	10 (1.0%)	17 (0.2%)	12 (0.1%)	
Other Services*	48 (7.5%)	14 (4.9%)	62 (7.1%)	39 (7.8%)	214 (7.7%)	104 (10.3%)	747 (8.4%)	662 (8.2%)	
Total	637 (100.0%)	289 (100.0%)	875 (100.0%)	497 (100.0%)	2786 (100.0%)	1016 (100.0%)	8896 (100.0%)	8050 (100.0%)	

## Net costs of infection (95%CI) increased with disease progression

Pre-diagnosis Ph	nase Initia	Phase Late	Phase Termina	al Phase	
Phase of Care, mean net cost per 30 days (95%CI)					
Resource Category	Pre-diagnosis	Initial	Late	Terminal	
Outpatient Visits	31 (12,54)	19 (-9,47)	-14 (-190,166)	-66 (-312,193)	
Physician Services	53 (41,65)	58 (47,69)	255 (181,338)	182 (-34,448)	
Emergency Room Visits	50 (43,56)	15 (10,20)	116 (66,170)	-22 (-77,30)	
Same Day Surgery	-1 (-4,3)	-1 (-2,0)	17 (3,34)	-14 (-31,1)	
Inpatient Care	150 (106,202)	153 (97,219)	975 (621,1,378)	696 (-975,2,487)	
Outpatient Prescriptions	15 (9,20)	102 (89,115)	300 (171,443)	14 (-73,120)	
Laboratory Tests/Services	17 (14,20)	8 (6,9)	11 (4,21)	5 (0,10)	
Other	34 (7,65)	23 (-4,54)	109 (10,205)	85 (-198,389)	
Total Cost	348 (277,427)	377 (288,470)	1,768 (1,153,2,427)	893 (-1,114,3,149)	

Net total costs per 30 days greatly increased when liver disease developed

## **Costs differed by community residence**

![](_page_43_Figure_1.jpeg)

Net costs differed the most in terminal phase between those who resided within versus outside of First Nations communities

# **Costs differed by sex**

![](_page_44_Figure_1.jpeg)

Only in terminal phase did males exhibit higher net total cost than females

## **Next Steps**

- Results are being transformed into reports
  - Provide study information and results in an accessible format

## • Updated to include 2015 to 2018 HCV testing data

• Recent availability of PHO hepatitis data at ICES allows for measures to be updated to include 2015 to 2018

### • Examine cascade of care for HCV infection

- Used to identify care services, access and program effectiveness at a broader population level
- Can identify which factors are associated with loss to follow up at each stage in engaging HCV-related care