



ᐃᐃᐃᐃ ᐃᐃᐃᐃ  
Mamow Ahyamowen  
PARTNERSHIP

Past, Present, and Future:  
**The Story of a Northern Ontario First Nations Health  
Data Partnership**

Loretta Loon, PhD(c)  
Jennifer Walker, PhD  
Maureen Gustafson, MPH

National Collaborating Centre for Indigenous Health  
October 3, 2022









## Outline

- Mamow Ahyamowen Background
- Data & Data Linkage Process
- Learning From Our Ancestors Report
- Knowledge Sharing & Impact
- Next Steps

# Mamow Ahyamowen Background

- Referred to colloquially as "the Partnership"
- Collaboration between First Nations health and social service organizations serving communities northern Ontario
- Formed in 2016
- Shared need for high quality, community-specific health data



# Partnership Background

Fort Frances Tribal Area Health Services



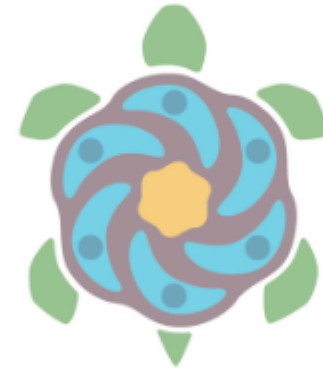
Weeneebayko Area Health Authority

Independent First Nations Alliance



Wabun Tribal Council

Keewaytinook Okimakinak



Sioux Lookout First Nations Health Authority

Kenora Chiefs Advisory



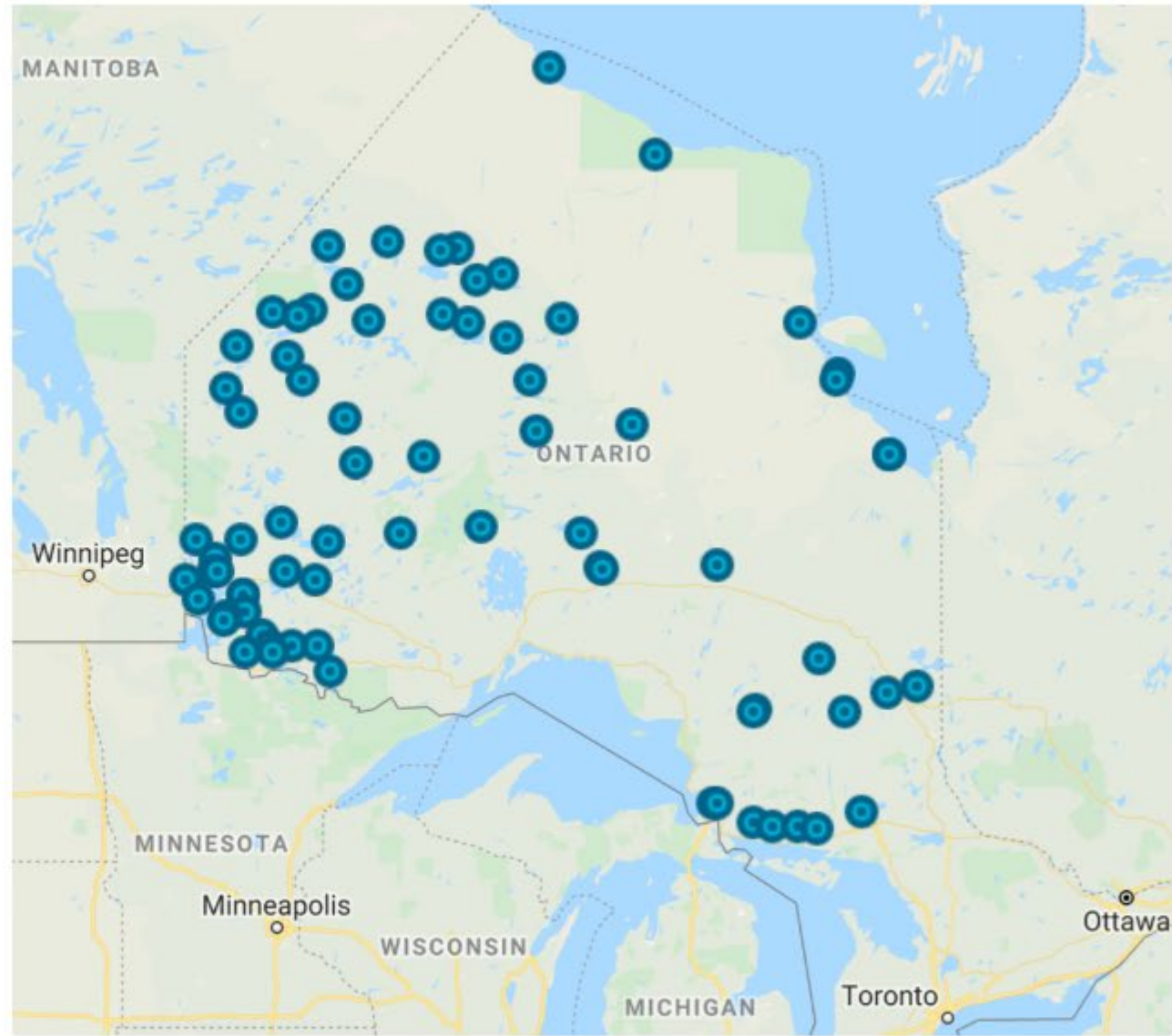
Shibogama First Nations Council

Maamawesying North Shore Community Health Services



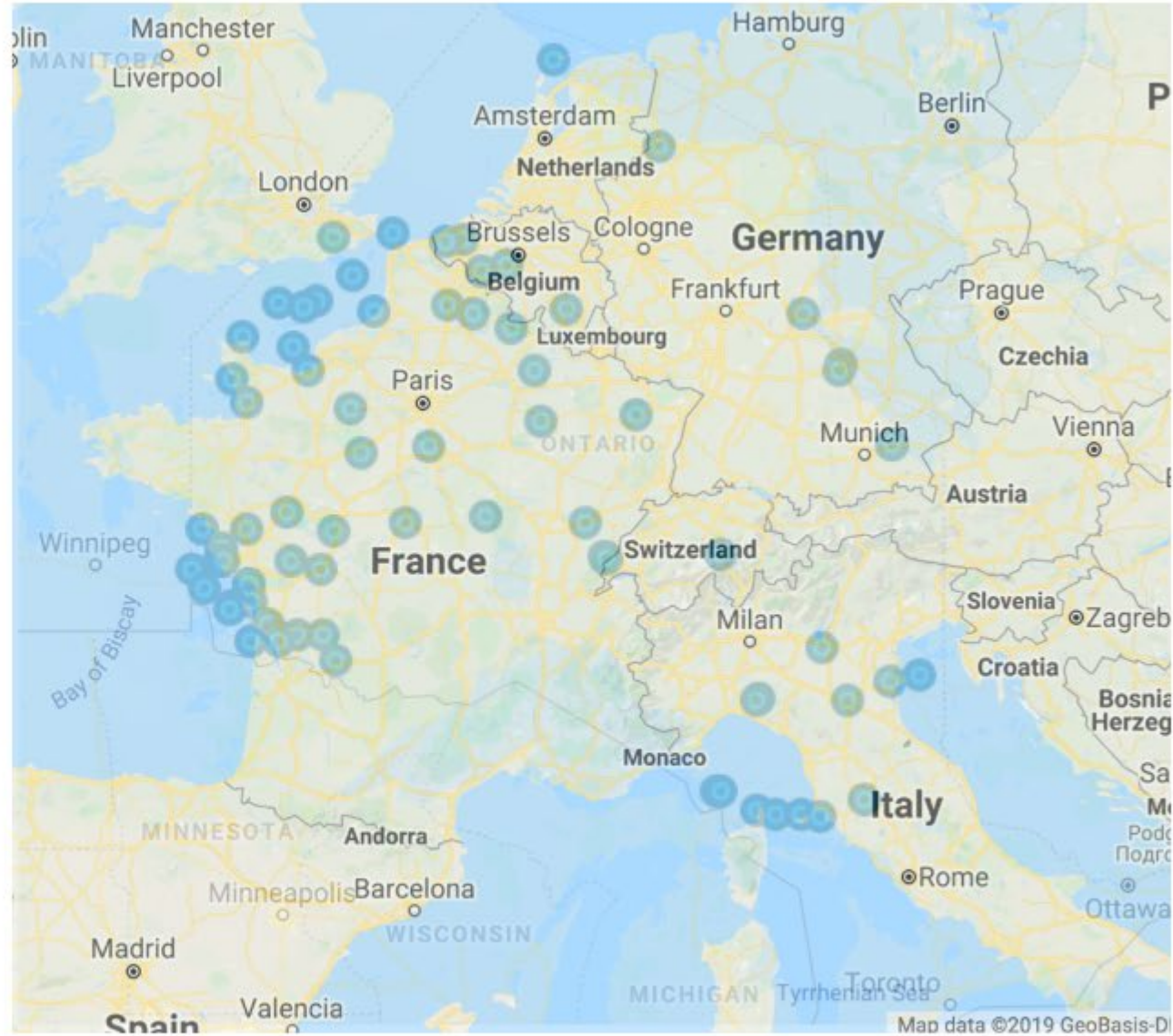
Mushkegowuk Health Department

Matawa First Nations Management



Map of First Nations communities served by Mamow Ahyamowen





Map of Mamow Ahyamowen service area overlaid with map of Western Europe

We work with communities to



find, analyze, and  
interpret data



in response to questions  
that they have prioritized




following a culturally-  
respectful path


# What is data?



Data

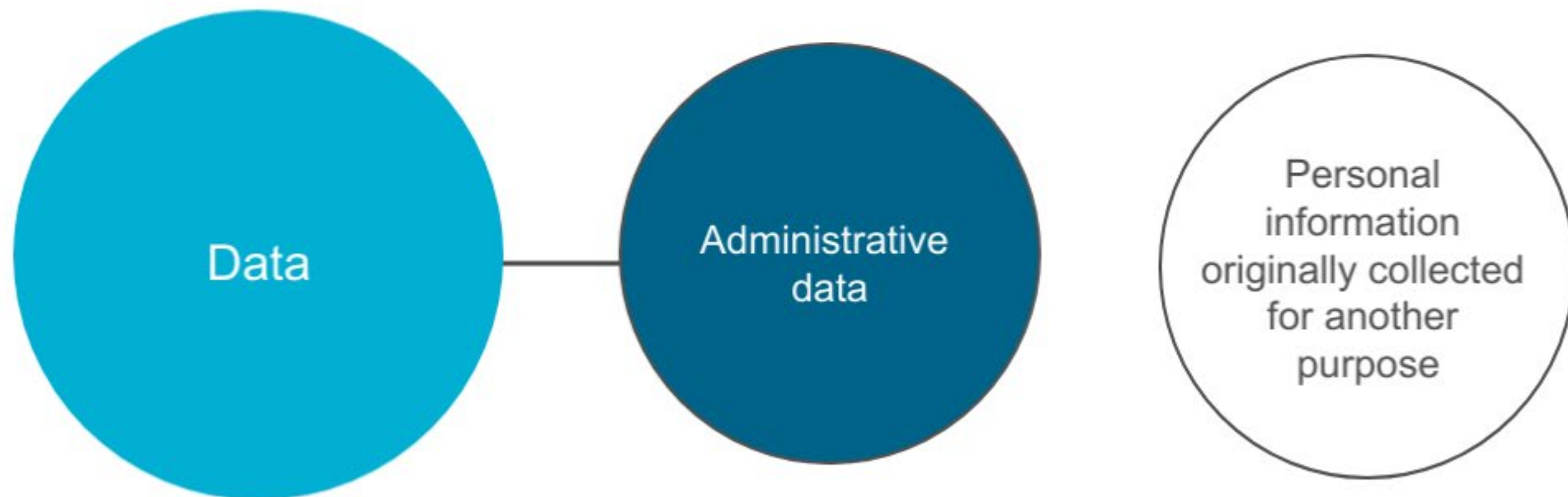


plural of datum:  
a piece of  
information



pieces of  
information  
collected together  
for reference or  
analysis

# What is data?





# Health Administrative Data in Ontario

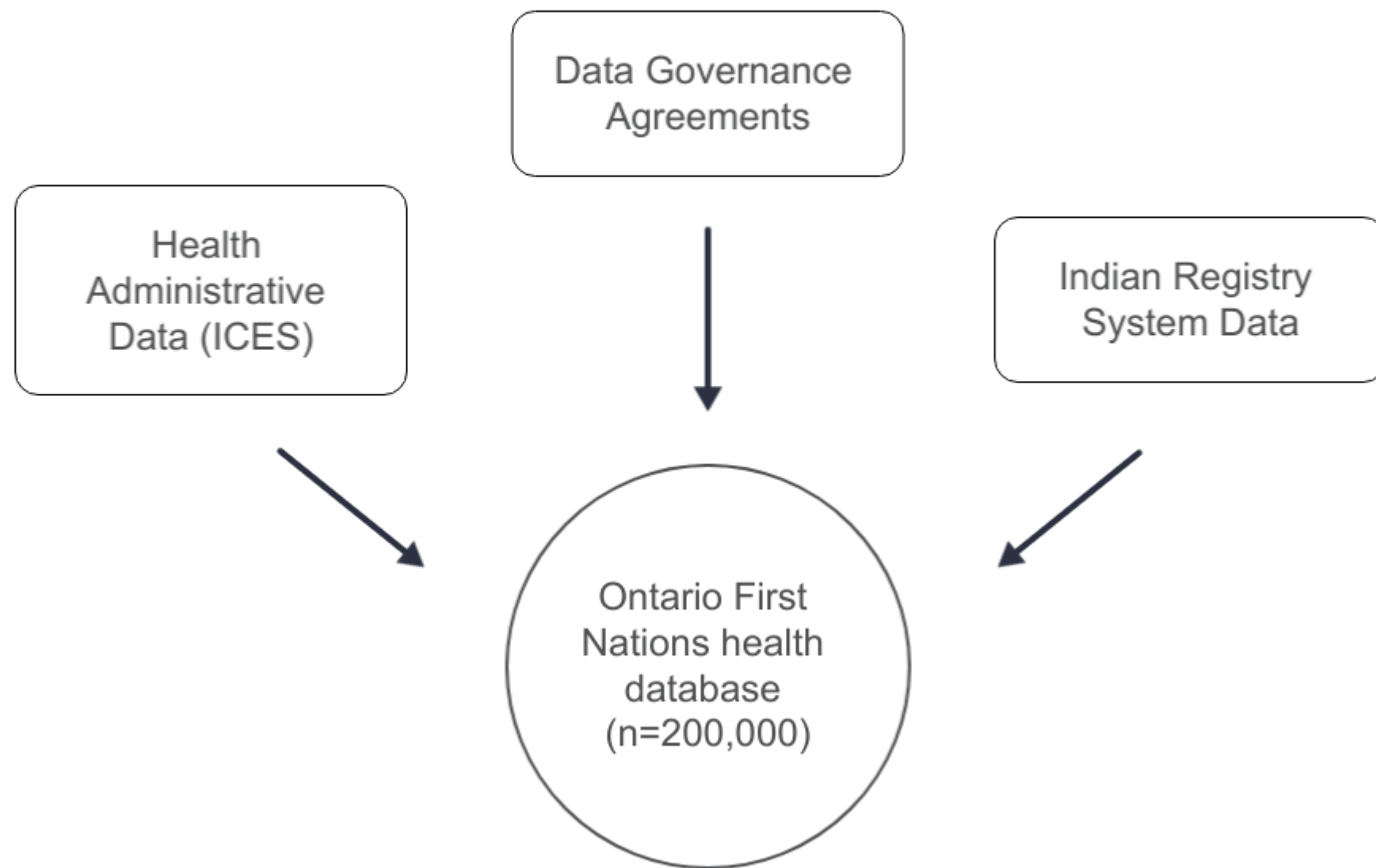
```
graph LR; A((ICES)) --- B(("prescribed entity" under the Personal Health Information Protection Act)); B --- C((collects administrative data to monitor and evaluate health system));
```

ICES

"prescribed  
entity" under the  
Personal Health  
Information  
Protection Act

collects  
administrative  
data to monitor  
and evaluate  
health system

# First Nations Health Data Platform in Ontario




# Data Governance

POLITICAL OFFICE:  
109 Mission Road  
First Nations First Nations, Ontario  
P1S 1K7  
(507) 876-1134  
(507) 876-1134 Fax

REGISTRATION OFFICE:  
First Nations First Nations  
R.R. #9  
Suite 101, 90 Assembly Drive  
First Nations First Nations Office Complex  
Thunder Bay, Ontario P7B 1A7  
(807) 426-4124  
(807) 426-4000 Fax

ADMINISTRATION OFFICE:  
111 Peter Street, Suite 404  
Thunder Bay, Ontario  
P7B 1G6  
(807) 921-1286  
Fax (807) 921-6369  
(877) 817-6327  
Website: www.chiefs-of-ontario.org



**CHIEFS OF ONTARIO**

**FIRST NATIONS DATA GOVERNANCE AGREEMENT**  
FINAL

THIS AGREEMENT made effective the 5<sup>th</sup> day of April, 2012.

BETWEEN:

**THE CHIEFS OF ONTARIO**  
[hereinafter referred to as "COO"]

and

**INSTITUTE FOR CLINICAL EVALUATIVE SCIENCES**  
[hereinafter referred to as "ICES"]

**PREAMBLE:**

WHEREAS COO is the coordinating body for 133 First Nation communities within the boundaries of the Province of Ontario, with a primary objective to facilitate the discussion, planning, implementation and evaluation of all local, regional and national matters affecting First Nations people of Ontario;

WHEREAS COO has been mandated by the Chiefs to negotiate a Data Governance Agreement with ICES to control and manage the collection, use and disclosure of First Nations health data, in accordance with OCAP principles;

WHEREAS ICES is a prescribed entity under section 45(1) of the Personal Health Information Protection Act, S.O. 2004, c. 3 ["PHIPA"] Sched. A (the Act) and O. Reg. 329/04 section 18(3) and has been entrusted as data steward of a broad range of provincial health data sets, including but not limited to the Ontario Cancer Care Registry, the Ontario Diabetes Database, the Ontario Myocardial Infarction Database, and the Canadian Stroke Network Registry;

WHEREAS ICES has in place the practices and procedures necessary under PHIPA, ss. (3) 2004, c. 3, Sched. A, s.45 (1) to protect the privacy of individuals and the confidentiality and security of personal health information it receives;

WHEREAS the Office of the Information & Privacy Commissioner of Ontario has reviewed the privacy, confidentiality and security practices and procedures of ICES and provided its necessary approval;

WHEREAS ICES and the Chiefs of Ontario wish to facilitate access by First Nations and by approved researchers to health databases for legitimate population health, health promotion, health services and clinical research studies, while maintaining confidentiality of the data and respect for OCAP principles;

# Chiefs of Ontario-ICES Collaboration

## Linkage of the Federal Indian Register

- Ontario-wide projects
- Community projects



## Data Governance Processes

- Data Governance Committee reviews researcher-driven, community-engaged projects
- Communities have access to their results

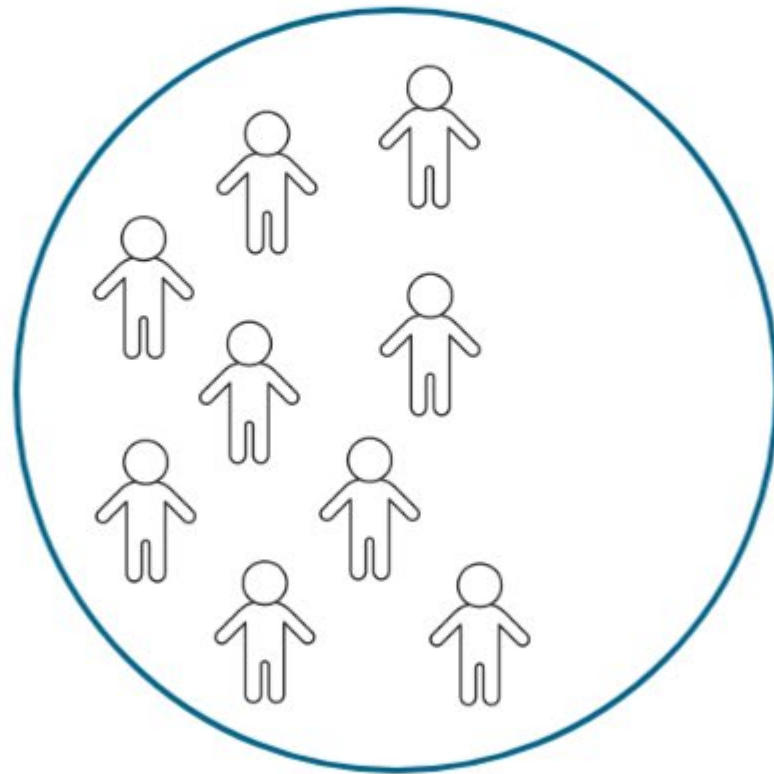
## Shared Learning and Resources

- Secondments
- International relationships



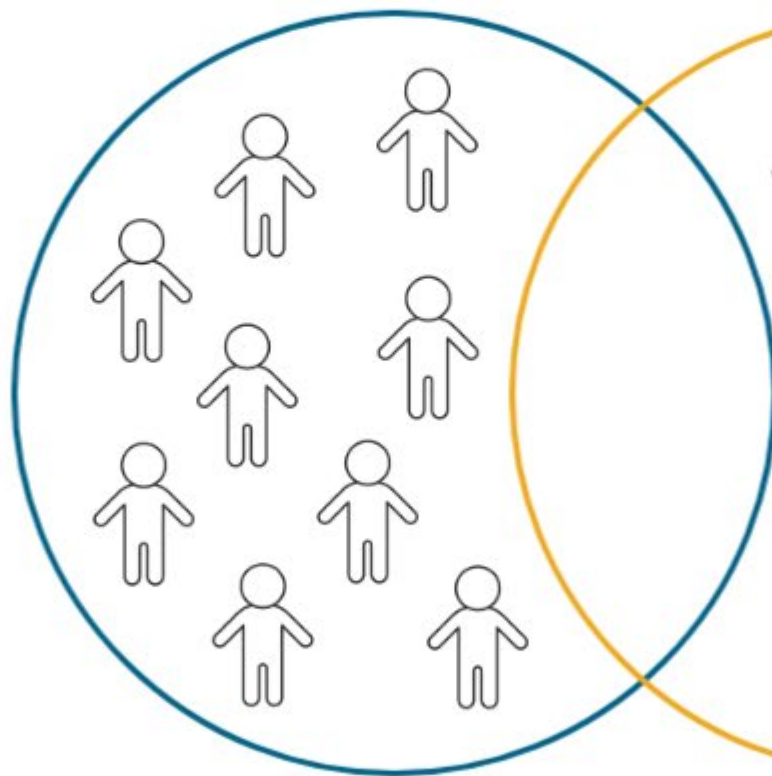
## Health Administrative Databases

Health claims and utilization  
data (e.g. doctors visits, lab  
results)



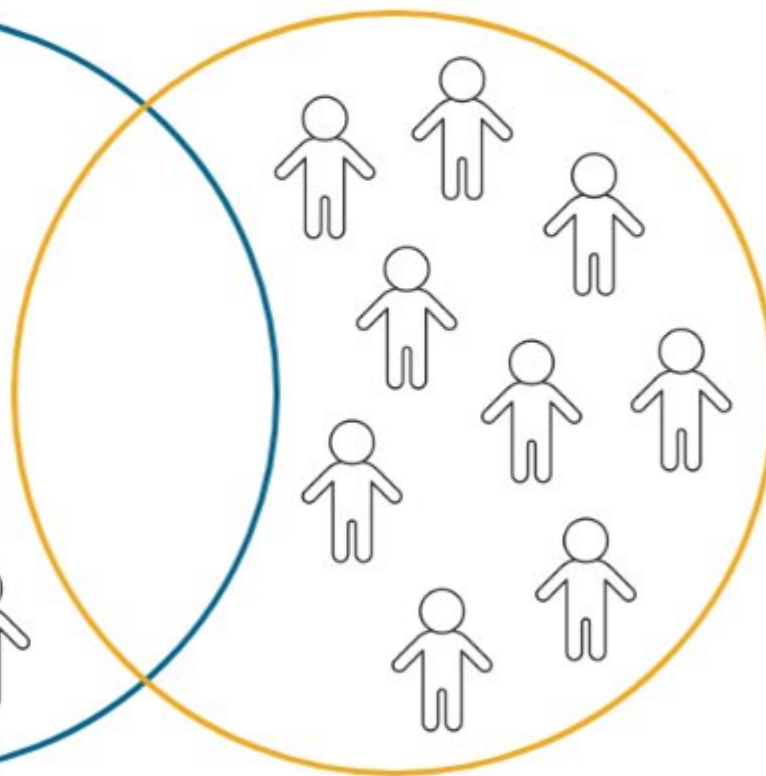
## Health Administrative Databases

Health claims and utilization data (e.g. doctors visits, lab results)



## Indian Registry System

Demographic and administrative information on all registered First Nations people

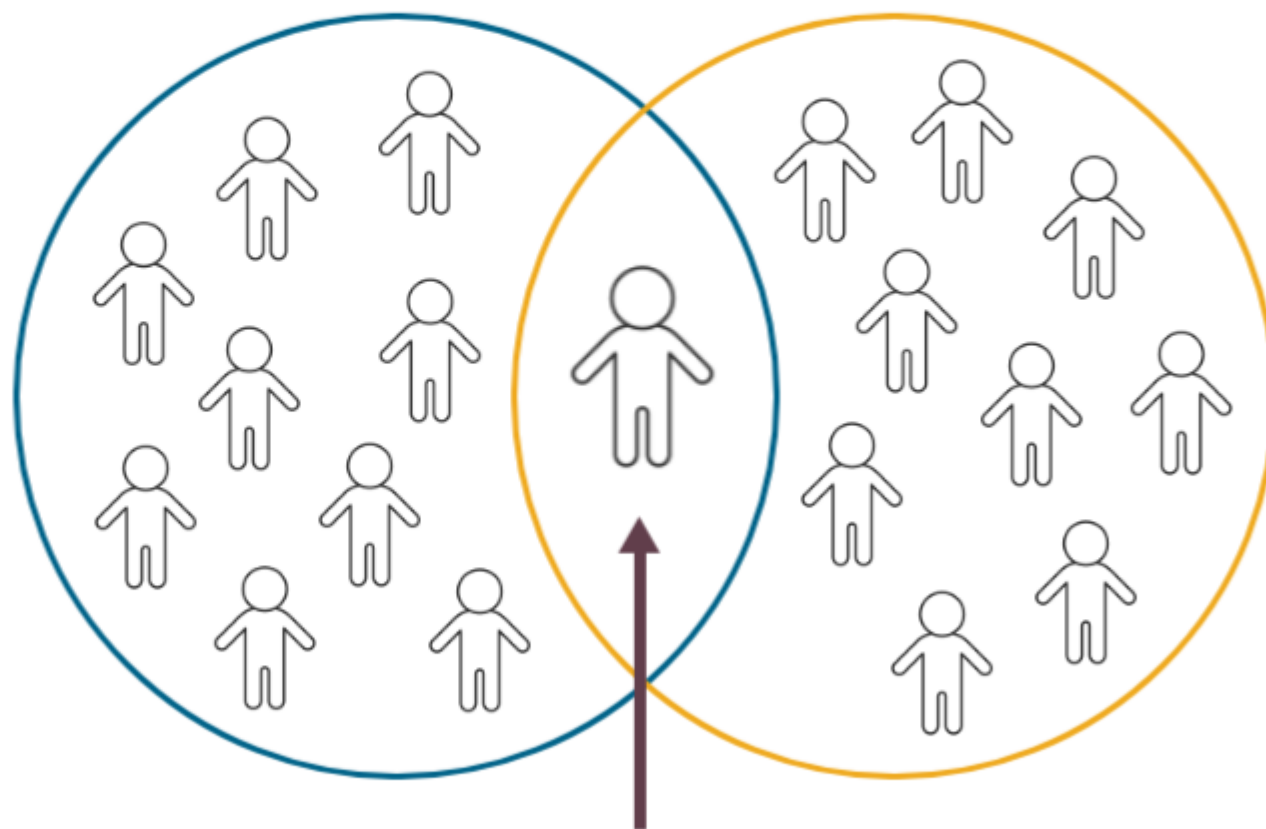


## Health Administrative Databases

Health claims and utilization data (e.g. doctors visits, lab results)

## Indian Registry System

Demographic and administrative information on all registered First Nations people



By linking these data together, we can learn more about the health of people from the communities we serve

## Learning From Our Ancestors

- Our first analysis project
- Focused on the health of people who passed away between 1992 and 2014
- 59 out of 74 communities opted in



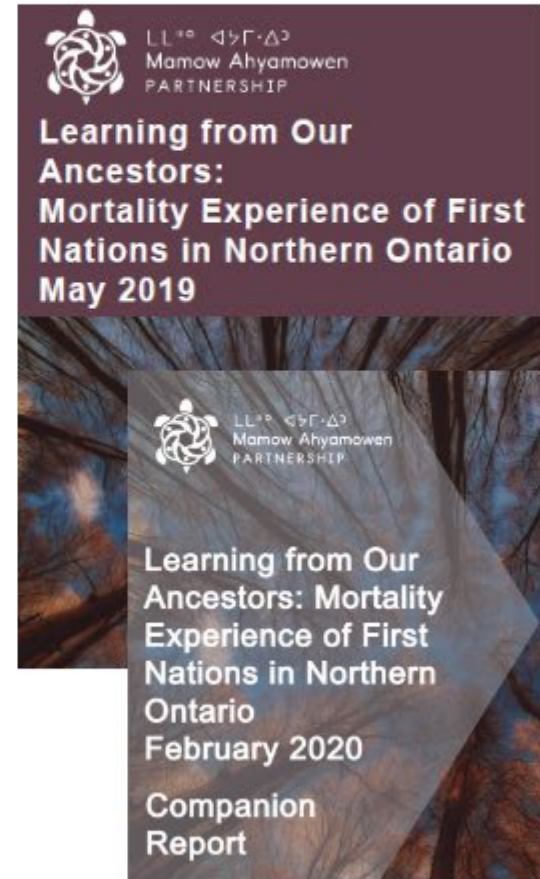
# Learning From Our Ancestors

- Our first analysis project
- Focused on the health of people who passed away between 1992 and 2014
- 59 out of 74 communities opted in
- Three levels of findings:
  - Partnership
  - Partners
  - Communities



# Learning From Our Ancestors

- Our first analysis project
- Focused on the health of people who passed away between 1992 and 2014
- 59 out of 74 communities opted in
- Three levels of findings:
  - **Partnership**
  - Partners
  - Communities



## **Hope for Wellness Helpline**

Available 24/7 to all Indigenous people across Canada

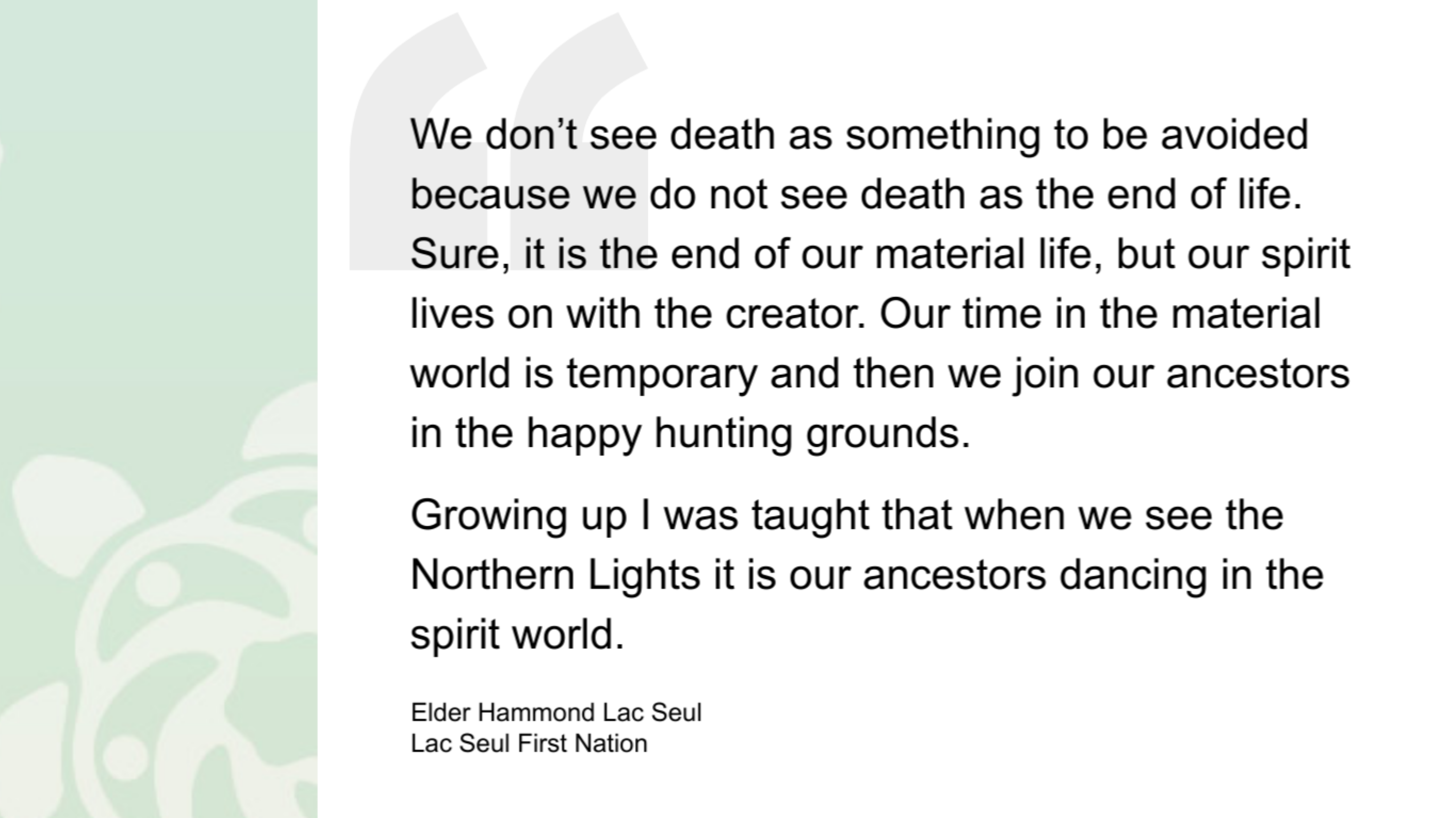
Chat online at [hopeforwellness.ca](https://hopeforwellness.ca)

Call 1-855-242-3310

## **Indian Residential School Crisis Line**

24-hour emotional support and crisis referral services for former students and those affected by Residential Schools

Call 1-866-925-4419



We don't see death as something to be avoided because we do not see death as the end of life. Sure, it is the end of our material life, but our spirit lives on with the creator. Our time in the material world is temporary and then we join our ancestors in the happy hunting grounds.

Growing up I was taught that when we see the Northern Lights it is our ancestors dancing in the spirit world.

Elder Hammond Lac Seul  
Lac Seul First Nation



## Overall Mortality

Between 1992 and 2014 there were 5,685 deaths among Mamow Ahyamowen community members

## Overall Mortality

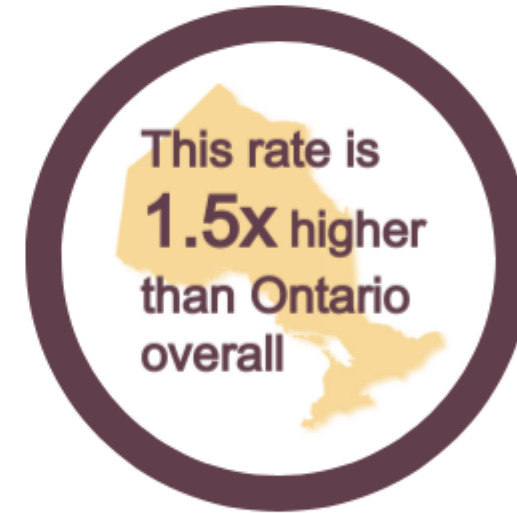
Between 1992 and 2014 there were 5,685 deaths among Mamow Ahyamowen community members

This means there were **110 deaths for every 1,000** community members

## Overall Mortality

Between 1992 and 2014 there were 5,685 deaths among Mamow Ahyamowen community members

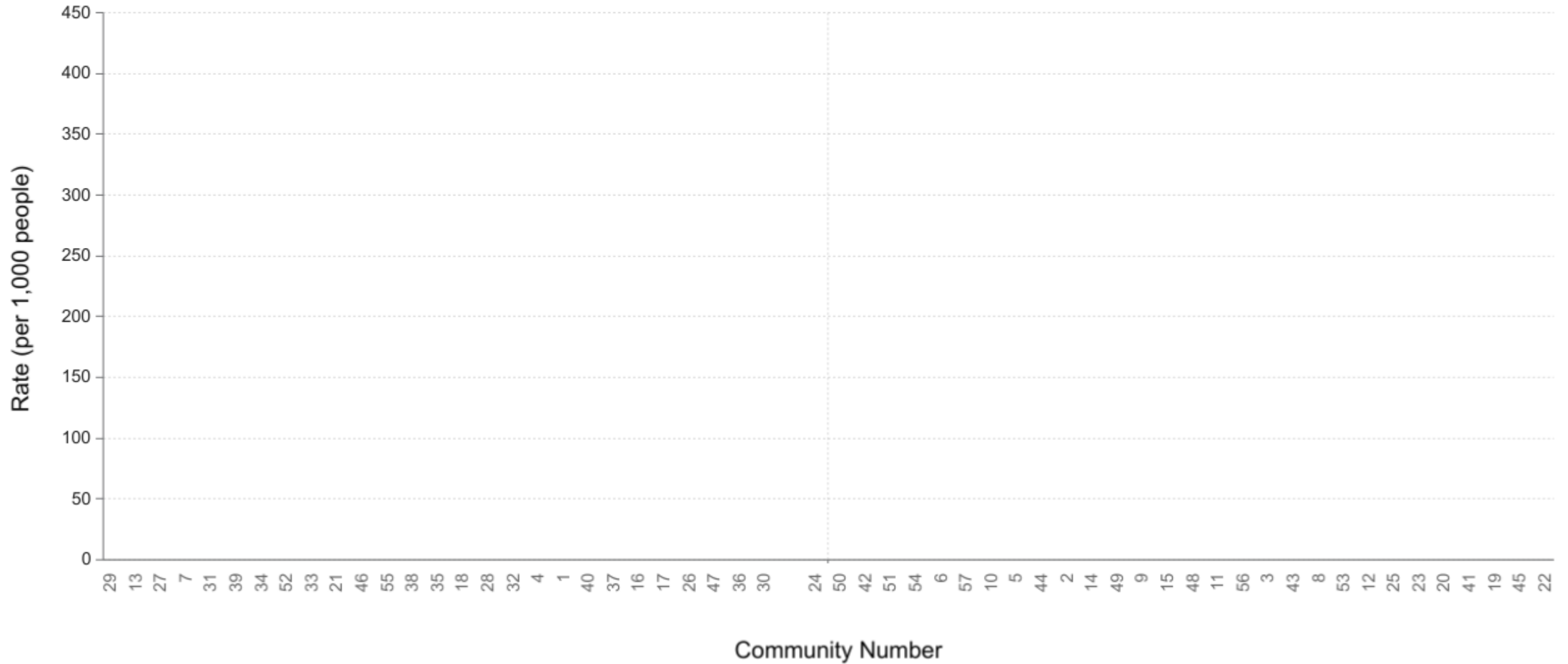
This means there were **110 deaths for every 1,000** community members



# Overall mortality

However, there was considerable variation in mortality rates across communities

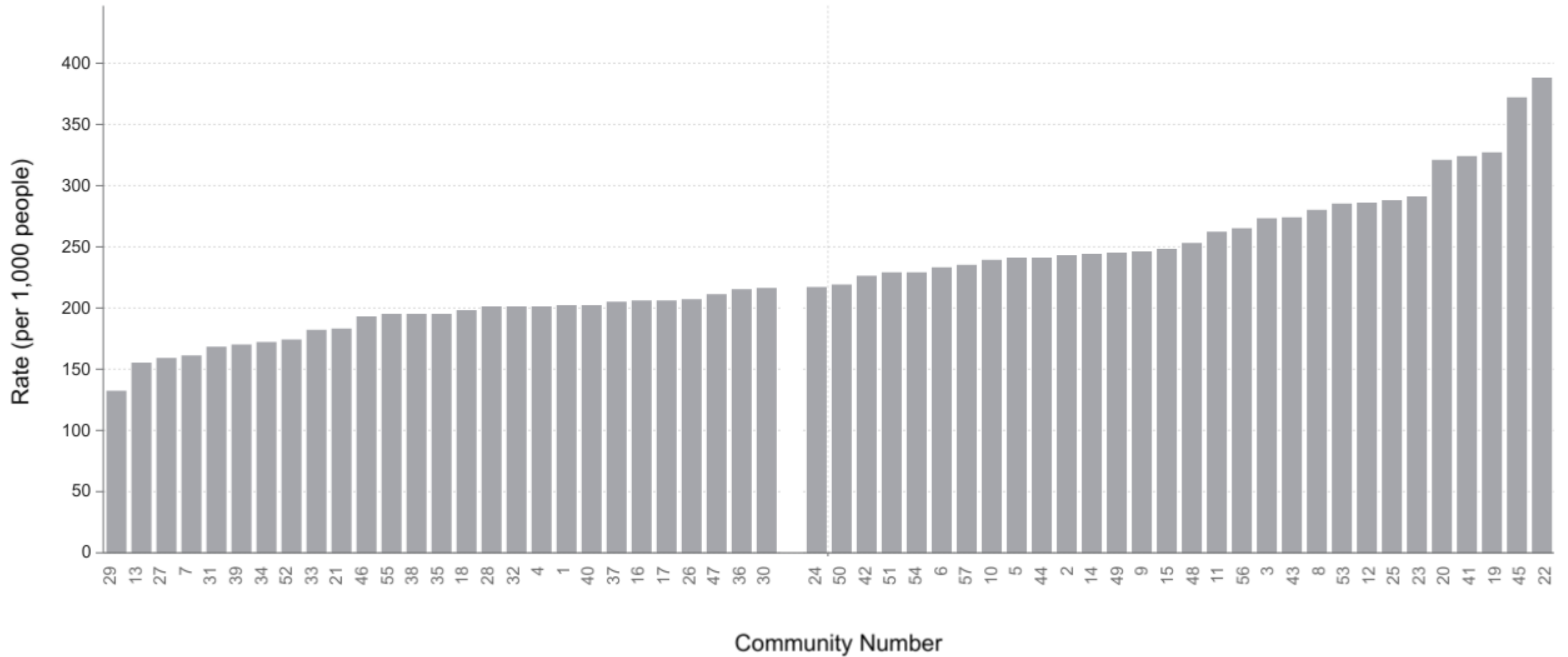
Age-standardized mortality rates, Mamow Ahyamowen communities



# Overall mortality

However, there was considerable variation in mortality rates across communities

Age-standardized mortality rates, Mamow Ahyamowen communities

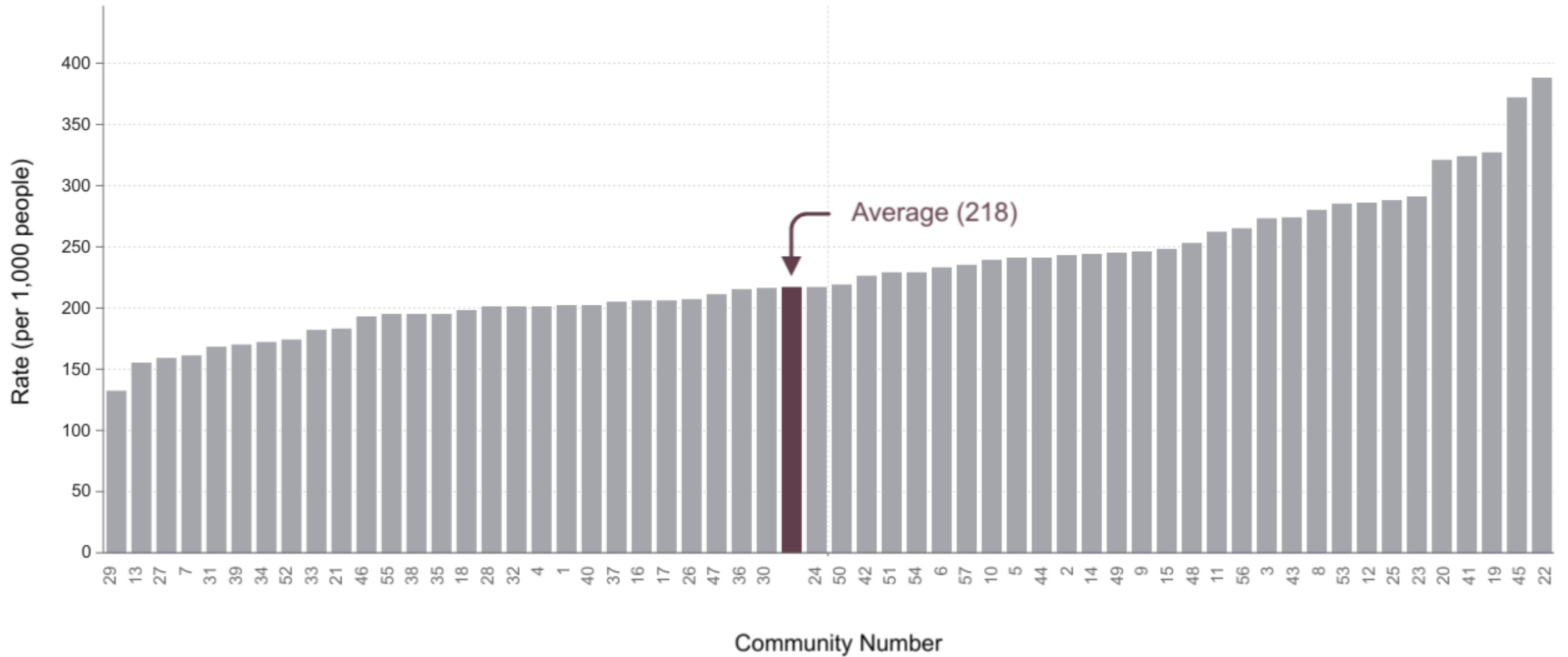




# Overall mortality

However, there was considerable variation in mortality rates across communities

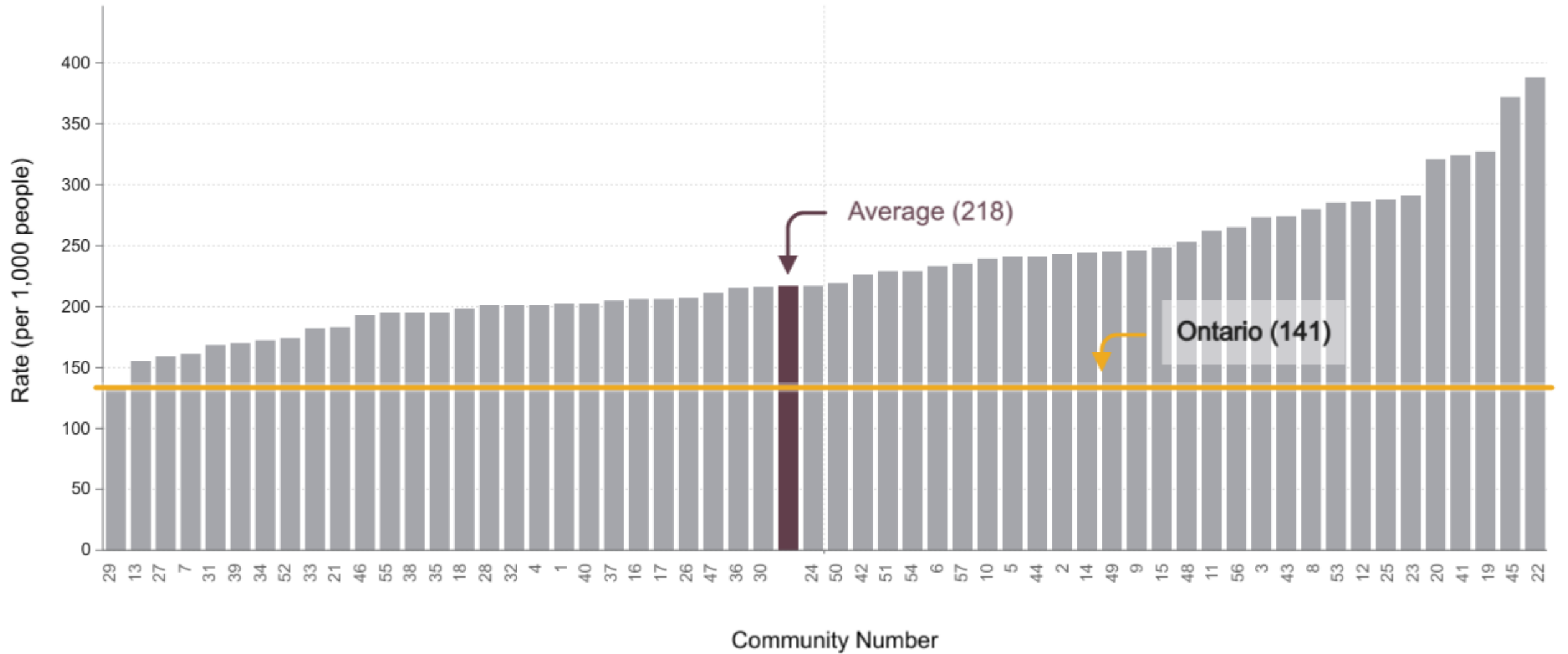
Age-standardized mortality rates, Mamow Ahyamowen communities



# Overall mortality

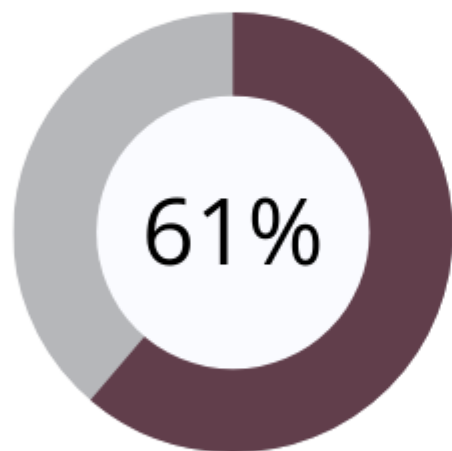
However, there was considerable variation in mortality rates across communities

Age-standardized mortality rates, Mamow Ahyamowen communities

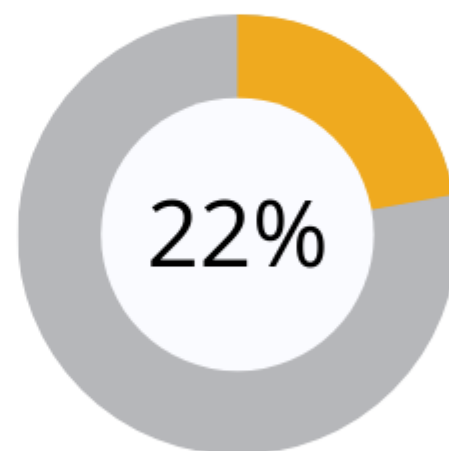


## Premature mortality

A higher proportion of Mamow Ahyamowen community members died before retirement age (65 years old) compared to Ontario overall



Mamow Ahyamowen

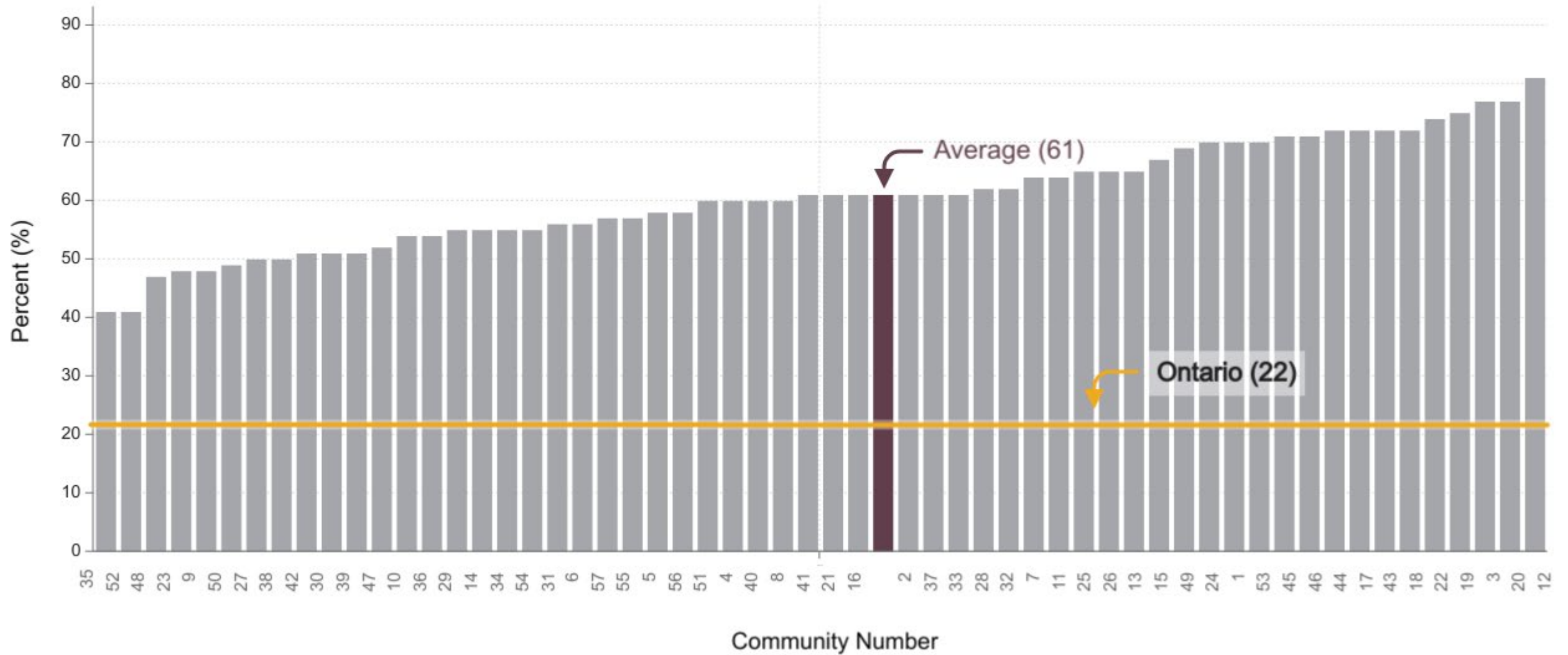


Ontario overall

# Premature mortality

However, there was considerable variation across communities who participated in the analysis

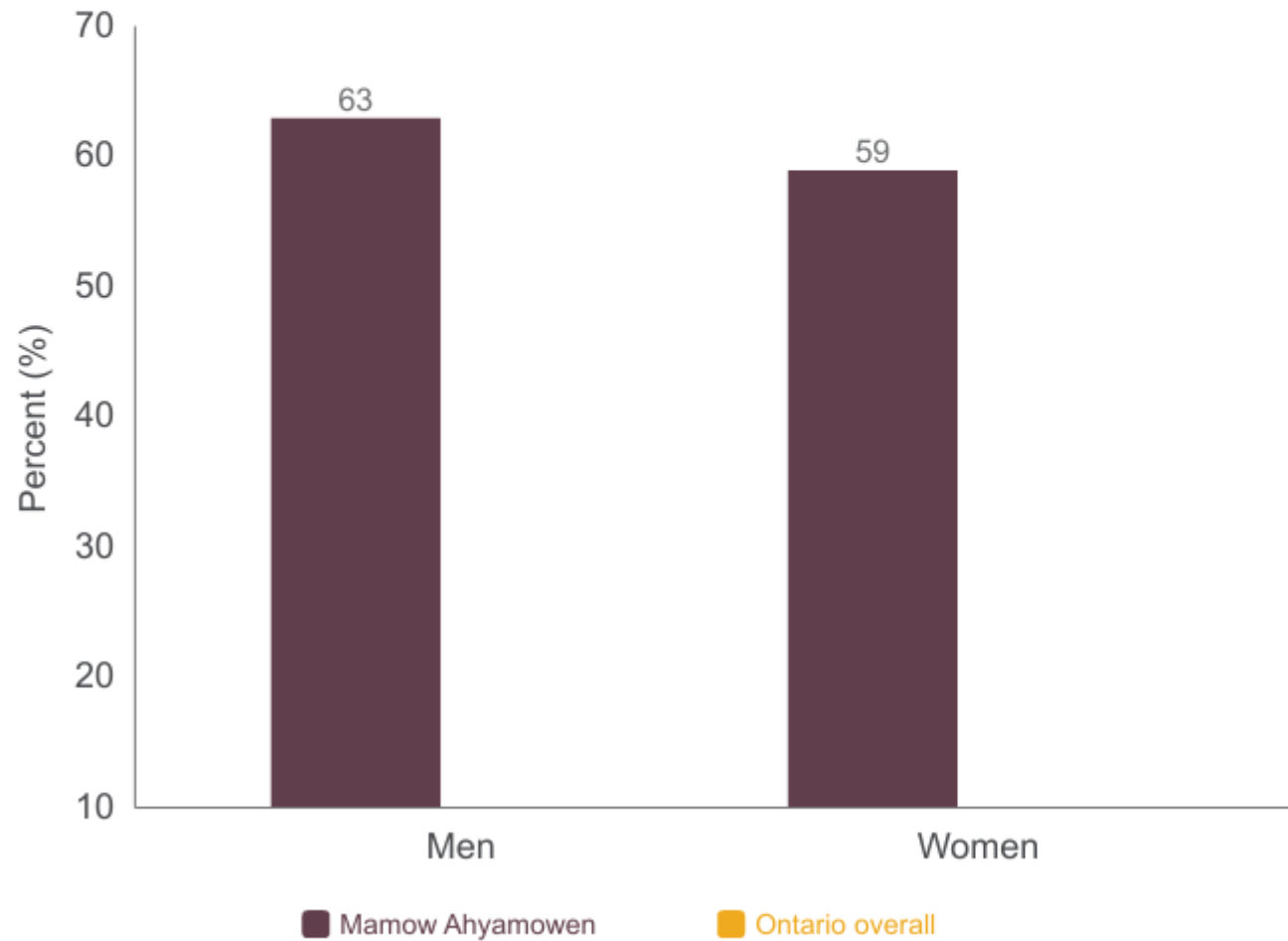
Percentage of deaths that were premature, Mamow Ahyamowen communities



## Premature mortality

There was also variation according to sex, with men from Mamow Ahyamowen communities being slightly more likely to die before retirement age than women

Percentage of deaths that were premature, Mamow Ahyamowen communities and Ontario, by sex

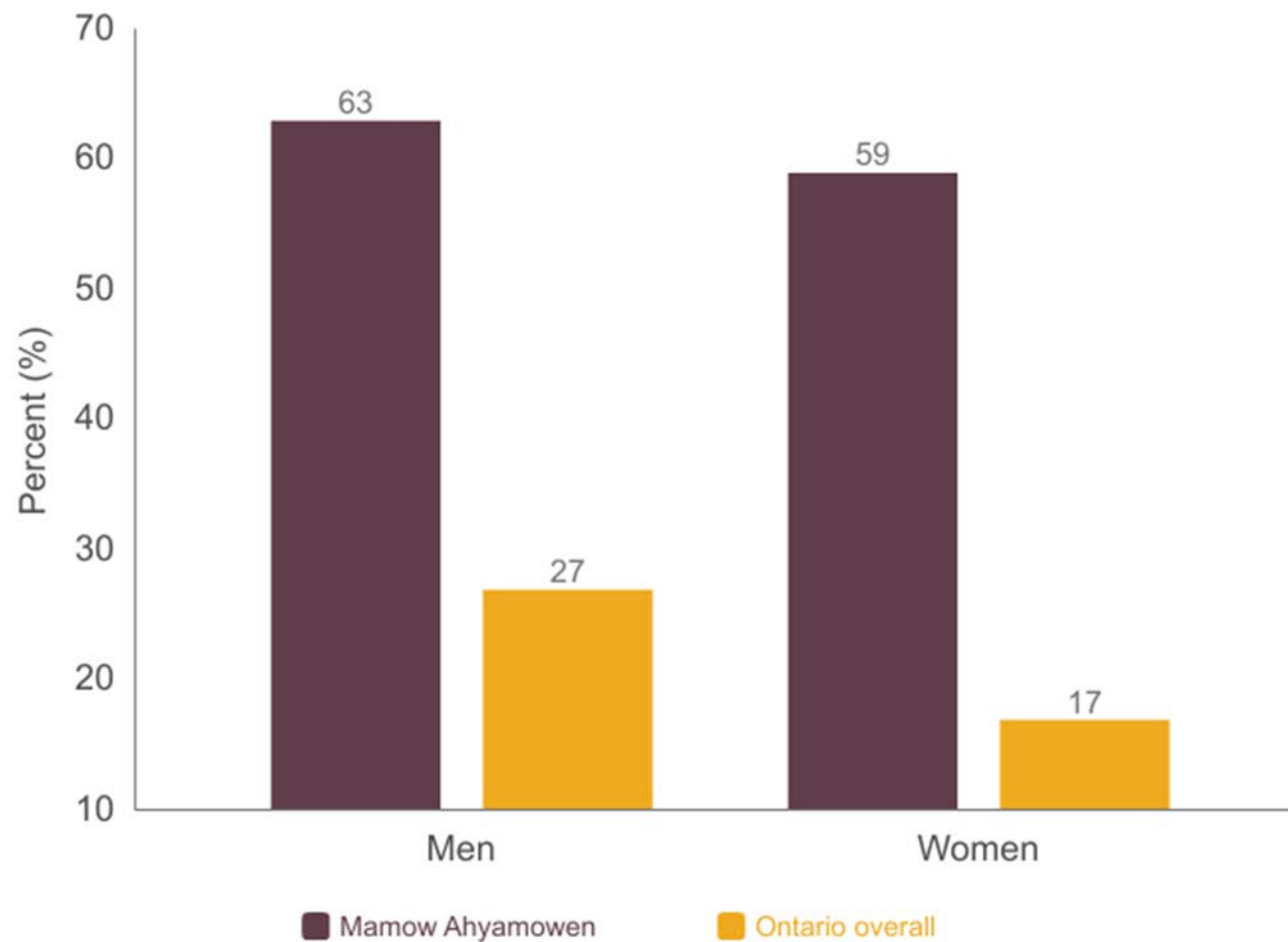




## Premature mortality

There was also variation according to sex, with men from Mamow Ahyamowen communities being slightly more likely to die before retirement age than women

Percentage of deaths that were premature, Mamow Ahyamowen communities and Ontario, by sex

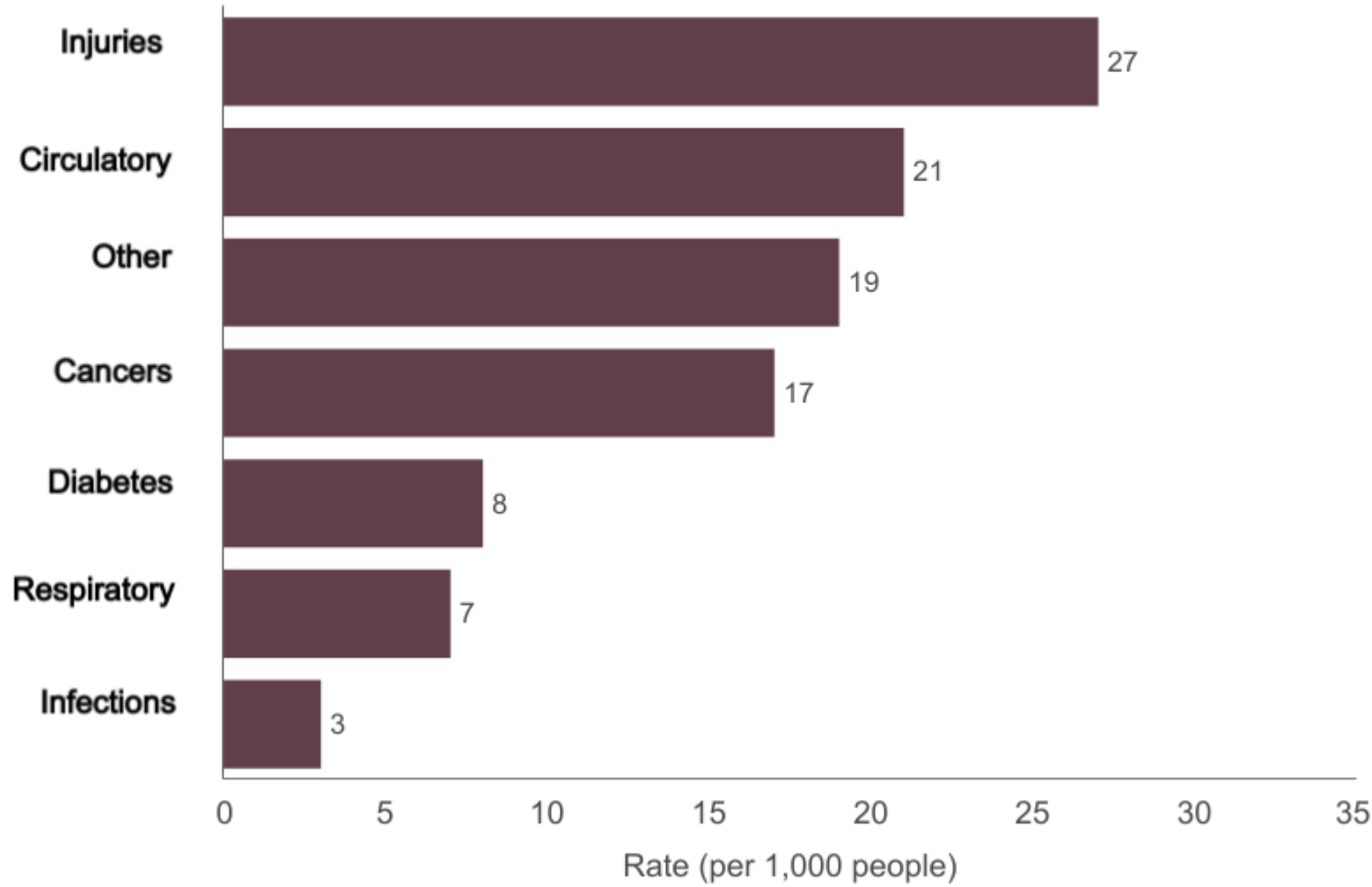


However, rates for both men and women in Mamow Ahyamowen communities were **still higher** than Ontario overall

# Common Causes of Death

Injuries and circulatory conditions were the most common causes of death for Mamow Ahyamowen community members

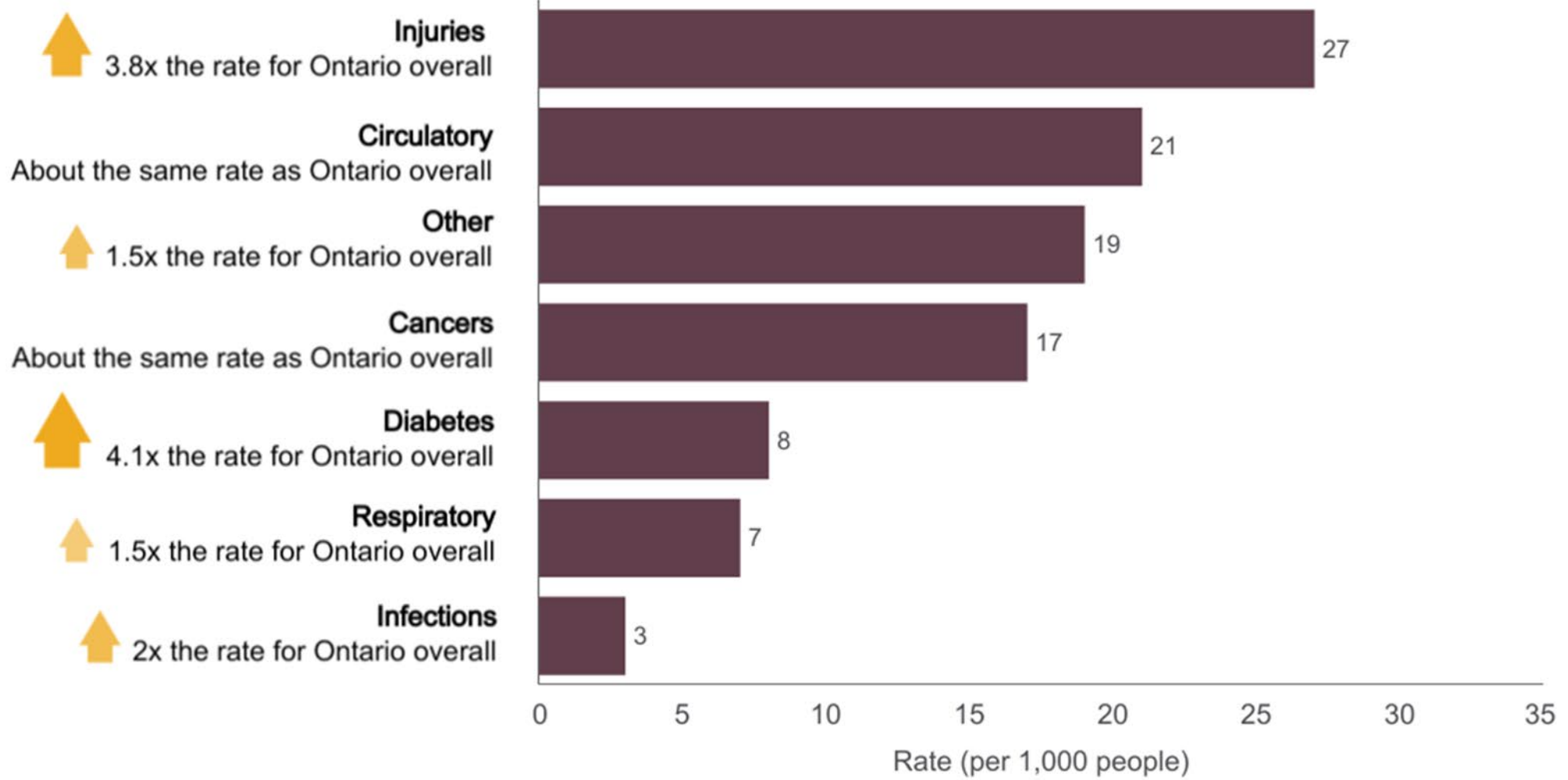
Common Causes of Death, Mamow Ahyamowen communities



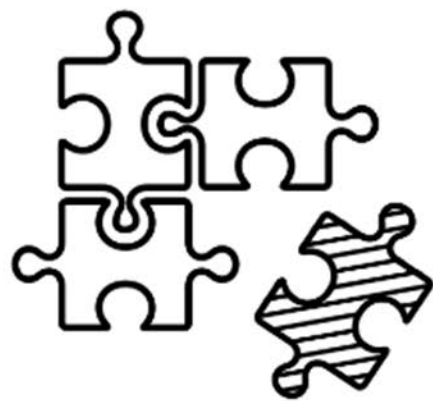
# Common Causes of Death

Injuries and circulatory conditions were the most common causes of death for Mamow Ahyamowen community members

Common Causes of Death, Mamow Ahyamowen communities



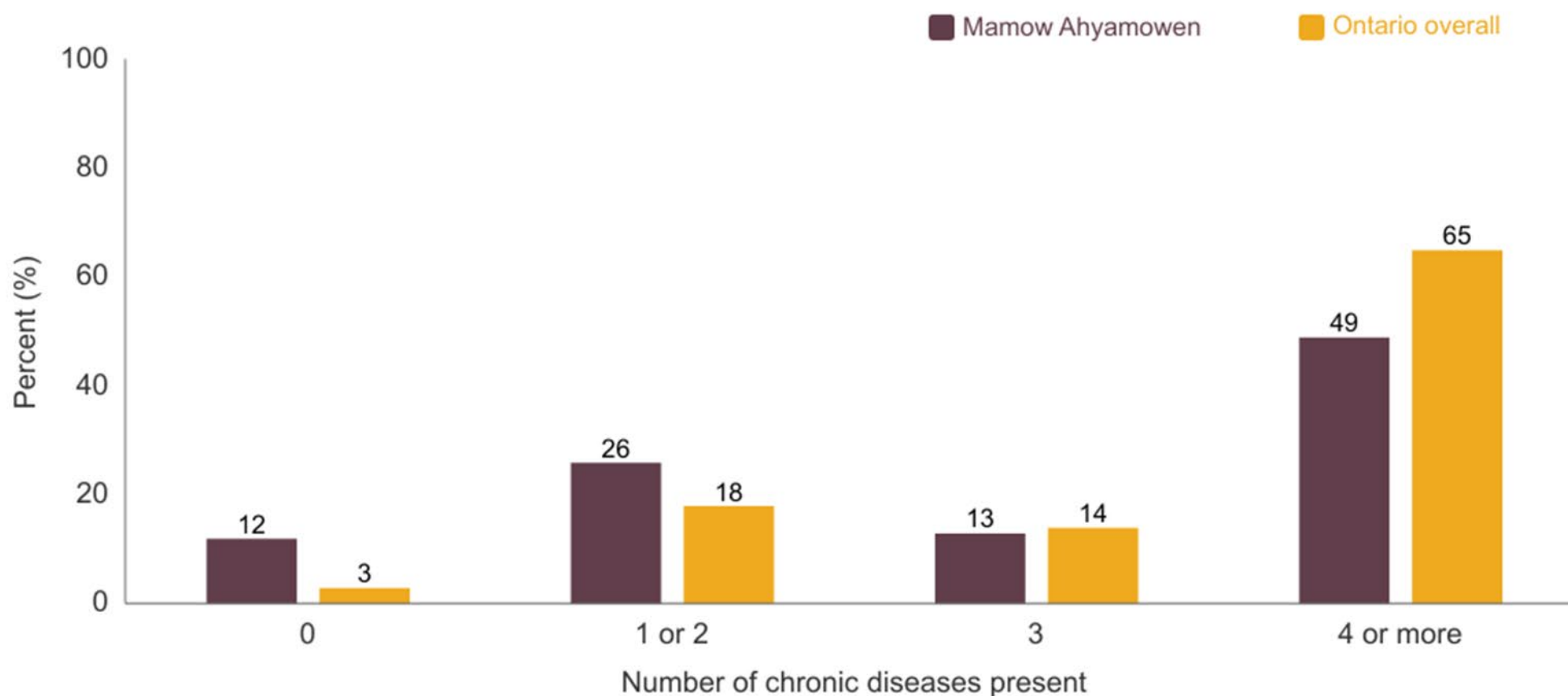
Cause of death alone doesn't provide a complete picture. Looking at the chronic conditions that people have when they pass away can help us understand more about their overall health.



## Chronic Conditions

Mamow Ahyamowen community members tended to have fewer chronic diseases when they died compared to Ontario overall

Deaths by number of chronic conditions present, Mamow Ahyamowen communities and Ontario overall

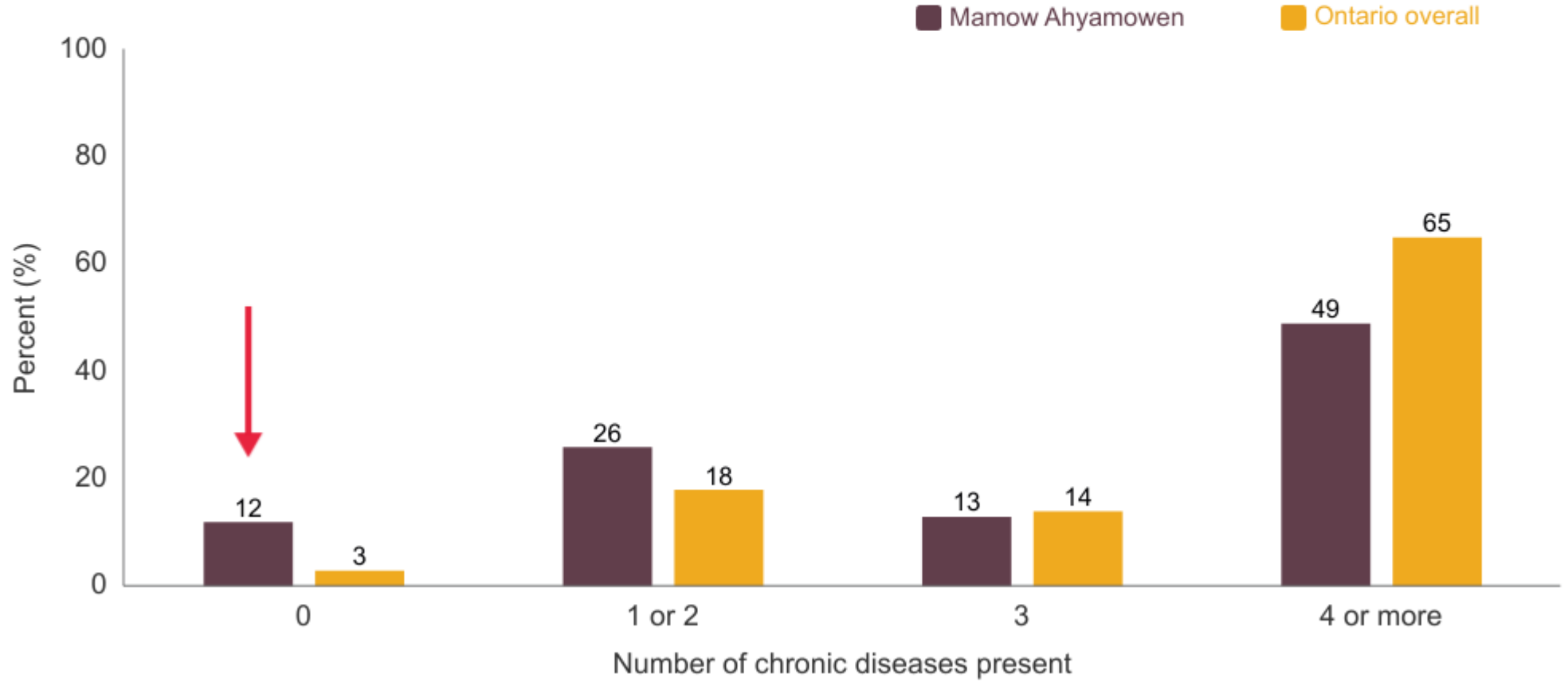




# Chronic Conditions

Mamow Ahyamowen community members tended to have fewer chronic diseases when they died compared to Ontario overall

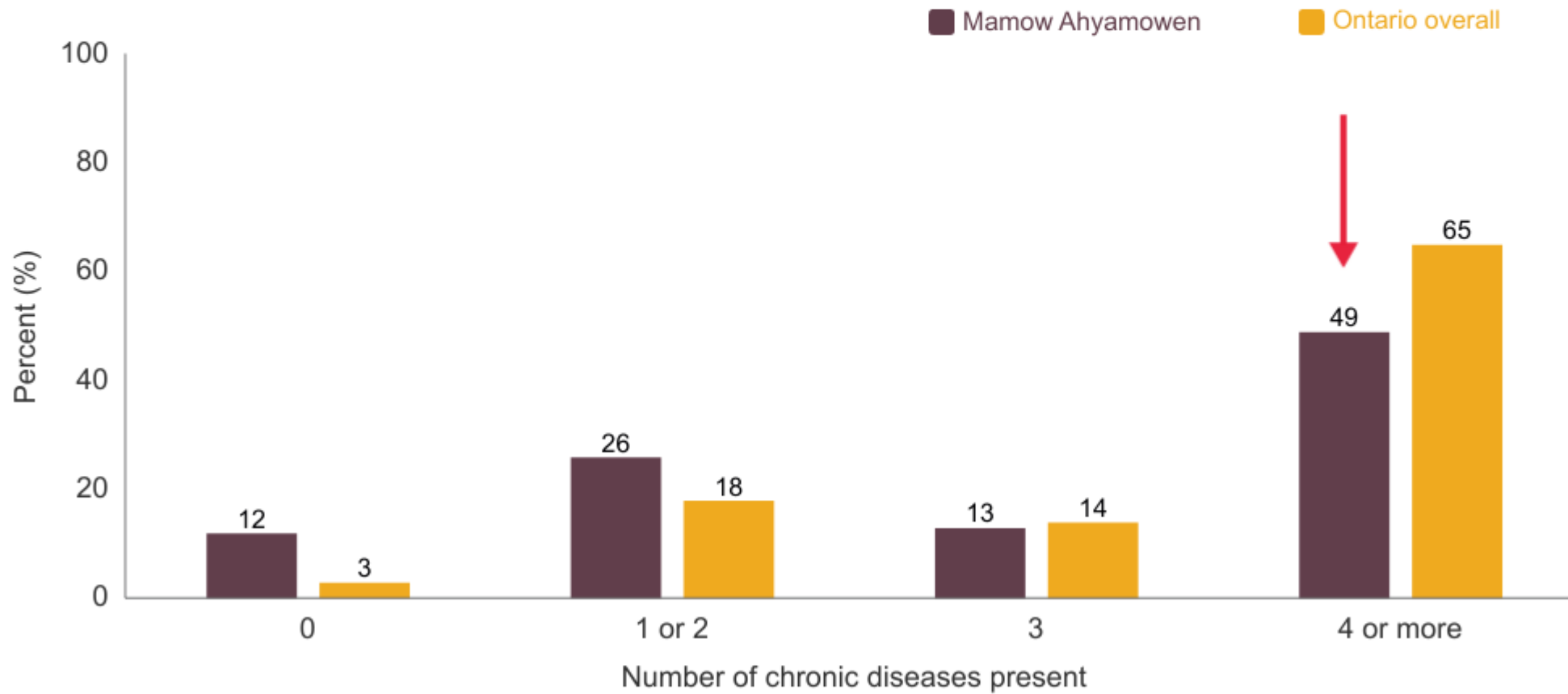
Deaths by number of chronic conditions present, Mamow Ahyamowen communities and Ontario overall



# Chronic Conditions

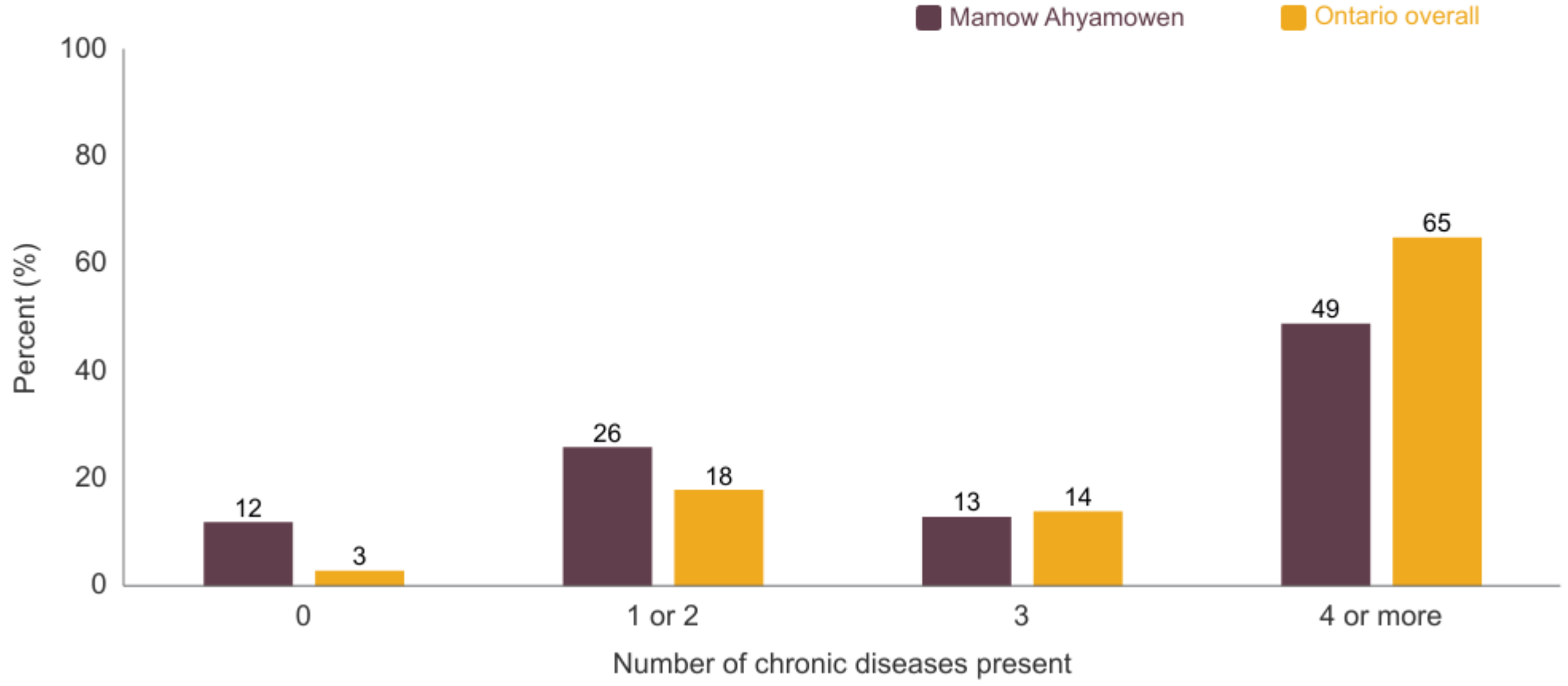
Mamow Ahyamowen community members tended to have fewer chronic diseases when they died compared to Ontario overall

Deaths by number of chronic conditions present, Mamow Ahyamowen communities and Ontario overall



# Chronic Conditions

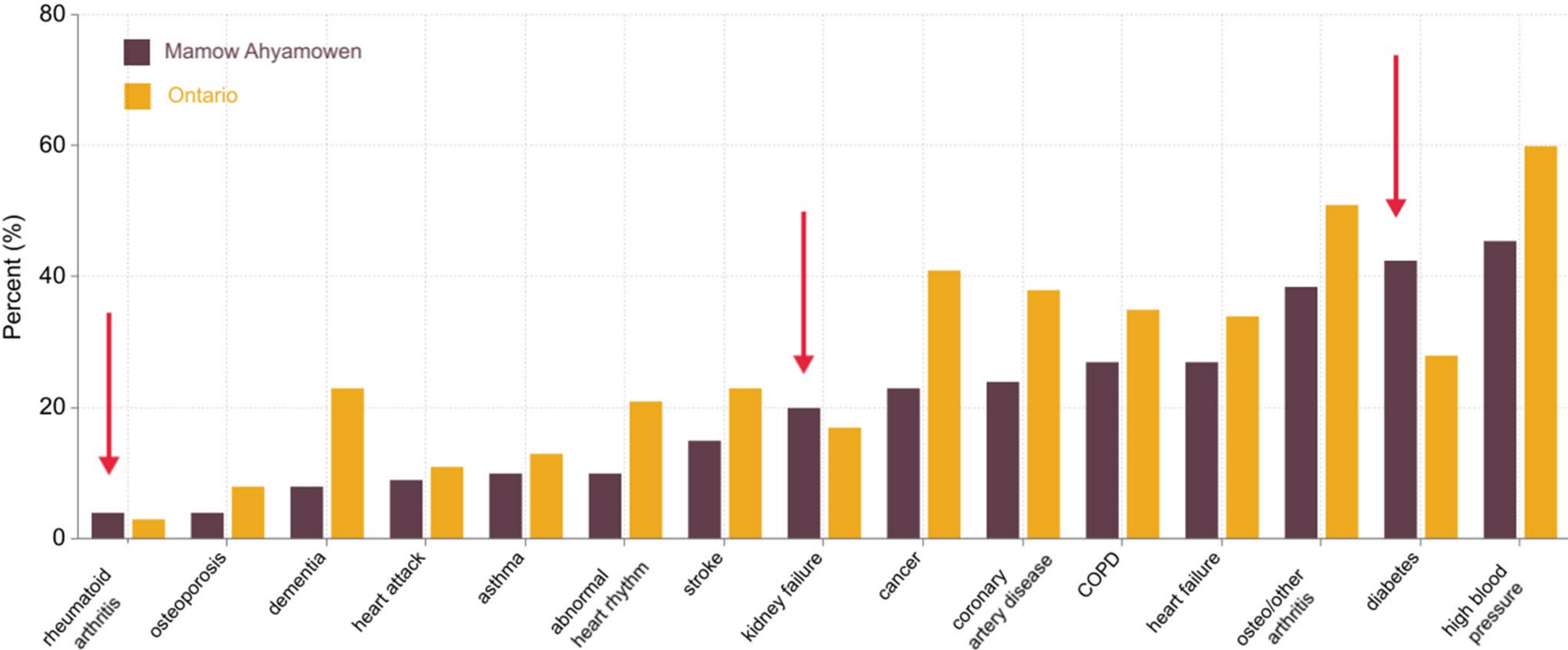
This is likely because our community members are dying so much younger, meaning they do not get old enough to have some of these chronic diseases



# Chronic Conditions

However, there are certain conditions that occurred more frequently among people in Mamow Ahyamowen communities compared to Ontario overall

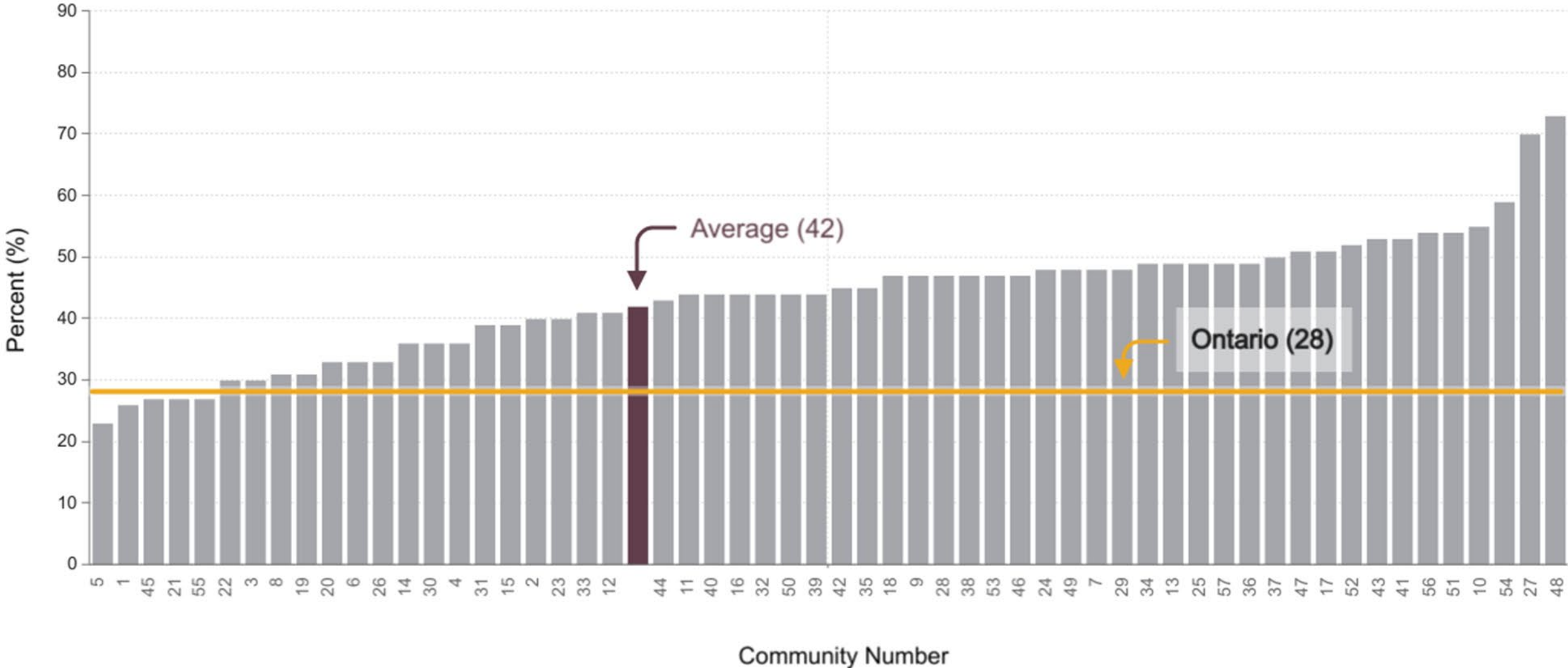
Deaths by history of chronic condition, Mamow Ahyamowen communities and Ontario overall




# Overall mortality

There was also considerable variation in the proportion of people with each chronic condition across communities

Deaths by history of diabetes, Mamow Ahyamowen communities







This information speaks to the wisdom and knowledge that our Elders and ancestors have passed down to us. It can provide us with important lessons about how to live a good and healthy life.

Shared by Elders and Knowledge Holders at the Partnership Planning Meeting in November 2017



# Knowledge Sharing

## Knowledge Products

- Reports - 4 different types:
  - Partnership level
  - Partner level
  - Community level
  - Companion reports
- Slide decks
- One-page infographics
- Whiteboard video (forthcoming)



# Knowledge Sharing

## Knowledge Products

- Reports - 4 different types:
  - Partnership level
  - Partner level
  - Community level
  - Companion reports
- Slide decks
- One-page infographics
- Whiteboard video (forthcoming)

## Engagement Strategies

Varied depending on the Partner and/or community.  
Examples:

- Interactive workshops
- Press releases
- Presentations at academic conferences
- Webinars
- Social media (TBD)

## Why is this important?

This data supports advocacy, evidence-informed decision making and, ultimately, self-determination



## Why is this important?

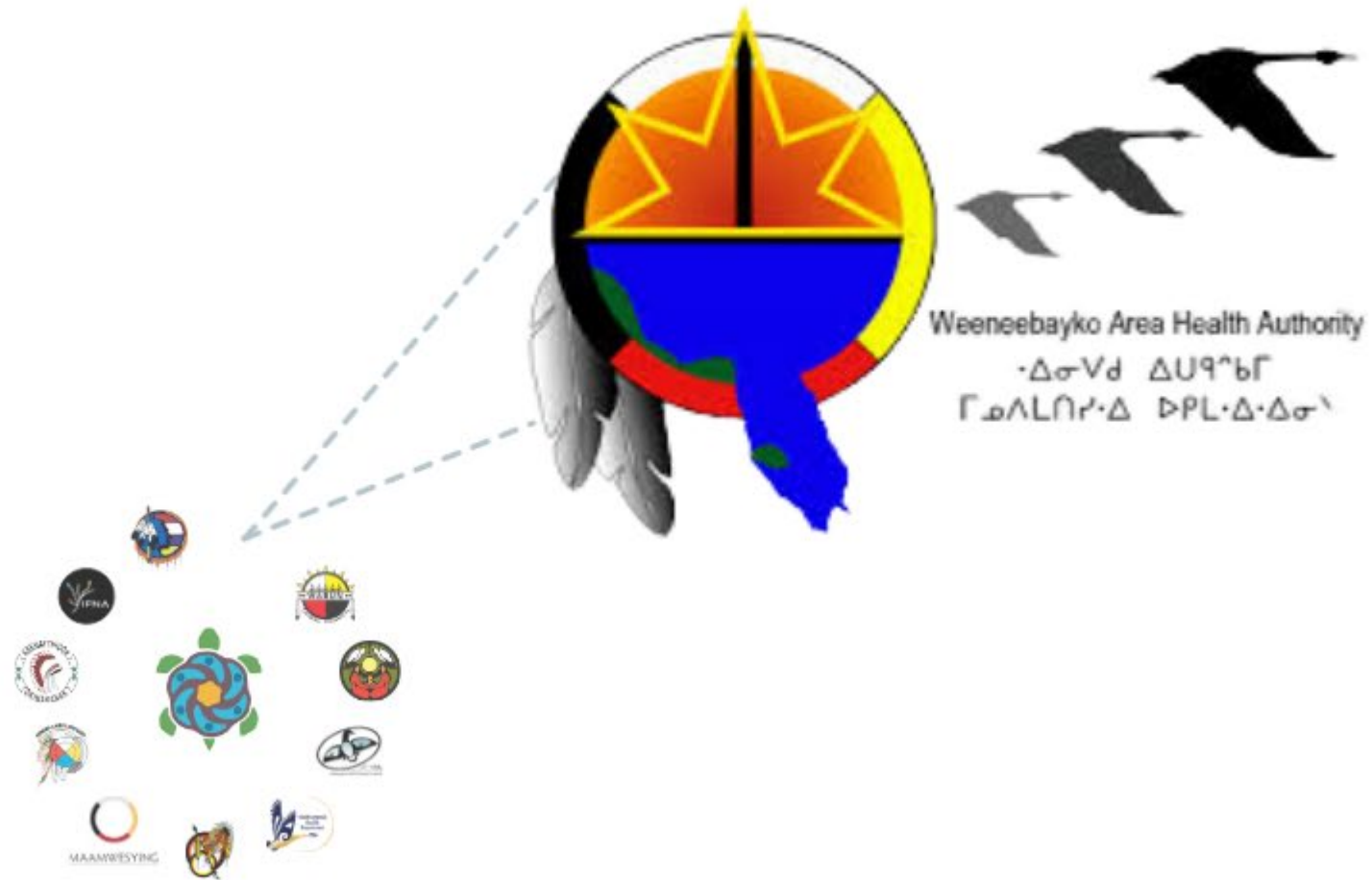
This data supports advocacy, evidence-informed decision making and, ultimately, self-determination

For example, Partners and communities have used information from our analyses to:

- Revise their IRS registration process
- Support a successful Jordan's Principle application
- Support a successful Long Term Care proposal
- Inform priority age groups for COVID-19 vaccine rollout
- Provide orientation to new staff members
- Inform priority setting and program planning

# Taking a closer look:

## Weeneebayko Area Health Authority




# Taking a closer look:

## Weeneebayko Area Health Authority



## Taking a closer look:

Weeneebayko Area Health Authority



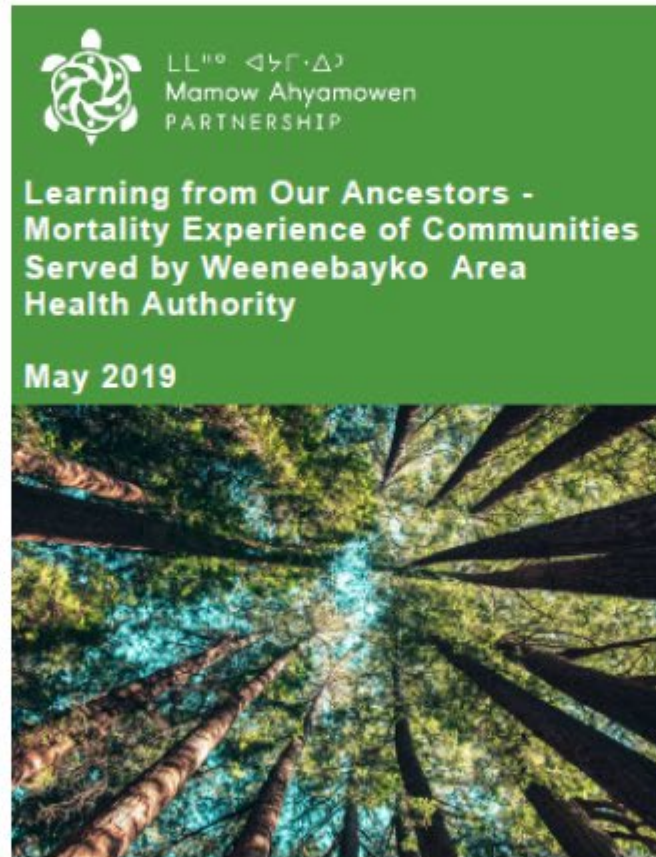
Minomathisowin  
Healthy Living

- Community-developed and -led public health model
- Work with communities to understand needs
- Provide community health leaders with the information they need



# Taking a closer look:

## Weeneebayko Area Health Authority



## What's next?

We are currently planning more in-depth analyses on:



Chronic Diseases



Mental Health &  
Addictions



Injuries



# Miigwech / Thank you

mamowahyamowen@gmail.com

[www.mamowahyamowen.ca](http://www.mamowahyamowen.ca)