

# The Backdrop for Development of First Nations Peoples' Data Governance and Health Indicators

Northern Data Governance Forum

Prince George, BC.

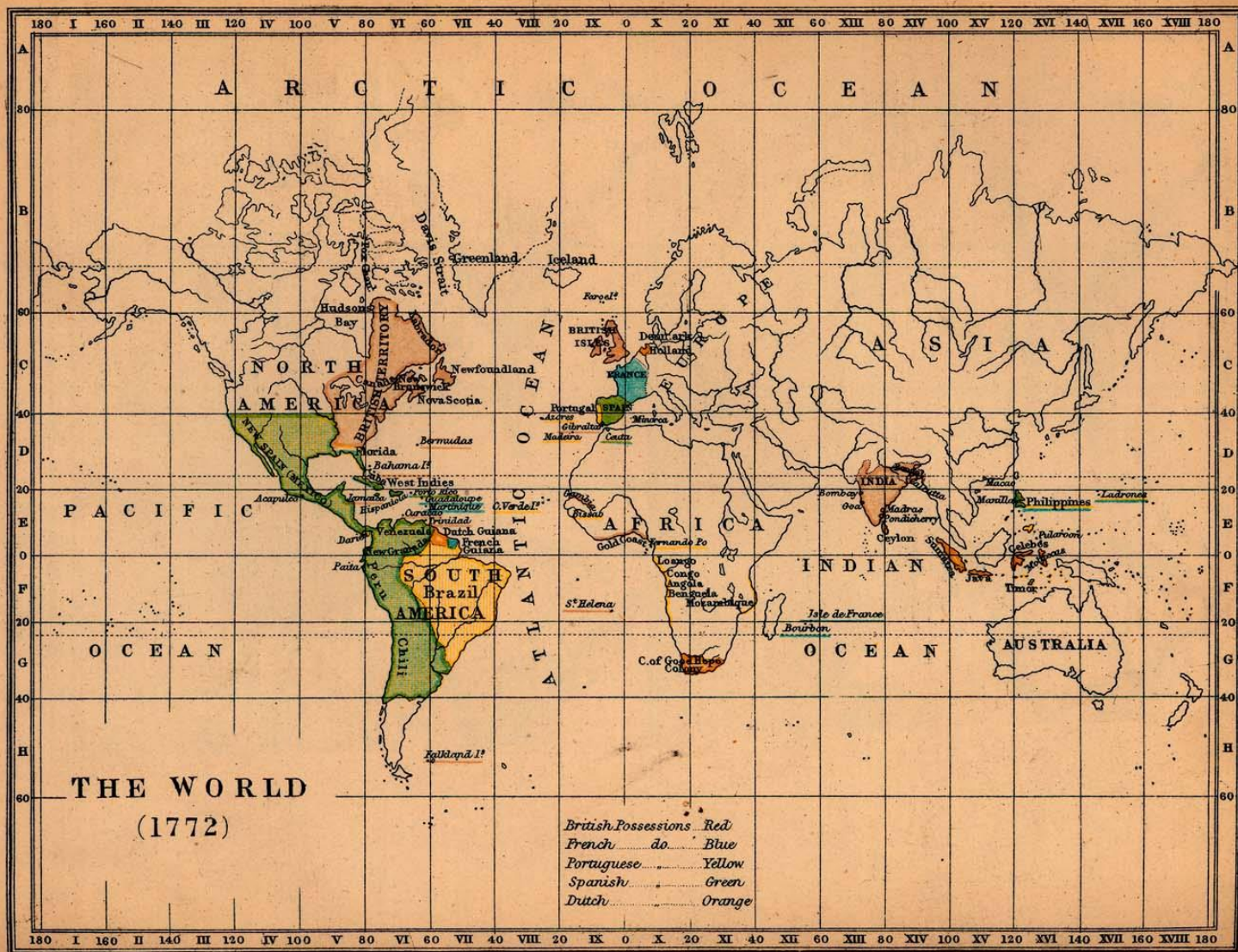
March 30-31, 2016



Jeff Reading, PhD.

British Columbia First Nations Health Authority Chair in Heart Health and Wellness at St.  
Paul's Hospital and Professor Simon Fraser University, Vancouver, British Columbia, Canada

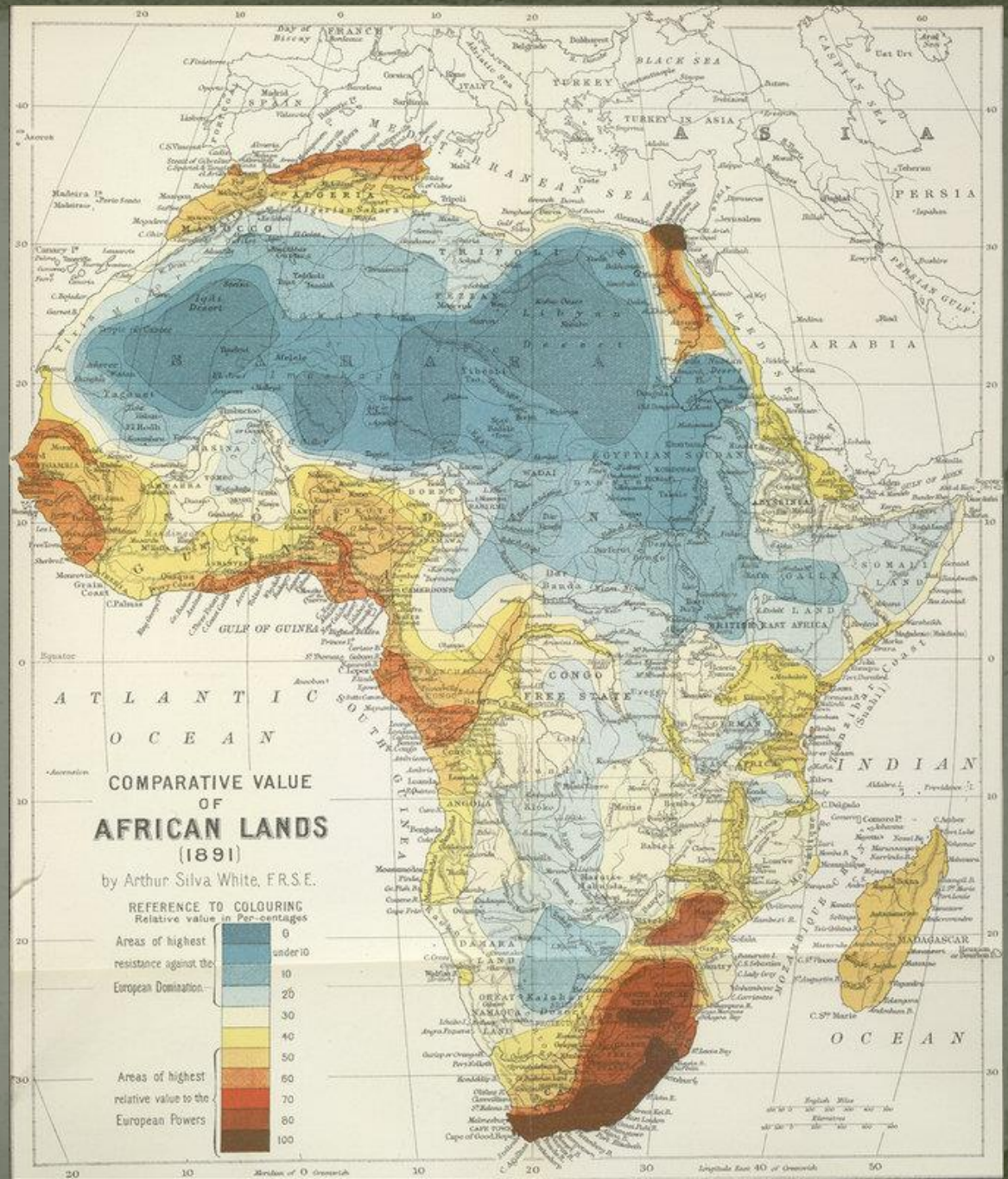
# Truth, Lies and the Political Economy of Colonization: Maps, Data, Indicators and Ideology



Ludlow's War of American Independence.

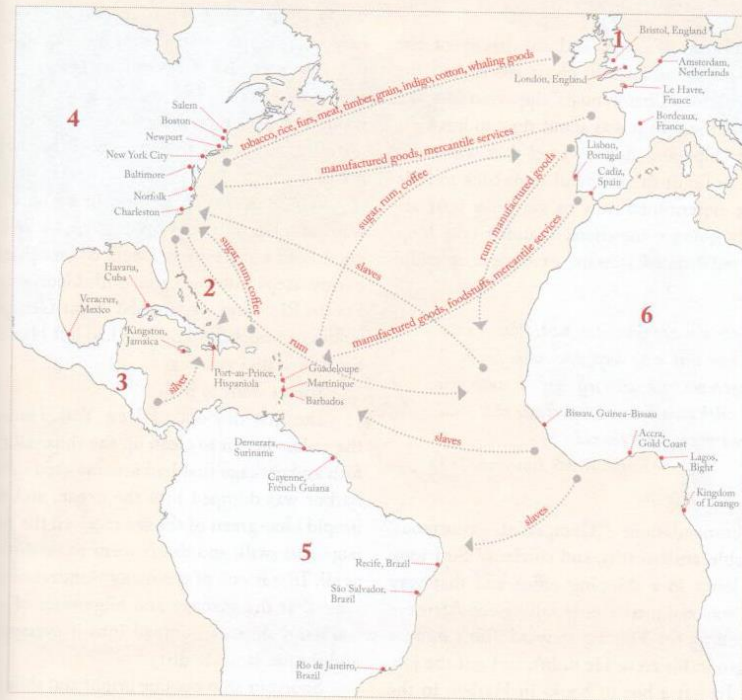
Longmans, Green & Co., London, New York & Bombay.

Source:  
Africa, and the European powers  
By Arthur Silva White  
Harper's Magazine Archive, 1891



## Shipping Lanes

Commerce on the Atlantic Ocean from 1501 to 1867



### 1. England:

1807: Slave trade abolished.  
1663–1775: Sugar consumption rose twentyfold.  
c. 1850: Cotton cloth was one of country's principal products; majority of raw material came from the American South.

### 2. West Indies:

1773: British West Indies exported nearly 2.8 million gallons of rum to Great Britain and 3.5 million gallons to North America.  
1804: Revolt against French rule on eastern Hispaniola culminated in creation of independent Haiti.

### 3. Central and South America:

1500–1600: Indigenous population declined by an estimated 40 million; Spanish began importing African slaves.  
1550–1640: 90 percent of materials exported to Spain was silver.

### 4. North America/United States:

1768–1773: Three slave-plantation products—tobacco, indigo, and rice—accounted for 75 percent of colonial American exports to Britain.  
c. 1822: Southern cotton constituted 40 percent of New York City's exports.  
1850: 27 percent of slaveholders owned 75 percent of the slaves in South.

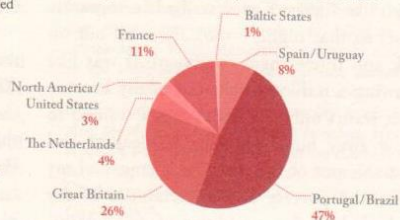
### 5. Brazil:

c. 1710: Portuguese began decreasing sugar output to focus on gold and diamond mining.  
1600–1800: Terrible labor conditions and harsh climate contributed to highest slave mortality rate of any country in the world.

### 6. Africa:

1501–1867: Estimated 12.5 million Africans taken.  
1501–1867: About 1.75 million Africans died en route to New World because of poor conditions (lack of food and water) and diseases (smallpox, yellow fever).

Percentage of Africans Taken by What Nation's Vessels:

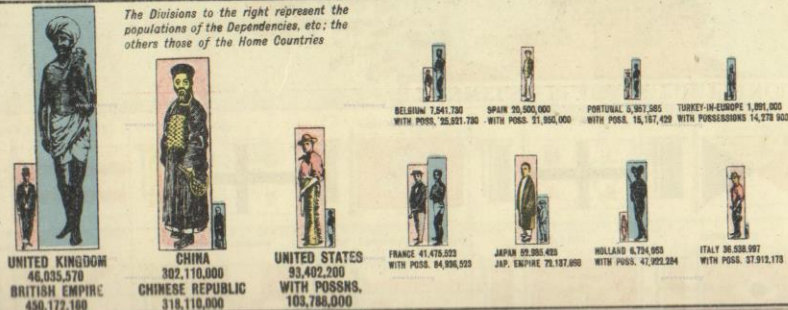


# THE WORLD—COLONIAL POWERS IN 1919



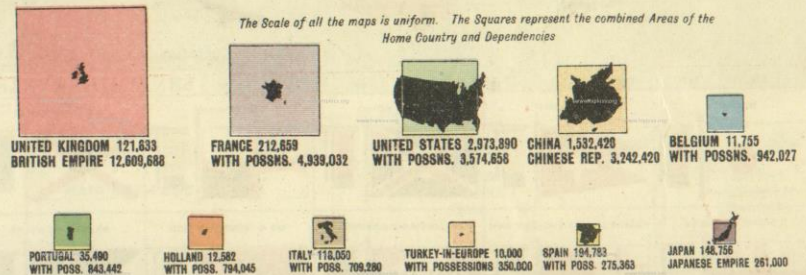
## POPULATIONS OF THE WORLD'S EMPIRES

The Divisions to the right represent the populations of the Dependencies, etc.: the others those of the Home Countries



## AREAS OF THE WORLD'S EMPIRES

The Scale of all the maps is uniform. The Squares represent the combined Areas of the Home Country and Dependencies



Source: Charles Booth's Inquiry into Life and Labour in London (1886-1903)



BLACK: Lowest class. Vicious, semi-criminal.  
DARK BLUE: Very poor, casual. Chronic want.  
LIGHT BLUE: Poor. 18s. to 21s. a week for a moderate family  
PURPLE: Mixed. Some comfortable others poor  
PINK: Fairly comfortable. Good ordinary earnings.  
RED: Middle class. Well-to-do.  
YELLOW: Upper-middle and Upper classes. Wealthy.

# Poverty: London, 1806

“Poverty...is a necessary and indispensable ingredient in society, without which nations and communities could not exist in a state of civilization. It is the lot of man - it is the source of wealth, since without poverty there would be no labour, and without labour there could be no riches, no refinement, no comfort, and no benefit to those who may be possessed of wealth - inasmuch as without a large proportion of poverty surplus labour could never be rendered productive in procuring either the conveniences or luxuries of life”

A treatise on indigence; exhibiting a general view of the national resources for productive labour; with propositions for ameliorating the condition of the poor, and improving the moral habits and increasing the comforts of the labouring people, particularly the rising generation. Patrick Colquhoun, London, 1806



Nineteenth century, New York City was full of trash. You can see what that meant in this horrific image of a dead horse rotting in the street where kids were playing.

<http://io9.com/heres-what-new-york-city-looked-like-before-sanitatio-565446786>



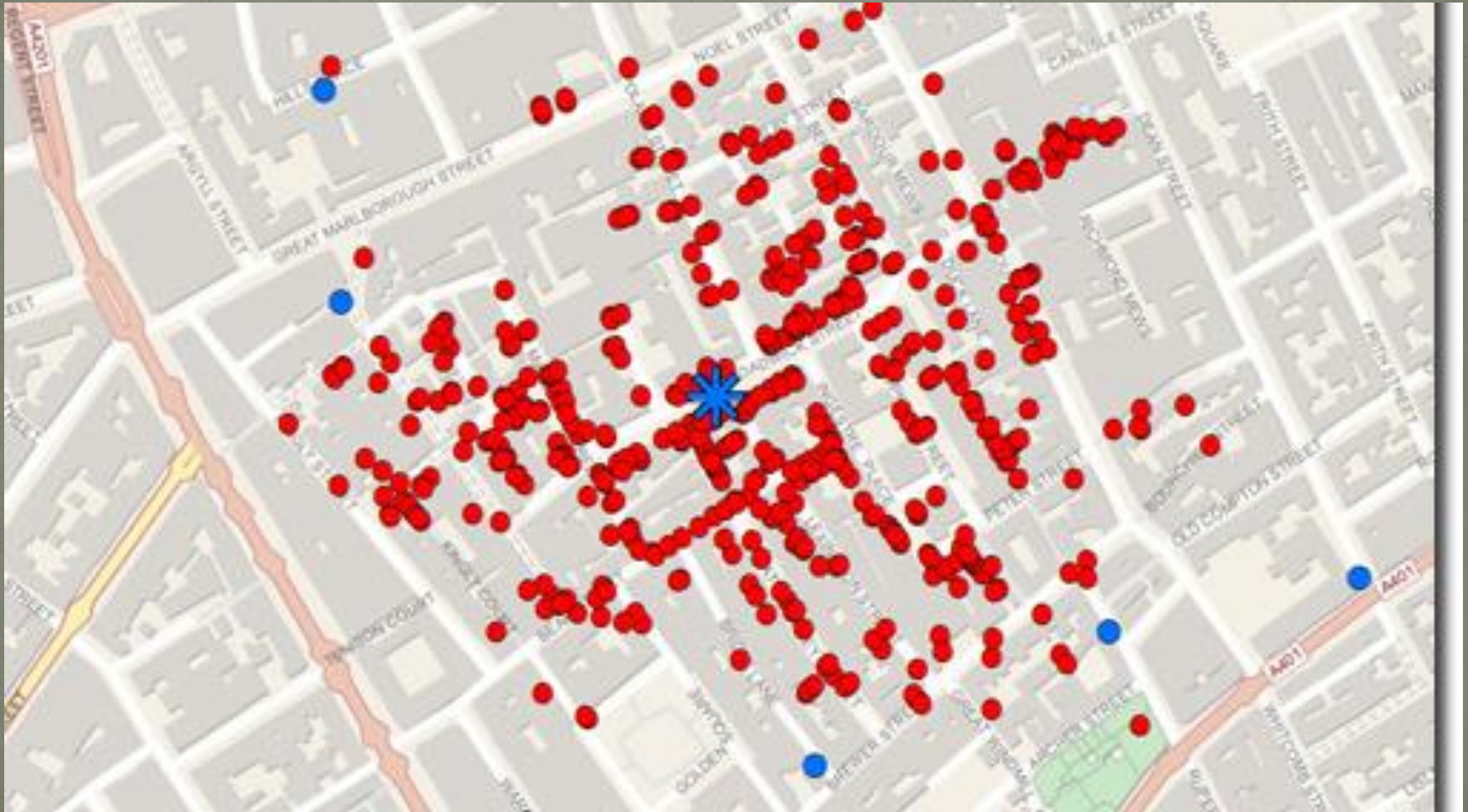
# Broad Street Water Pump and Cholera Outbreak, John Snow London and Reverend Henry Whitehead, 1854



Broad Street Water Pump and Cholera Outbreak,  
John Snow London and Reverend Henry Whitehead, 1854



# Broad Street Water Pump and Cholera Outbreak, John Snow London and Reverend Henry Whitehead, 1854



# Density Dependent Diseases and Housing



# Knowledge is Power and Data is Currency

- The Data Control Era (1900 to 1990)
- The Gatekeeper Era (1990 – 1994)
- Data Stewardship (1994 – 2015+)
- The future?

# The Data Control Era

- data was used mostly by government to construct an image about Indigenous health and social conditions, characterized as the Indian Problem
- data was used to support a forced assimilation agenda
- Justified fiscal ask to treasury board and cabinet, mostly for INAC and MSB.
  - For example, deplorable living conditions created by government policy (Indian Act) then justified a host of other failed policies of that aimed to force assimilation including residential schools, outlawed ceremonies, missionary religious indoctrination etc.

## The Data Control Era (1900 to 1990, 2011 to 2015)

Duncan Campbell Scott (Superintendent of Indian Affairs):

“I want to get rid of the Indian problem. Our object is to continue until there is not a single Indian in Canada that has not been absorbed into the body politic and there is no Indian question, and no Indian Department”

# Dr. Peter Henderson Bryce

Dr. Peter Bryce (1853-1932) who was a graduate of University of Toronto (B.A., UofT, 1876; M.A., UofT, 1877; M.D., UofT, 1886) and founder of Public Health Service of Ontario and the Chief Medical Officer with the Departments of the Interior and Indian Affairs (1904-1907).

After fighting Duncan Campbell Scott (First Superintendent of Indian Affairs) and the Federal government, Peter Bryce's funding was suspended for his public health research for Scott who stated that the cost of gathering statistics on child deaths far outweighed the "benefit" of the information provided.





## Dr. Peter Henderson Bryce

In 1907, Bryce conducted a special inspection of 35 residential schools in three Prairie Provinces. The report found that 24 percent of the children who had been in the schools were dead while over 75 percent of children were dead at File Hills residential school which filed a complete report. The cause of death was primarily related to tuberculosis and Bryce famously said "medical science knows just what to do" to stop the children from dying and he sent a number of recommendations to the Canadian Government for urgent implementation. The Government of Canada, however, largely ignored Bryce's calls for action and the children continued to die, prompting Bryce to step up his advocacy by publishing articles in the Ottawa Citizen newspaper, Saturday Night Magazine and a book called "The Story of a National Crime: An appeal for Justice to the Indians of Canada."

## The Gatekeeper Era (1990 – 1994)

- certain individuals were given access to data but this was at the impulse and discretion of the data controller (aka government data controller).
- Provincial and territorial governments could access Federal Data but it had to be in a 'partnership' and the rules for how the data was to be used were very tightly controlled or access would be revoked
- researchers (non-native) were given access to data but similarly access was strictly mission-oriented and data access approved by the data gatekeeper.

Frank and Ernest



# Data Stewardship (1994 – 2015+)

- RCAP changes everything - expectation that Indigenous Peoples would manage their own affairs.
  - Communities resist external examination and representation of health concerns.
  - Wherever Aboriginal people and communities have achieved success in developmental activities, these successes have occurred in the context of self determination.
  - Aboriginal people have fundamental rights to autonomous institutional development that can only be met through independent institutional development.

## Data Stewardship continues (1994 – 2015+)

- The advent of the so-called information age technologies made it possible for PTOs, communities and researchers to get more open access, which led to sharing agreements between Federal Depts. and Central Agencies (Stats Can, Census, INAC, FNIHB etc.).
- Creation of new Federal Institutions like the First Nations Statistical Institute, which was created but then dissolved before it was able to accomplish any national level data systems implementation.
- OCAP took hold as a spinoff of the RCAP aspiration and the RHS is thriving success story in a relatively new era of First Nations control. But OCAP is still a one-off and did not yet pervade all ownership to data.
- The CIHR and TCPS gave OCAP a big boost in ethics guidelines public policy reinforcing the notion of data as a community asset,
- Knowledge is Power and First Nations in particular are not interested in giving up ownership and control. Inuit and Metis are also on the same path.

# Indigenous Self Determination

- Communities resist external examination and representation of health concerns.
- Wherever Aboriginal people and communities have achieved success in developmental activities, these successes have occurred in the context of self determination.
- Aboriginal people have fundamental rights to autonomous institutional development that can only be met through independent institutional development.

## Three factors key to Indigenous health research

- The development of networks of Indigenous health advocates and researchers
- The emphasis of Indigenous people and communities as agents of research, rather than subjects
- The incorporation of an Indigenous lens on health and health equity with existing and evolving global and local health research capacities





TCPS2

TRI-COUNCIL POLICY STATEMENT

# Ethical Conduct for Research Involving Humans

2010

---

Canadian Institutes of Health Research  
Natural Sciences and Engineering Research Council of Canada  
Social Sciences and Humanities Research Council of Canada

Please cite this document as follows:

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, December 2010.

Note: For the most recent information on amendments, please consult the official online version of the TCPS at [www.practice.ca/gccc](http://www.practice.ca/gccc).

Permission is granted to photocopy this material.

© Her Majesty the Queen in Right of Canada (2010)  
Catalogue No. MR21-18/2010E-PDF  
ISBN 978-1-100-17257-61

# Chapter 9

## RESEARCH INVOLVING THE FIRST NATIONS, INUIT AND MÉTIS PEOPLES OF CANADA

### Introduction

#### Preamble

This chapter on research involving Aboriginal peoples in Canada, including Indian (First Nations<sup>1</sup>), Inuit and Métis peoples, marks a step toward establishing an ethical space for dialogue on common interests and points of difference between researchers and Aboriginal communities engaged in research.

First Nations, Inuit and Métis communities have unique histories, cultures and traditions. They also share some core values such as reciprocity – the obligation to give something back in return for gifts received – which they advance as the necessary basis for relationships that can benefit both Aboriginal and research communities.

Research involving Aboriginal peoples in Canada has been defined and carried out primarily by non-Aboriginal researchers. The approaches used have not generally reflected Aboriginal world views, and the research has not necessarily benefited Aboriginal peoples or communities. As a result, Aboriginal peoples continue to regard research, particularly research originating outside their communities, with a certain apprehension or mistrust.

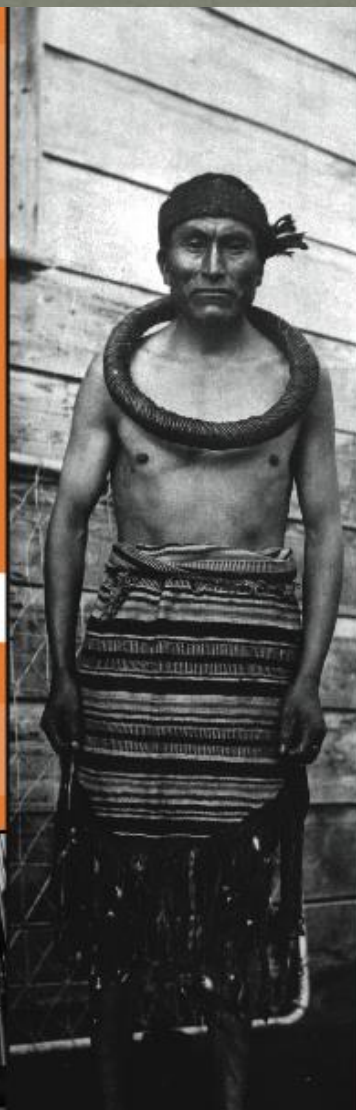
The landscape of research involving Aboriginal peoples is rapidly changing. Growing numbers of First Nations, Inuit and Métis scholars are contributing to research as academics and community researchers. Communities are becoming better informed about the risks and benefits of research. Technological developments allowing rapid distribution of information are presenting both opportunities and challenges regarding the governance of information.

This chapter is designed to serve as a framework for the ethical conduct of research involving Aboriginal peoples. It is offered in a spirit of respect. It is not intended to override or replace ethical guidance offered by Aboriginal peoples themselves. Its purpose is to ensure, to the extent possible, that research involving Aboriginal peoples is premised on respectful relationships. It also encourages collaboration and engagement between researchers and participants.

Building reciprocal, trusting relationships will take time. This chapter provides guidance, but it will require revision as it is implemented, particularly in light of the on going efforts of Aboriginal peoples to preserve and manage their collective knowledge and information generated from their communities. The Agencies – the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council (NSERC), and the Social Sciences and Humanities Research Council (SSHRC) – are committed to the continued evolution of this Policy, as noted in the Introduction. As the Policy comes into effect, the approach of engaging communities will be

# Developing Community eHealth

*Starting the eHealth Discussion with BC First Nations*



# The future: data democratization and increased International Indigenous cooperation?

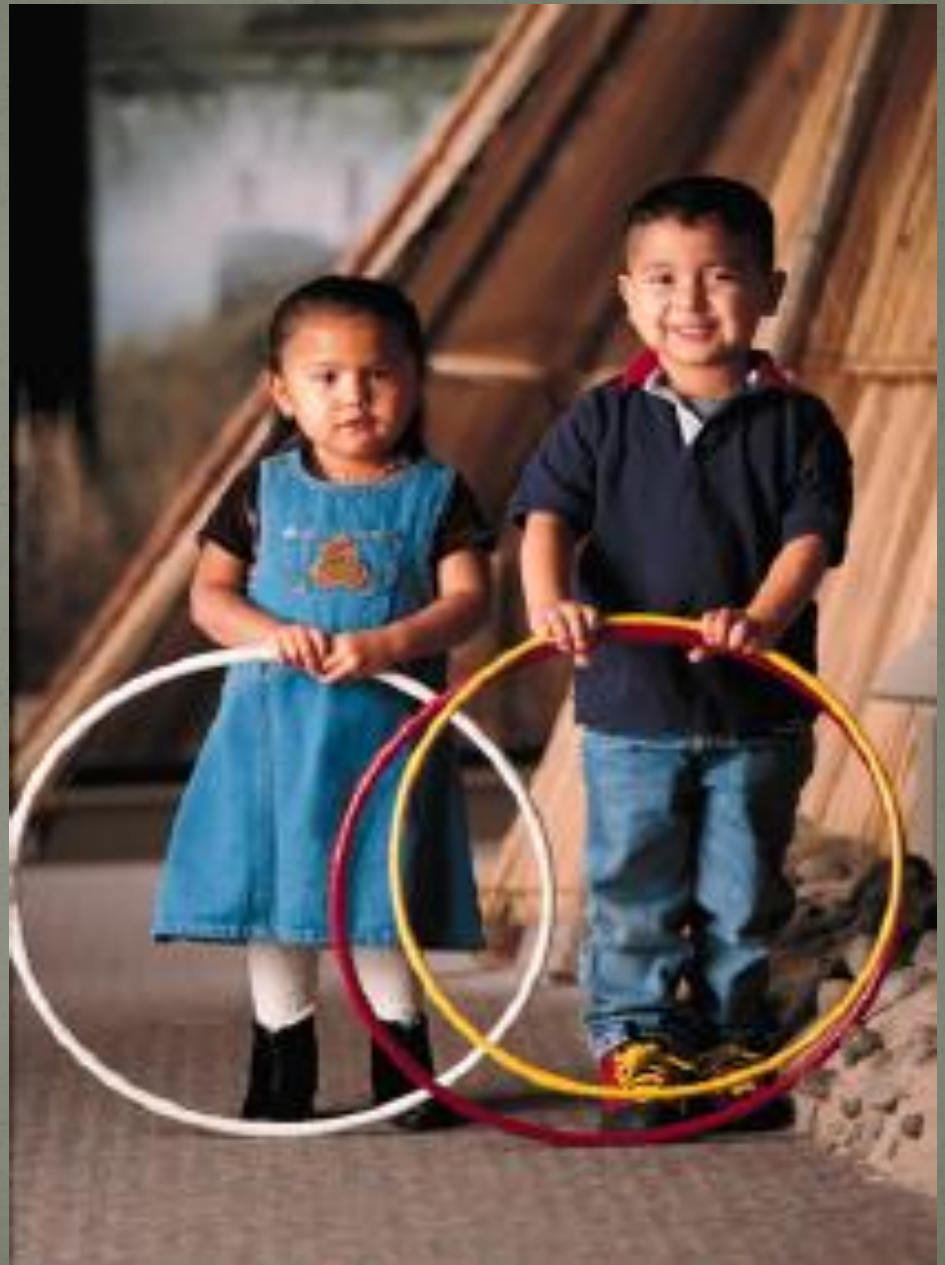
- shared governance model that recognize data as a tool for research and change
- a need exists for foundational investment in Indigenous led information science capacities (infrastructure, human capital and operations)
- needs to include qualitative methods and research on new methods and tools like big data analysis solving wicked (complex) problems with complex solutions. Focus on interdisciplinary and cross-disciplinary research.
- reliance on descriptive data to guide solutions is not working because complexity is accelerating and change is unpredictable and increasing in speed, i.e. the global cut to oil prices and financial interdependence of nations means upstream forces occupy a more important role in local economic and social conditions and leaders don't know what to do about it except to say somehow we will weather the storm.
- This can be an opportunity for Indigenous minority populations if we embrace change as inevitable and lobby for investments in data capacities and develop new tools using innovative methods that embrace complexity and inter- and trans-disciplinarity.

# ***'You Can't Influence What You Don't Measure'***

- **Indigenous Peoples** need to be included in all research and policy developed including priority setting, design, analysis, interpretation, implementation, policy development, monitoring, evaluation and dissemination.
- **Missing Data** – uneven reporting
- **Obscured Data** - Indigenous perspective is lost because data is lost inside large datasets, population health data from national and regional holdings needs to disaggregate Indigenous Peoples' health information to profile population health and to describe community
- **Addressing Data Gaps** – recognition of indigenous peoples role in collecting, collating and analyzing their own population data
- **Addressing the data challenges** – Indigenous status is not acknowledged for all indigenous peoples', indigenous peoples are diverse but are often lumped into one group, states discourage tribal affiliations to promote nationalism, data on indigenous peoples is considered difficult to obtain due to remoteness, and populations are relatively small so will not have a major impact on overall results, can include language barriers between data collectors and respondents, low literacy can be a barrier in some regions
- Indigenous research is not a priority for research funding agencies and councils
- Acknowledge inherent rights of Indigenous Peoples'
- Enforcement of equal opportunities policy

## Conclusion

A future where funding needs to grow to support Indigenous led data centres and institutions, disconnected from government interference, connected to the Academy (as long as it supports First Nations autonomy) and funded with a vision to shift Indigenous communities health and social well being to help create a healthy and sustainable future.



For the first time ever, the Canada Games have an Official Host First Nation. The 2015 Canada Winter Games are taking place on the traditional territory of the Lheidli T'enneh.



**Ts'uhooont'l Whuzhadel – Welcome – Bienvenue** February 26, 2015 Theresa Healy  
<http://blog.northernhealth.ca/general/tsuhooontl-whuzhadel-welcome-bienvenue/>



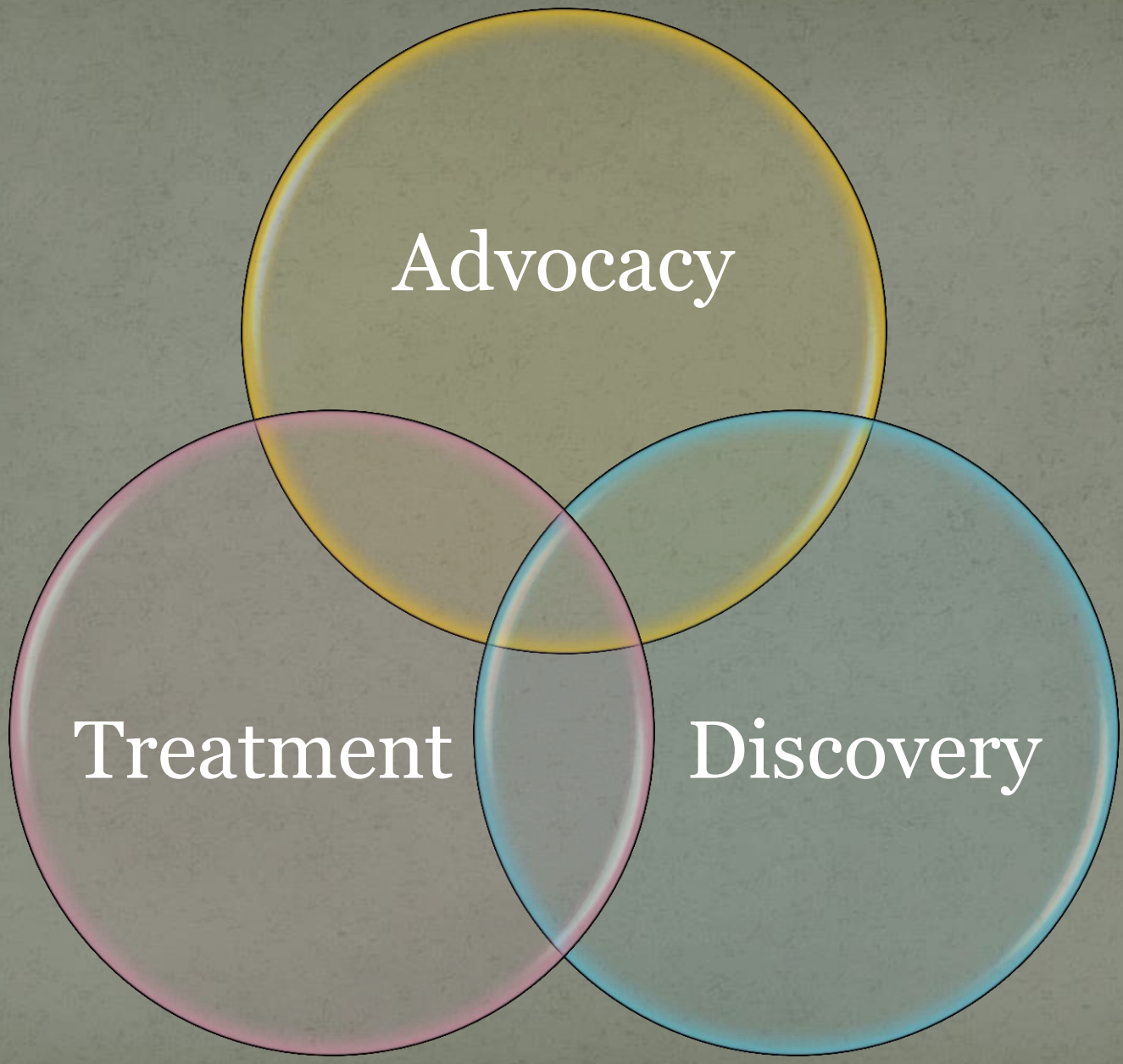
A Venn diagram consisting of three overlapping circles. The top circle is yellow and labeled 'SFU'. The bottom-left circle is pink and labeled 'St. Paul's'. The bottom-right circle is blue and labeled 'FNHA'. The circles overlap in the center and at the intersections between pairs of circles.

SFU

St.  
Paul's

FNHA





Advocacy

Treatment

Discovery



ELSEVIER



CrossMark



Canadian Journal of Cardiology 31 (2015) 1077–1080

## Viewpoint

# Confronting the Growing Crisis of Cardiovascular Disease and Heart Health Among Aboriginal Peoples in Canada

Jeffrey Reading, BPE, MSc, PhD, FCAHS\*

*Waakebiness-Bryce Institute for Indigenous Health, Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada*

### ABSTRACT

Although the prevalence of cardiovascular disease (CVD) has been decreasing worldwide, Aboriginal populations of Canada (including First Nations, Métis, and Inuit Peoples) continue to experience a rapidly growing burden of CVD morbidity and mortality. This article provides a succinct summary of the current crisis of CVD among Canadian Aboriginal peoples, including how and why it originated, elucidates the underlying population health risks driving higher rates of aboriginal CVD, and articulates the urgent need for community-engagement solutions and innovations in the areas of prevention, treatment and care, rehabilitation services, aboriginal-specific CVD surveillance, and advanced knowledge. In the past, particularly in rural and remote communities, Aboriginal Peoples' survival depended (and often still does) on hunting, fishing, and other forms of traditional food-gathering. However, the traditional life is being changed for many Aboriginal communities, resulting in significantly impaired dietary options and the

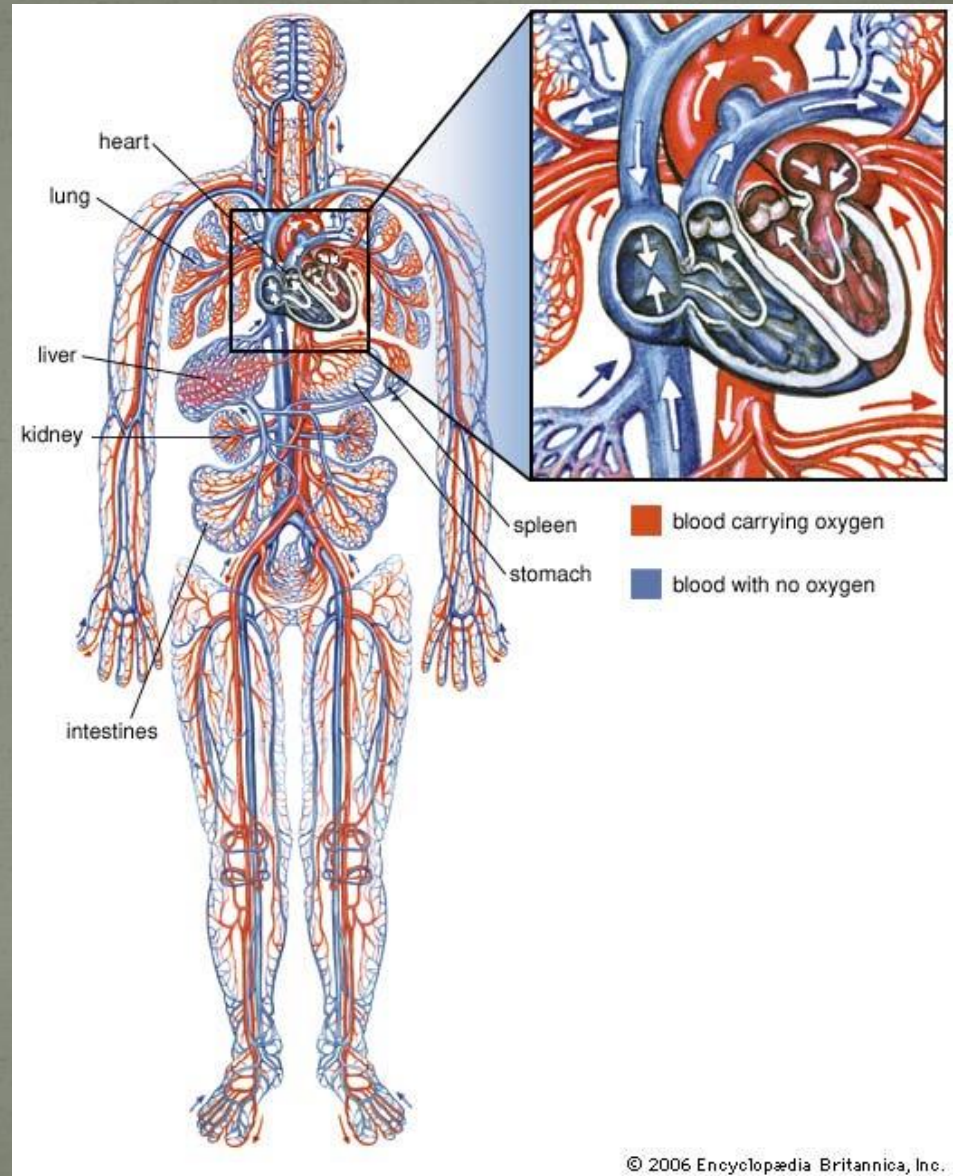
### RÉSUMÉ

Bien que la prévalence des maladies cardiovasculaires (MCV) ait diminué à travers le monde, les populations autochtones du Canada (y compris les Premières nations, les Métis et les Inuits) continuent de subir une augmentation rapide du fardeau de la morbidité et de la mortalité liées aux MCV. Cet article fournit un résumé succinct de la crise actuelle des MCV chez les peuples autochtones du Canada, y compris comment et pourquoi cela a commencé, met en évidence les risques sous-jacents pour la santé de la population conduisant à des taux plus élevés de MCV chez les autochtones, et articule le besoin urgent de solutions communautaires pour un engagement et des innovations dans les domaines de la prévention, le traitement et les soins, les services de réadaptation, la surveillance particulière des MCV chez les autochtones, et des connaissances avancées. Par le passé, en particulier dans les collectivités rurales et éloignées, la survie des peuples autochtones dépendait (et c'est encore souvent le cas) sur la

# Central and Peripheral Oxygen Transport

$$MAP/TPR = Q = SV \times HR$$

$$VO_2 = Q \times (a-v O_2 \text{ diff})$$



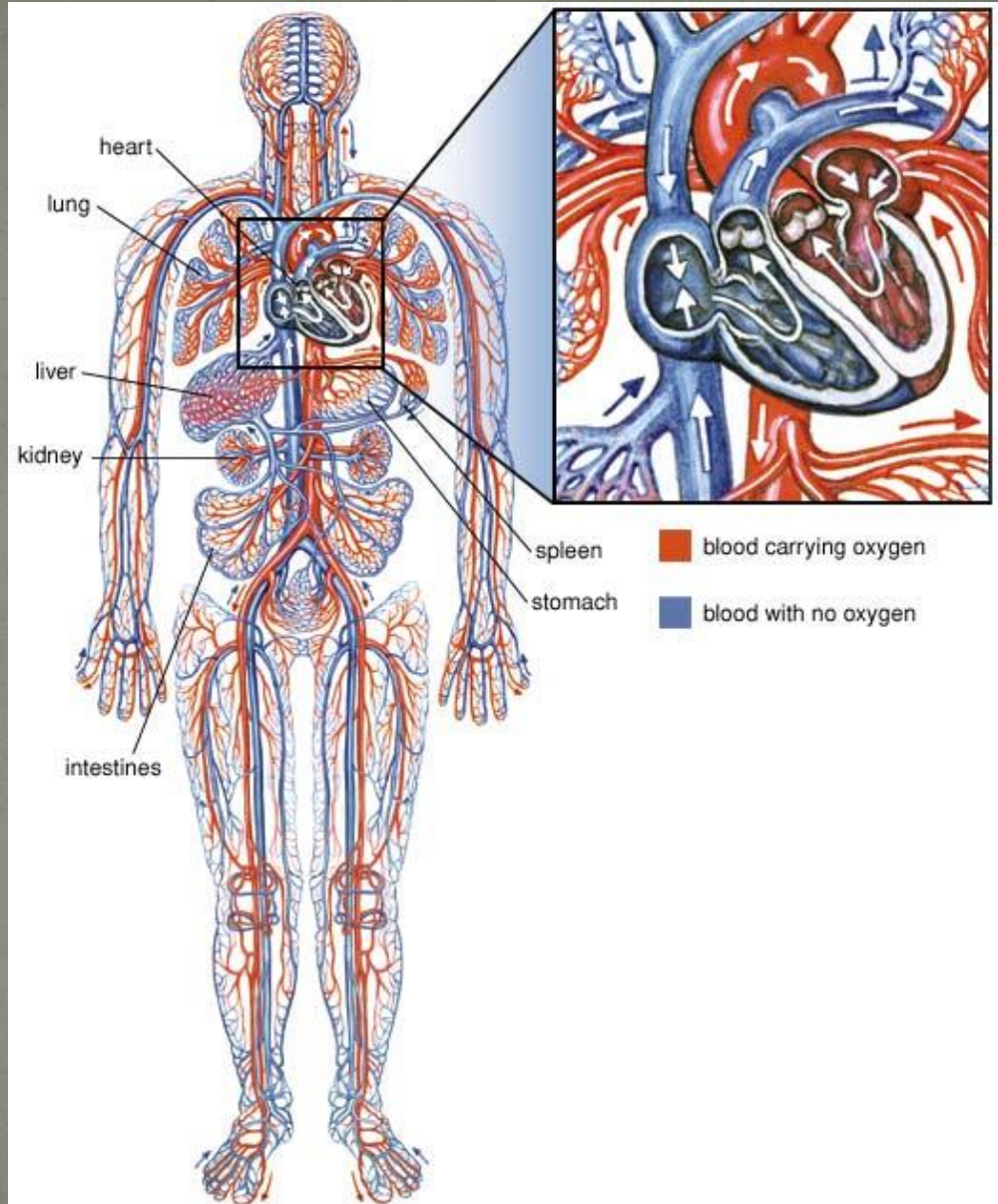
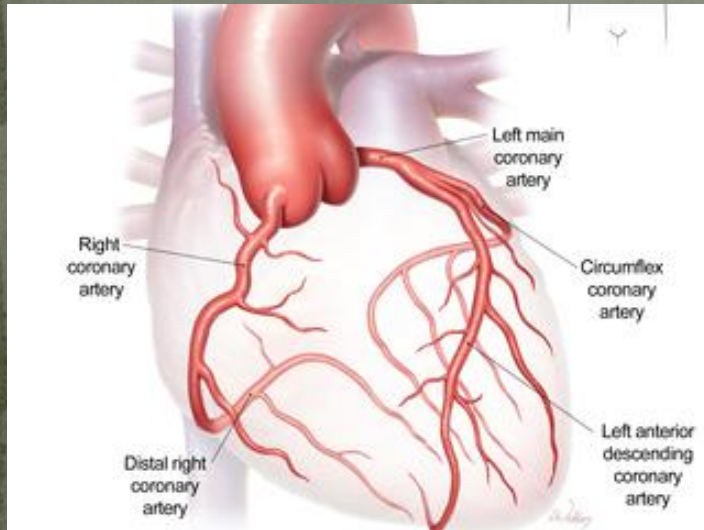
# Central and Peripheral Oxygen Transport Adaptation

$$(a-v \text{ O}_2 \text{ diff}) \times (\text{MAP/TPR}) = \dot{\text{V}}\text{O}_2 = (\text{SV} \times \text{HR}) \times (a-v \text{ O}_2 \text{ diff})$$

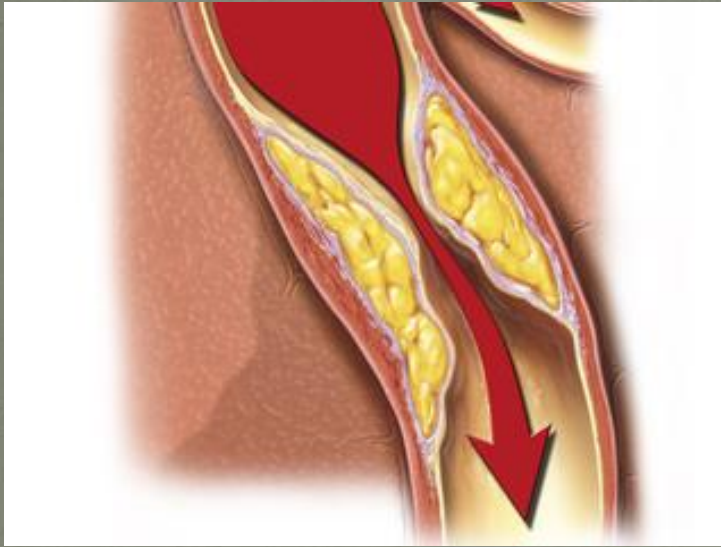


Nuclear Cardiology Laboratory, Toronto General Hospital, Circa 1990

# Cardiac and Vascular System



# Coronary Artery Angioplasty Revascularization



## FDA to review Abbott's one-of-a-kind dissolving medical implant to weigh its potential risks



Submitted by Diana Bretting on Tue, 03/15/2016

<http://perfsience.com/content/2143438-fda-review-abbotts-one-kind-dissolving-medical-implant-weigh-its-potential-risks>

## Likelihood of coronary angiography among First Nations patients with acute myocardial infarction

Lauren C. Bresee PhD, Merril L. Knudtson MD, Jianguo Zhang MSc, Lynden (Lindsay) Crowshoe MD, Sofia B. Ahmed MD MSc, Marcello Tonelli MD SM, William A. Ghali MD MPH, Hude Quan PhD, Braden Manns MD MSc, Gabriel Fabreau MD MPH, Brenda R. Hemmelgarn MD PhD; for the Alberta Kidney Disease Network (AKDN) and the Alberta Provincial Project for Outcome Assessment in Coronary Heart Disease (APPROACH)

**Competing interests:** None declared.

This article has been peer reviewed.

**Correspondence to:** Brenda Hemmelgarn, [brenda.hemmelgarn@albertahealthservices.ca](mailto:brenda.hemmelgarn@albertahealthservices.ca)

*CMAJ* 2014, DOI:10.1503/cmaj.131667

### ABSTRACT

**Background:** Morbidity due to cardiovascular disease is high among First Nations people. The extent to which this may be related to the likelihood of coronary angiography is unclear. We examined the likelihood of coronary angiography after acute myocardial infarction (MI) among First Nations and non-First Nations patients.

**Methods:** Our study included adults with incident acute MI between 1997 and 2008 in Alberta. We determined the likelihood of angiography among First Nations and non-First Nations patients, adjusted for important confounders, using the Alberta Provincial Project for Outcome Assessment in Coronary Heart Disease (APPROACH) database.

**Results:** Of the 46 764 people with acute MI, 1043 (2.2%) were First Nations. First Nations patients were less likely to receive angiography within 1 day after acute MI (adjusted

odds ratio [OR] 0.73, 95% confidence interval [CI] 0.62–0.87). Among First Nations and non-First Nations patients who underwent angiography (64.9%), there was no difference in the likelihood of percutaneous coronary intervention (PCI) (adjusted hazard ratio [HR] 0.92, 95% CI 0.83–1.02) or coronary artery bypass grafting (CABG) (adjusted HR 1.03, 95% CI 0.85–1.25). First Nations people had worse survival if they received medical management alone (adjusted HR 1.38, 95% CI 1.07–1.77) or if they underwent PCI (adjusted HR 1.38, 95% CI 1.06–1.80), whereas survival was similar among First Nations and non-First Nations patients who received CABG.

**Interpretation:** First Nations people were less likely to undergo angiography after acute MI and experienced worse long-term survival compared with non-First Nations people. Efforts to improve access to angiography for First Nations people may improve outcomes.



# 'I'm too young to die': the disease of disadvantage forcing Indigenous children to have open-heart surgery

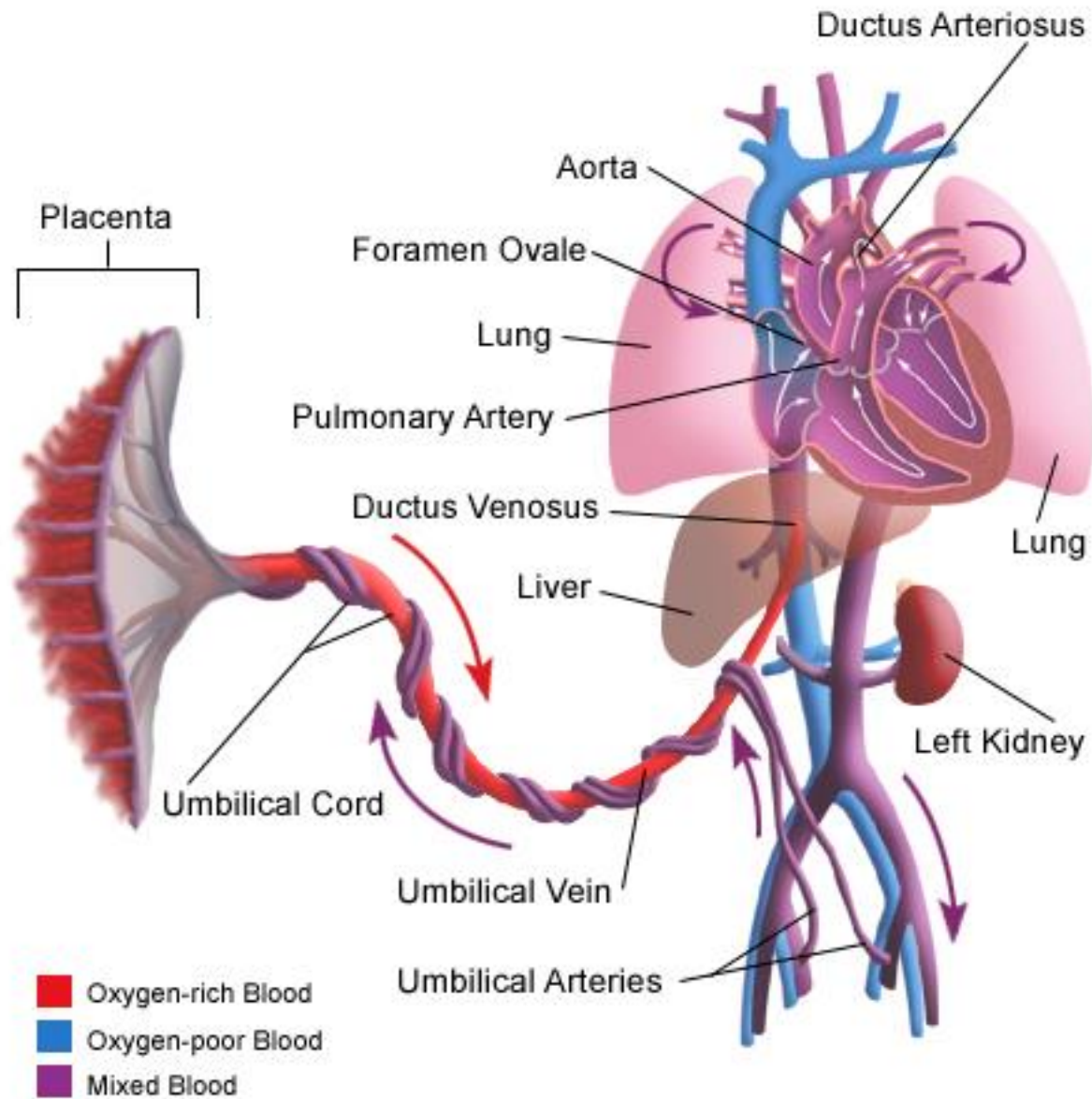
An entirely preventable condition called rheumatic heart disease is leaving Indigenous children with severe and irreversible heart damage

● [Podcast: Melissa Davey discusses the health emergency in the Tiwi Islands](#)



📷 Trenton Cunningham, now 10, who had open heart surgery when he was just seven years old to treat rheumatic heart disease, has a heart scan. Photograph: Mike Hill and Sue Collins

# Fetal Circulation



## The quest to improve Aboriginal health

The epidemic of diabetes mellitus is still growing in many of Canada's First Nations communities, and the causes remain to be fully elucidated.<sup>1,2</sup> Various intervention projects have been tried, and some show promise. However, much still needs to be understood.

One in 5 First Nations adults has received a diagnosis of diabetes, primarily type 2. They are more than 4 times as likely as First Nations people without diabetes to have hypertension.<sup>3</sup> Having both conditions puts them at increased risk of ischemic heart disease and other disorders affecting renal, visual, peripheral and cerebral vascular function, especially if they also smoke or are overweight or obese. An effective program for controlling hypertension in the presence of diabetes is therefore crucial.

In this issue (page 1267), Tobe and colleagues report the findings of the third Diabetes Risk Evaluation and Microalbuminuria study (DREAM 3).<sup>4</sup> They compared 2 community-based strategies for controlling hypertension in First Nations people with existing hypertension and type 2 diabetes. All participants had their blood pressure measured by a home care nurse and underwent laboratory tests at regular intervals over 12 months, with updates reported back to the patients' primary care physicians. For patients randomly assigned to the intervention group, the nurse followed a predefined algorithm of pharmacologic antihypertensive therapy. For those in the control group, the nurse arranged follow-up with the patient's primary care physician if the blood pressure was elevated. Both study groups experienced significant reductions in blood pressure by the final visit; the difference between the groups was significant only for the change in diastolic pressure.

The DREAM 3 study is important because it shows the feasibility, effectiveness and efficiency of a method for following patients in First Nations communities. It also represents an important milestone in building a capacity for advanced research that aims to improve the health and well-being of one of Canada's most vulnerable populations.<sup>4</sup> Although it is more convenient and less costly to undertake clinical trials in highly populated urban centres, it is important to conduct high-quality research in Aboriginal communities. It is not sufficient to attempt to "translate" outcomes from other population-based research and apply the findings directly to the unique and diverse Aboriginal populations.

To be useful to Aboriginal populations, clinical research studies need to meet the highest standards of excellence in quality and be initiated in partnership with the priorities of First Nations, Inuit and Métis communities.<sup>5</sup> Unravelling the mysteries of diabetes and why it is so prevalent among Aboriginal people in Canada and around the world requires a renewed exploration of indigenous "ways of knowing," with the integration of innovative ideas derived from ancient tradi-

tional practices of Aboriginal healers with the modern scientific methods of inquiry practised by a new generation of researchers.

Non-Aboriginal health care professionals need to understand how Aboriginal people interpret their illness experience and respond to treatment regimens, and to respect the logic and rationale of another system of thought. They need to adapt their treatment plans and education programs to the cultural, social and economic circumstances of their Aboriginal patients and to recognize that many First Nations, Inuit and Métis communities are geographically remote, with little access to specialty services.<sup>5</sup>

Diabetes is a complicated disease that is nested in the experience of rapid social and cultural change; thus, its prevention and control may need new ideas that go beyond an individual approach in a clinic or hospital ward. Long-term change will probably require broader community-level action and collaboration between researchers, policy-makers, Aboriginal community organizations, governments, volunteer agencies and health care professionals. In addition, the broader population health determinants need to be addressed and social repercussions of the disease better understood.

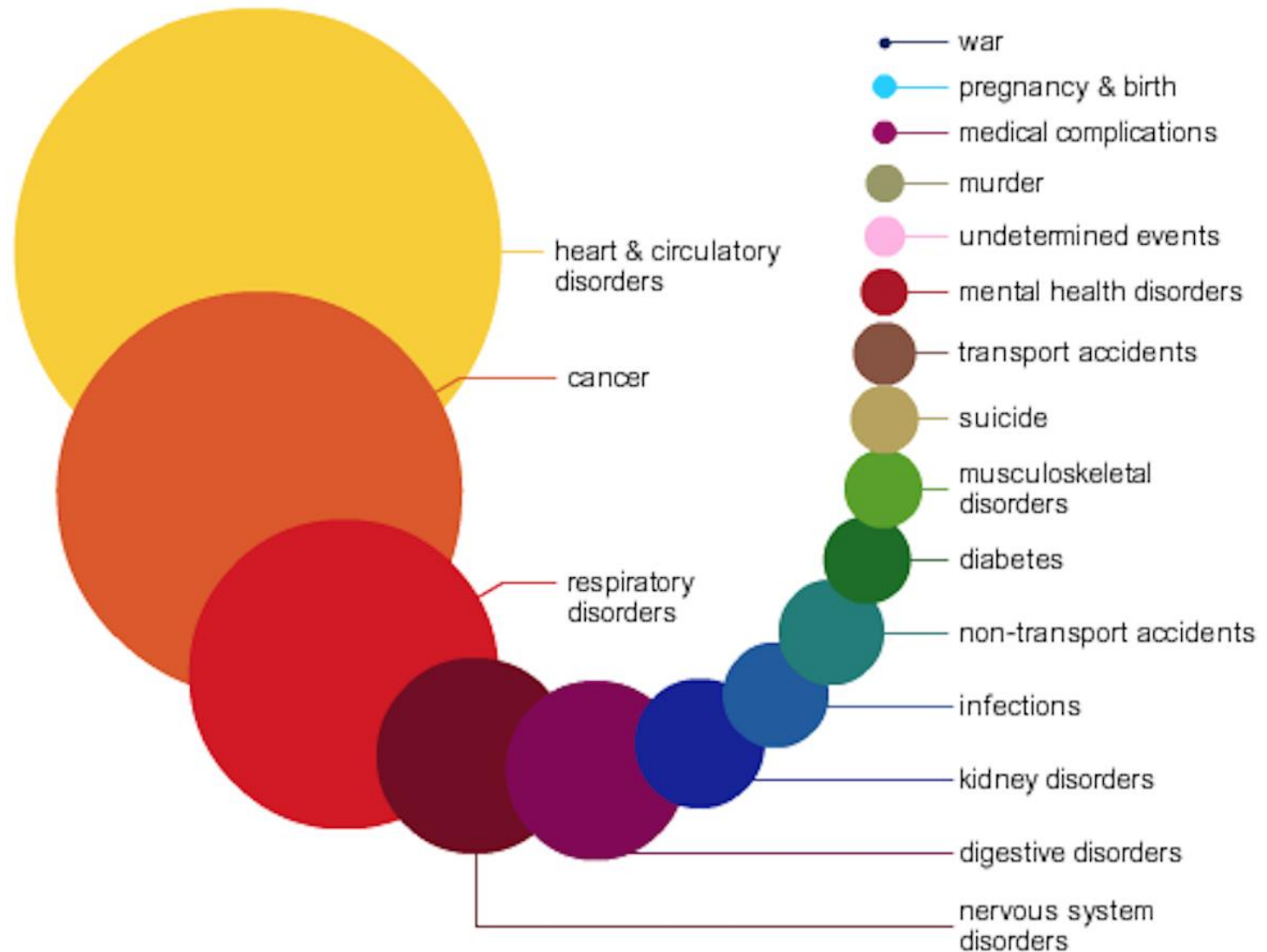
Finally, important clinical findings gained from advanced health research must be shared with other Aboriginal communities and translated into evidence-based guidelines to improve the health of all Canadians. The Canadian Institutes of Health Research (CIHR) supports knowledge translation, and Aboriginal communities are eager to see the products of research be strategically targeted to improve health services and narrow the gap in health and well-being between Aboriginal people and other Canadian populations. — Jeff Reading, Scientific Director, CIHR Institute of Aboriginal Peoples' Health, and Professor, Faculty of Human and Social Development, University of Victoria, Victoria, BC.

This article has been peer-reviewed.

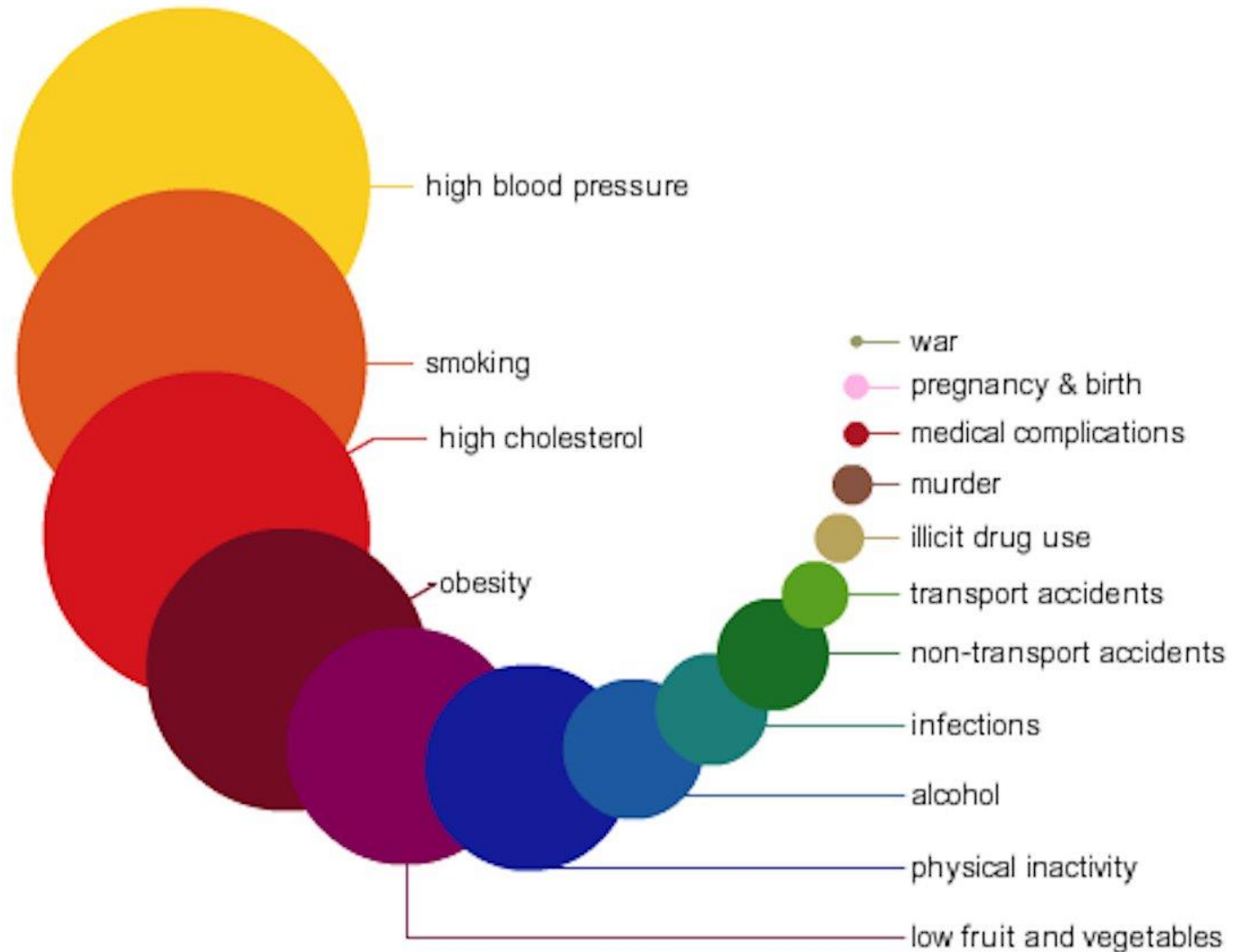
### REFERENCES

1. Diabetes. In: *First Nations Regional Longitudinal Health Survey (RHS) 2002/03: results for adults, youth and children living in First Nations communities*. Ottawa: First Nations Centre; 2005. p. 69-76. Available: [www.naho.ca/firstnations/english/documents/RHS2002-03TechnicalReport\\_001.pdf](http://www.naho.ca/firstnations/english/documents/RHS2002-03TechnicalReport_001.pdf) [accessed 2006 Mar 21].
2. Young TK, Reading J, Elias B, et al. Type 2 diabetes mellitus in Canada's First Nations: status of an epidemic in progress. *CMAJ* 2000;163(15):610-6.
3. Tobe SW, Palychuk G, Wenzworth I, et al. Effect of nurse-directed hypertension treatment among First Nations people with existing hypertension and diabetes mellitus: the Diabetes Risk Evaluation and Microalbuminuria (DREAM 3) randomized controlled trial. *CMAJ* 2006;174(6):1287-71.
4. Reading J, Nowgic E. Improving the health of future generations: the Canadian Institutes of Health Research Institute of Aboriginal Peoples' Health. *Am J Public Health* 2002;92:1396-400.
5. Reading J. The Canadian Institutes of Health Research. Institute of Aboriginal Peoples' Health: a global model and national network for Aboriginal health research excellence. *Can J Public Health* 2003;94:385-9.

## Leading causes of death in perspective



# Risks leading to death in perspective





# Life Course Epidemiology

Life course epidemiology has been defined as the study of long-term effects of physical or social exposures during gestation, childhood, adolescence, young adulthood, and adult life on one's developmental health and later disease risk

## Heart Disease and Life Course Epidemiology

Life course epidemiology goes beyond traditional risk factors and questions the importance of intrauterine nutrition, birth weight, childhood obesity, smoking initiation ages and rates, adolescent blood pressure, and socioeconomic status across an individual and community's life course.





## The Goal:

To optimize the developmental trajectory over entire life course



What matters:

Address the complex interaction of health determinants, in particular Aboriginal contexts, over entire life course

gender and  
culture

Health  
services

Genetic  
endowment

Biology

Child  
development

Income

Social status

Social support

Education  
and literacy

Working  
conditions

Physical  
environments

Health  
practices

Coping skills

Social  
exclusion

Trauma and  
stress



**What matters:**

**Address the complex interaction of health determinants, in particular Aboriginal contexts, over entire life course**

# Barriers to adequate care that are experienced by Indigenous people include:

- poor coordination across the health system
- socioeconomic disadvantage
- poor access to acute care services
- poor access to primary and specialist health care
- sub-optimal (less than best) provision of in-hospital services
- the availability of transport to health services
- delays in presentation
- language and cultural differences

# Health system issues

- **Health care delivery** – better coordination between levels of government
- **Team approach** – solo practices are inadequate to address multiple health needs
- **Traditional practices / medicines** – longstanding knowledge should be supported and integrated within health teams
- **Access to health services** – equitable access to care must be made available
- **Health human resources** – qualified Aboriginal professionals are lacking in health care and public health
- **Post-event follow-up** – adequate follow-up can save lives
- **Tele-health** – technology provides opportunities, but requires significant investment.

Source: Canadian Heart Health Strategy and Action Plan Addressing and enhancing Aboriginal / indigenous cardiovascular health. May 28, 2007

# Community based approach

- Community-based perspective and approach – matches community needs and state of readiness
- Self-determination – recognize and support the right of Aboriginal people to look after their own health
- Partnerships and collaboration – combine efforts and resources to build capacity within communities
- Planning – lack of funding, support and capacity building/training for communities to define and address their own needs
- Community development – success factors can be identified and supported
- Advocates – identify and take full advantage of them

Source: Canadian Heart Health Strategy and Action Plan Addressing and enhancing Aboriginal / indigenous cardiovascular health. May 28, 2007

# Research

- **Evidence-base** – best practices and successful programs must be identified
- **Epidemiology** – better data and analysis required to understand the issues
- **Surveillance** – health information is required at the national and community levels to inform decisions
- **Evaluation and intervention research** – better data are required to document whether interventions are having an effect
- **Barriers to achieving progress** – these need to be identified and addressed

Source: Canadian Heart Health Strategy and Action Plan Addressing and enhancing Aboriginal / indigenous cardiovascular health. May 28, 2007

# Cardiovascular Care and Research

- Quantitative and Qualitative (mixed methods approach)
  - Clinical guideline concordance
    - Administrative data linkage, very useful but has limits
  - Clinician-patient engagement and decision making
    - Severity of disease
    - Patient preference
    - Patient frailty and cognitive ability
    - Pharmacological contraindication
  - Qualitative
    - Cultural context possible
    - Underlying interactions
    - Explanation of disparities as experienced by patients
    - Multi-dimensional including the 'lived experience'



# Cardiovascular Study Design Issues

- Methodological studies
- Observational studies
  - Comparative observational studies
- Interventional studies