Research with Indigenous people:
Ethical considerations and community engagement

Harvard University Native American Program and Dept. of Global Health and Social Medicine
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Malcolm King, PhD, FCAHS
Mississaugas of the Credit First Nation
Saskatchewan Centre for Patient-Oriented Research
University of Saskatchewan
malcolm.king@usask.ca

Alexandra King, MD, FRCPC
Nipissing First Nation
Cameco Chair in Indigenous Health and Wellness
University of Saskatchewan
alexandra.king@usask.ca

UNIVERSITY OF SASKATCHEWAN

Acknowledgement of the Territory:

We respectfully acknowledge that we live, work and play in Treaty 6 Territory and the Homeland of the Métis.

We acknowledge the Massachusett people, on whose traditional and ancestral homelands we are gathered.

Goals

- How did we get to the health inequities that currently exist? - a snapshot of history and geopolitics.
- What are Indigenous determinants of health?
- What are the ethical principles of engagement with Indigenous people and communities?
- How can engaged, ethical research move us forward to achieving wellness?

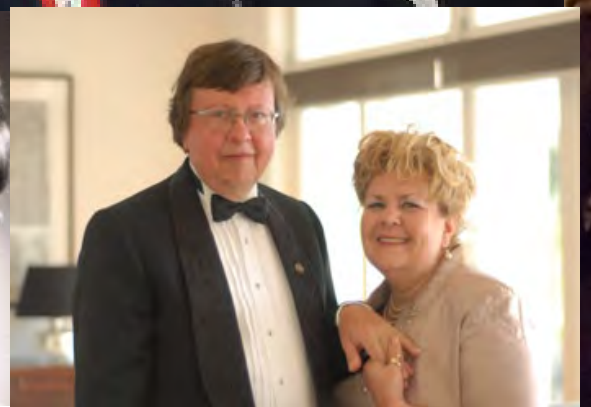


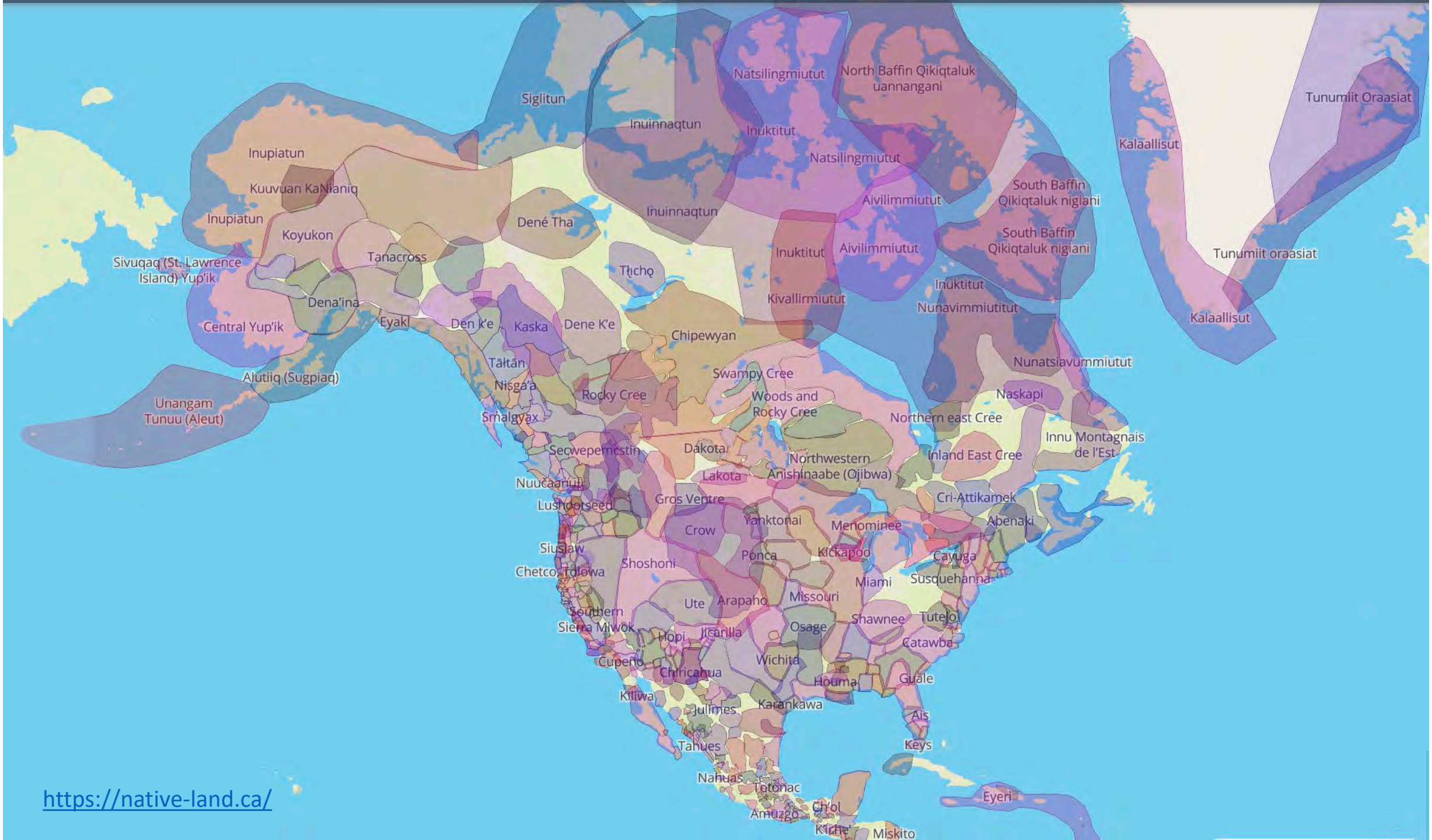




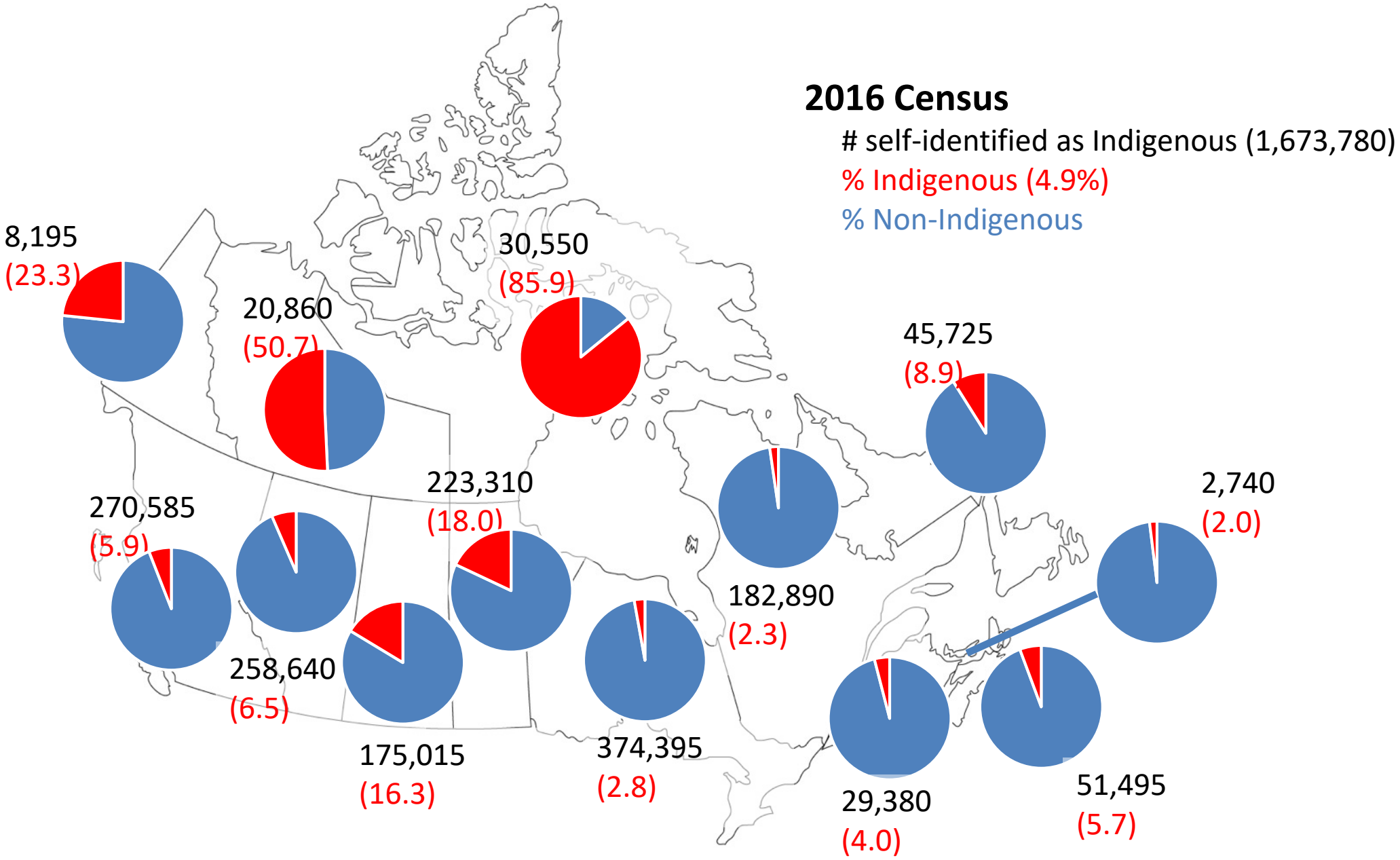






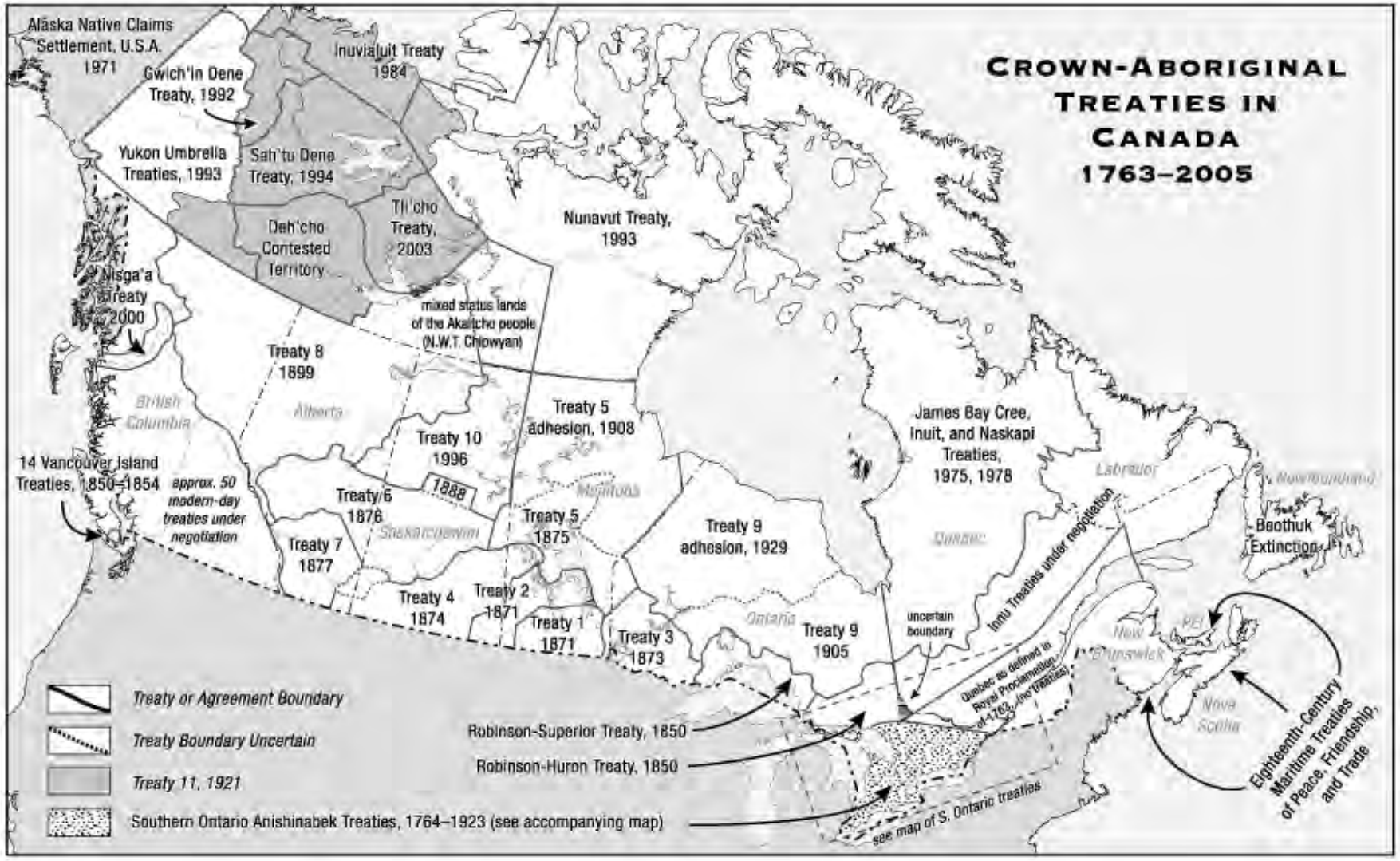
https://native-land.ca/


2016 Census
self-identified as Indigenous (1,673,780)
% Indigenous (4.9%)
% Non-Indigenous
8,195
(23.3)
20,860
(50.7)
30,550
(85.9)
45,725
(8.9)
2,740
(2.0)
270,585
(5.9)
223,310
(18.0)
182,890
(2.3)
258,640
(6.5)
175,015
(16.3)
374,395
(2.8)
29,380
(4.0)
51,495
(5.7)

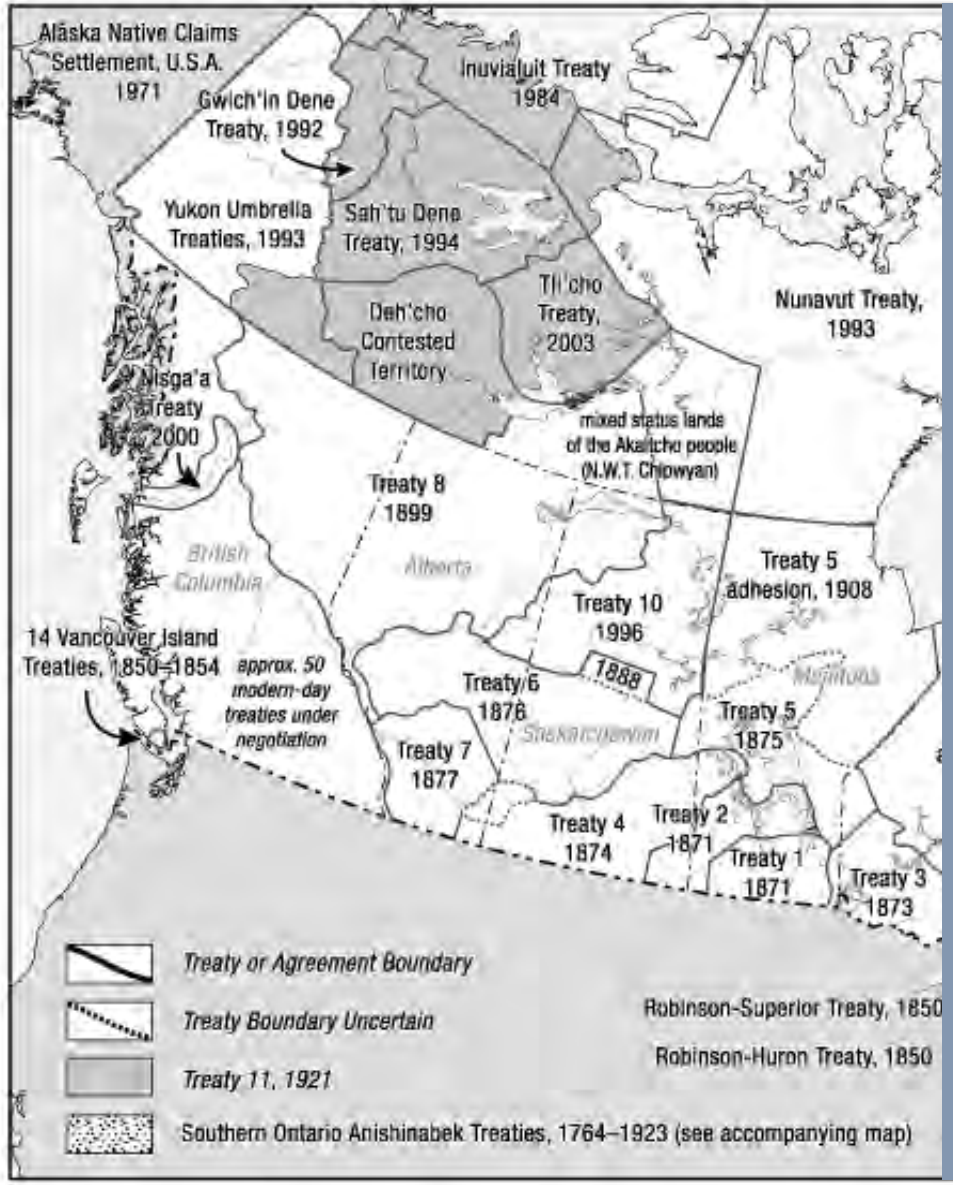
A Brief History of Canada:

What you need to know to understand Indigenous health

Pre-and post-confederation treaties



Pre-confederation treaties



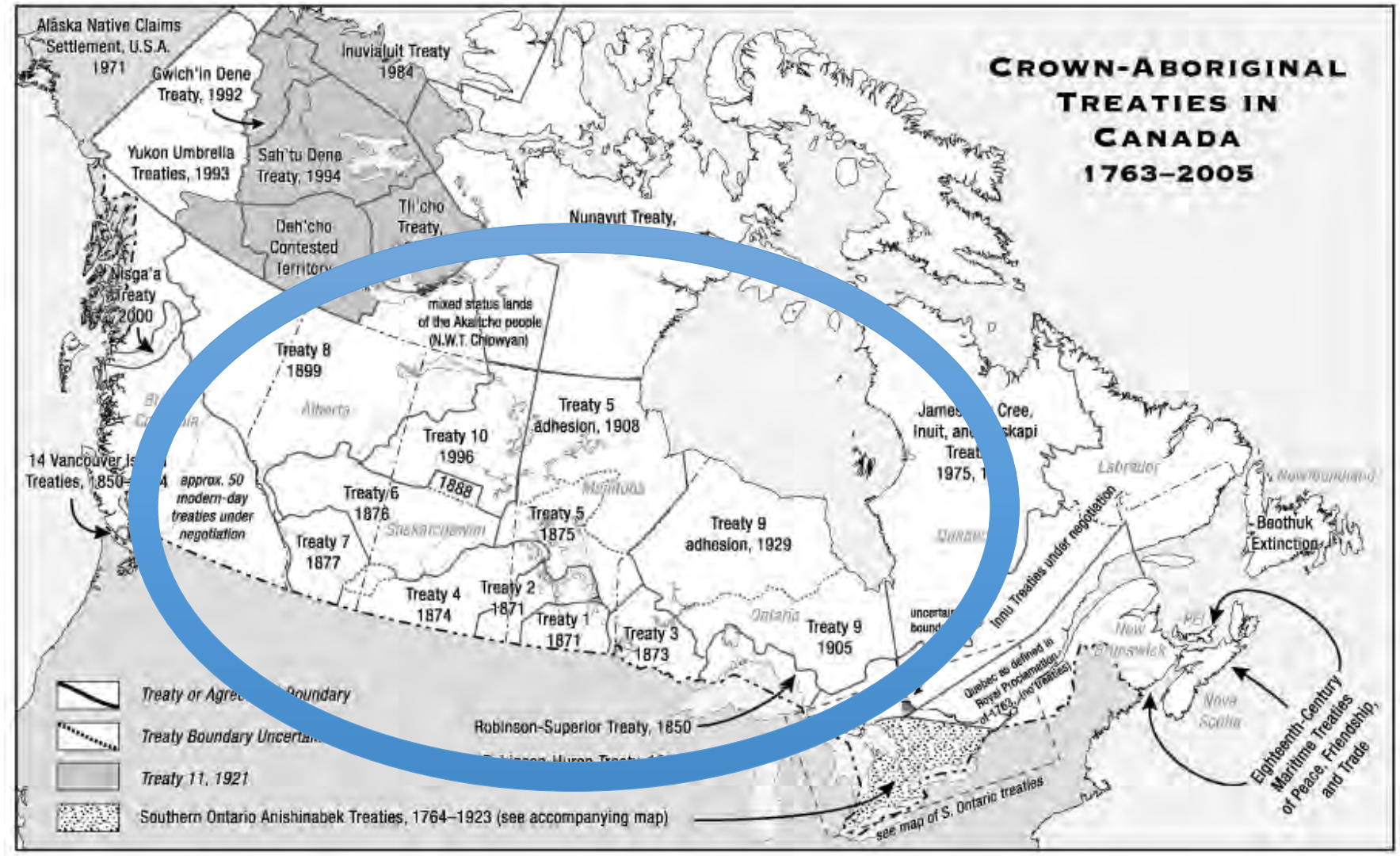
Venables, R.W. *The 1613 treaty.*

Haudenosaunee People

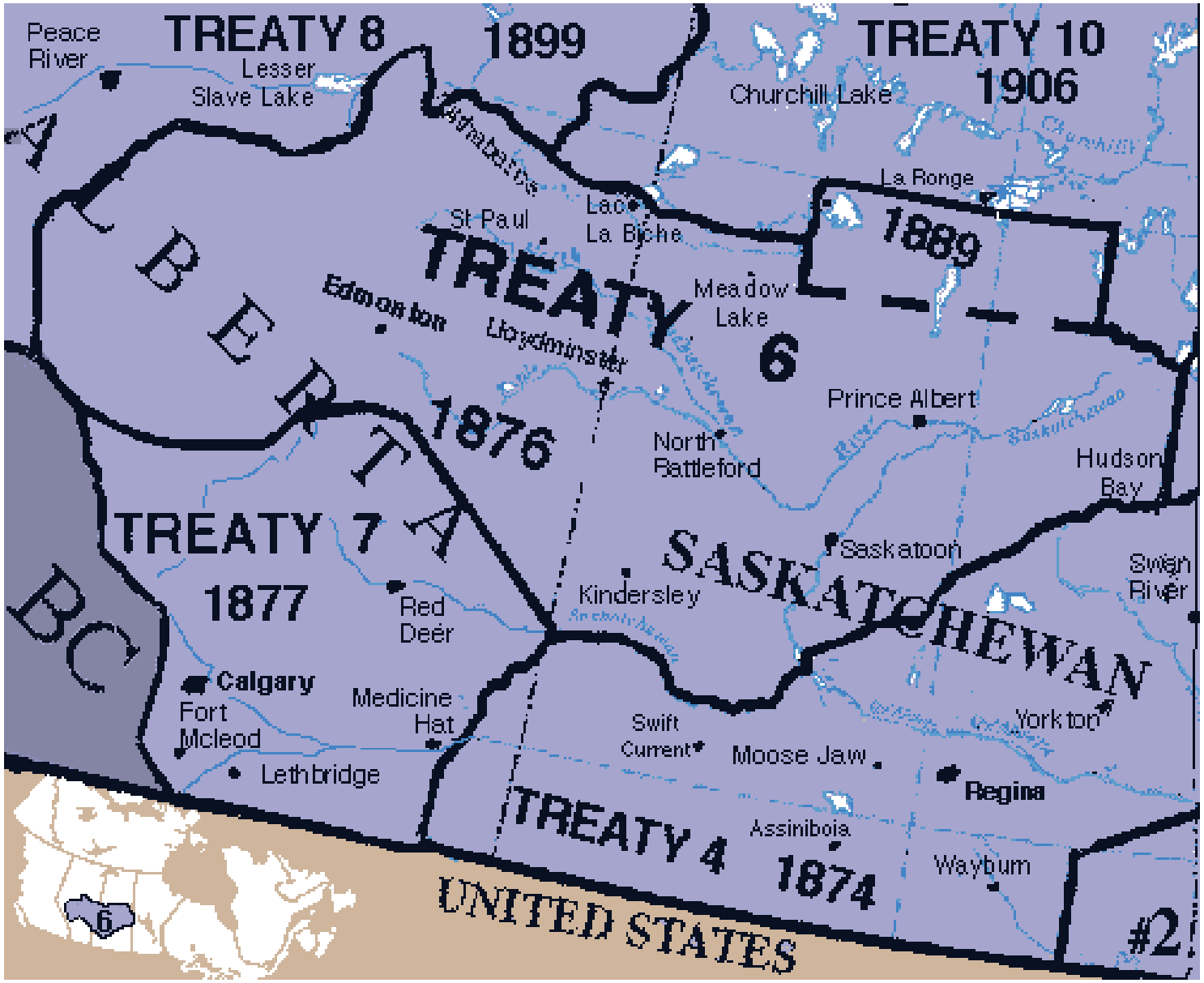
- ***Guswenta*** - Two Row Wampum belt:
  - Made of white and purple trade beads.
  - One purple row = a sailboat, representing the Europeans.
  - Other purple row = a canoe, representing the Native Americans.
  - 3 rows of white beads:
    - 1st row = peace.
    - 2nd row = friendship.
    - 3rd row = forever.

"We shall travel down the road of life, parallel to each other and never merging with each other."

The Numbered Treaties



Map of Treaty 6 (1876)



Treaty 6 included a *Medicine Chest* clause.

At the time the Treaty was made, all Medicine chests contained the contemporary medicines of the period, as well as all the instruments used to compound, measure and dispense the drugs.

The Treaty Commissioner representing the Crown committed the following: "What you have will remain intact and what we have to offer you is on top of what you already have."

The First Nations had medicine bags ("mewut") that contained medicine for the traditional health and health care system and the medicine chest is understood to provide for the contemporary health coverage and benefits.

https://www.fsin.ca/treaty-right-to-health/

Indian Act (1876)

- Defines who is and who is not recognized as a “Status Indian”
- Outlines rules for governing Indian Reserves
- Indians considered minors in law
- Indians need permission to leave reserve or return

Previous policies enacted under the Indian Act:

- Gender discrimination
- Residential school system
- Bans on religious ceremonies
- Restrictions on education, access to counsel
- “Informed” consent purvue of Indian Agent

Canada's Residential Schools (1876-1996)

The Truth and Reconciliation Commission of Canada. Accessed at www.trc.ca.

First Nations Children in Care (1960s to present)

- Starting in the 1960s, under funding transfer agreements, First Nations children were increasingly placed in foster care under provincial jurisdiction.
- Most children were taken from their home communities, and raised away from their cultures, their languages and their extended families.
- This is known as the *60s scoop*; many never re-connected.
- The traumas of disconnection bear many similarities to those of the residential schools.

Royal Commission on Aboriginal Peoples, 1996 [3].

The Royal Commission on Aboriginal Peoples (1996)

RCAP's third volume, *Gathering Strength*, probes social conditions among Aboriginal people. The picture it presents is unacceptable. Aboriginal people's living standards have improved in the past 50 years, but they do not come close to those of non-

Aboriginal people:

- Life expectancy is lower. Illness is more common. Human problems, from family violence to alcohol abuse, are more common too.
- Fewer children graduate from high school. Far fewer go on to colleges and universities.
- The homes of Aboriginal people are more often flimsy, leaky and overcrowded. Water and sanitation systems in Aboriginal communities are more often inadequate.
- Fewer Aboriginal people have jobs. More spend time in jails and prisons.

The Royal Commission on Aboriginal Peoples (cont'd)

Aboriginal people do not want pity or handouts. They want recognition that these problems are largely the result of loss of their lands and resources, destruction of their economies and social institutions, and denial of their nationhood.

They seek a range of remedies for these injustices, but most of all, **they seek control of their lives**.

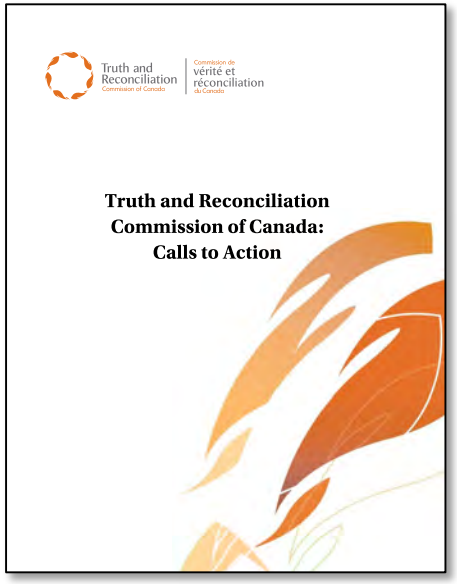
http://www.aadnc-aandc.gc.ca/eng/1100100014597/1100100014637
see also King, Smith & Gracey, Lancet 2009.

Footnote: RCAP "celebrated" the 20th anniversary of the release of their report in November 2016. The description of the disparities has barely changed in 20 years. Almost none of the recommendations were addressed or implemented. The gaps remain.

Truth and Reconciliation Commission - Dec'15

94 <u>Calls to Action</u>:

- Child welfare
- Education
- Language and culture
- ***Health (18-24)***
- Justice
- ***Reconciliation (43-94)***



Reconciliation Considerations - Health

C2A 18:

- Acknowledge that current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools.

C2A 19:

- Set measurable targets and work collaboratively to achieve them, with clear reporting. *This should be an ethical obligation!*

C2A 22:

- Recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders.

Reconciliation Considerations - Health

C2A 23:

i. Increase the number of Aboriginal professionals working in the health-care field.

ii. Ensure the retention of Aboriginal healthcare providers in Aboriginal communities.

iii. Provide cultural competency training for all healthcare professionals.

C2A 24:

- Require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the *United Nations Declaration on the Rights of Indigenous Peoples*, Treaties and Aboriginal rights, and Indigenous teachings and practices.

Indigenous Determinants of Health

Indigenous Worldviews

- *Critical bond to land, nature*
- *Territory and natural environment reflected in our knowledge systems, social arrangements*
- *Part of and interconnected with our landscape*
- *Knowledge is experiential, observational, wholistic, ecological, systems-based*
- *Extensive kinship, including the spirit realm*
- *Time is cyclical and synchronical*

Indigenous health part 2: the underlying causes of the health gap

Malcolm King, Alexandra Smith, Michael Gracey

Lancet 2009; 374: 76–85

See **Editorial** page 2

See **Perspectives** page 19

See **Review** page 65

Department of Medicine, University of Alberta, Edmonton, AB, Canada (Prof M King PhD)**; University of Toronto, Toronto, ON, Canada** (A Smith MD)**; and Unity of First People of Australia, Perth, WA, Australia** (Prof M Gracey MD)

Correspondence to:
Prof Malcolm King, Department of Medicine, University of Alberta, Edmonton, AB, T6G 2S2, Canada
malcolm.king@ualberta.ca

In this Review we delve into the underlying causes of health disparities between Indigenous and non-Indigenous people and provide an Indigenous perspective to understanding these inequalities. We are able to present only a snapshot of the many research publications about Indigenous health. Our aim is to provide clinicians with a framework to better understand such matters. Applying this lens, placed in context for each patient, will promote more culturally appropriate ways to interact with, to assess, and to treat Indigenous peoples. The topics covered include Indigenous notions of health and identity; mental health and addictions; urbanisation and environmental stresses; whole health and healing; and reconciliation.

Introduction

In the companion piece[1] Gracey and King explored some of the present trends in Indigenous health. In this second review we will consider more closely the underlying causes of Indigenous health disparities. Our major thrust is Indigenous perspectives on the causes of the poor health of Indigenous peoples, which are not the usual causes of health disadvantage—as brought out, for example, in the 1986 Ottawa Charter[2] and the work of the WHO Commission on Social Determinants of Health.[3] We focus to a considerable degree on the Indigenous people of North America, although we draw on the experiences of New Zealand and Australia as well. Within that context, much of our material is drawn from our Canadian perspective.

The idea of the analytical framework of this Review is that enabling the reader to arrive at an understanding of the interplay of the processes affecting Indigenous health factors related to colonisation, globalisation, migration, loss of language and culture, and disconnection from the land, lead to the health inequalities of Indigenous peoples. The specifics will vary across cultures, dependent on a range of external factors, but the principles are the same. Indigenous health inequalities arise from general socioeconomic factors in combination with culturally and historically specific factors particular to the peoples affected.

This analytical framework aligns with the key themes identified in the Symposium on the Social Determinants of Indigenous Health held in Adelaide in April, 2007.[4] The colonisation of Indigenous peoples was seen as a fundamental health determinant. Mowbray, writing in the report[4] said: "This process continues to impact health and well being and must be remedied if the health disadvantages of Indigenous Peoples are to be overcome. One requirement for reversing colonisation is self determination…to help restore to Indigenous Peoples

Lancet article – critical messages

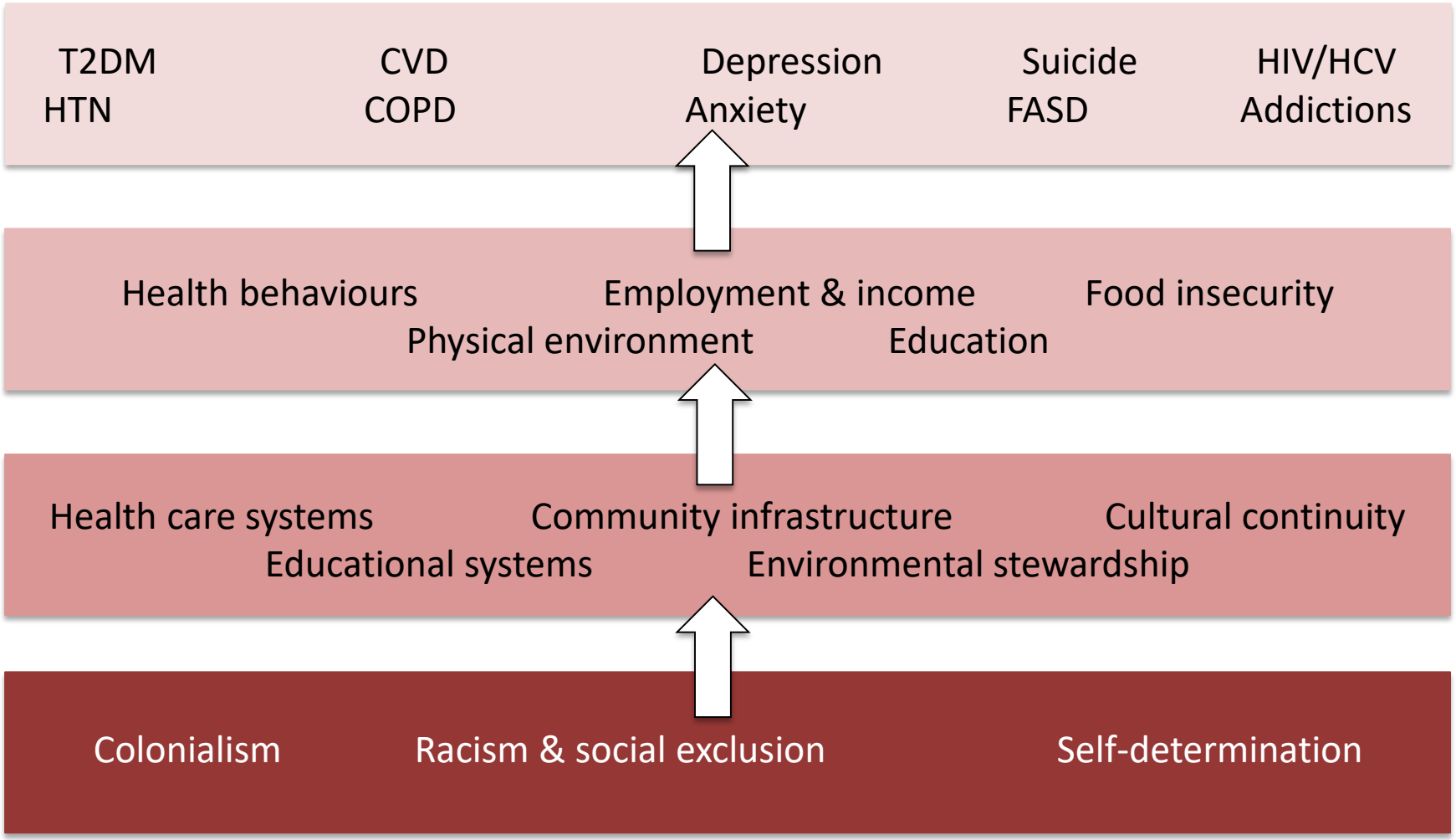
- Self-determination (individual, family, community, nation)
- Connections with land, culture, language
  - Lost through colonization, residential schools, foster care
  - Regained through resilient action and reconciliation
- Indigeneity as a health determinant

Indigenous Determinants of Health

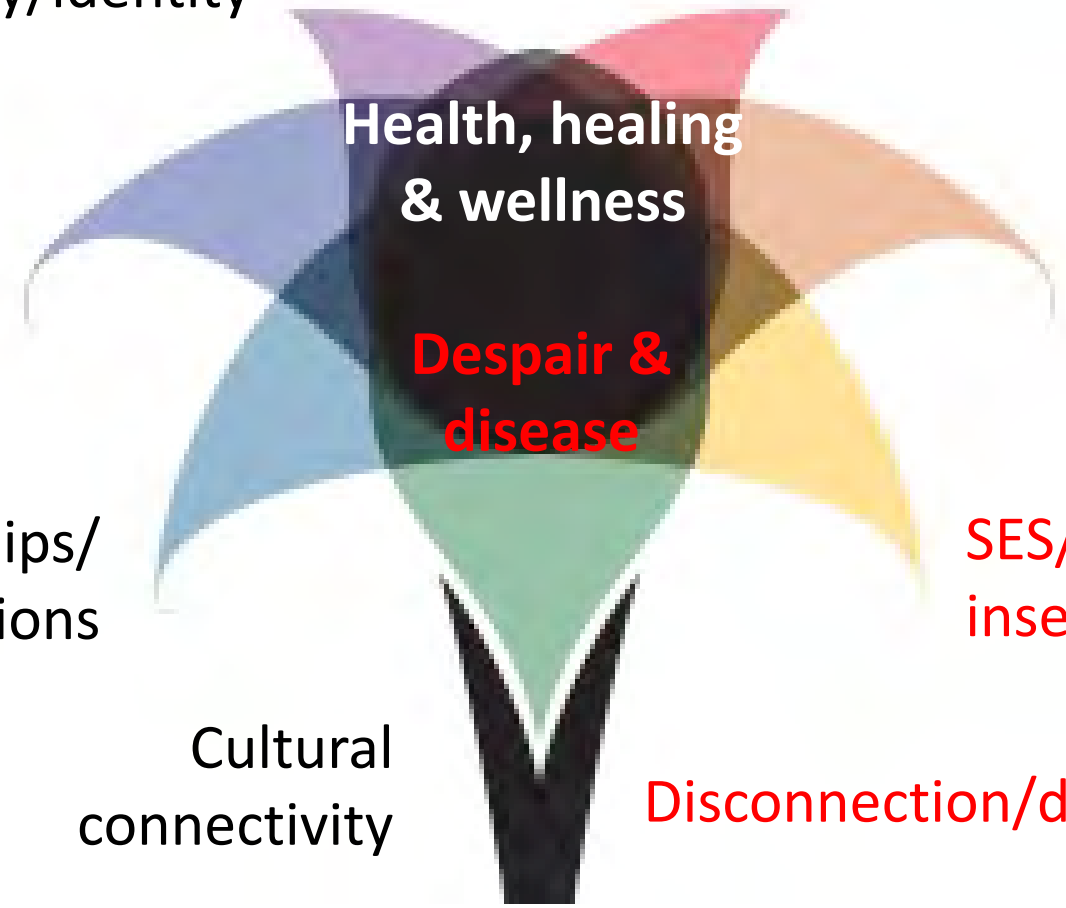
- Conventional DoH:
  - Income
  - Social status / differential
  - Poverty
  - Education
  - Employment
  - Social support networks
  - Genetics
- Indigenous DoH:
  - Indigenous-specific:
    - Colonization
    - Connectivity to land / country
    - Self-determination
  - Other DoH with Indigenous-specific impact:
    - Globalization
    - Racism
    - Gender
    - Worldview

King, M. *et al.* (2009). Indigenous health part 2: the underlying causes of the health gap. *Lancet* 374: 76–85.

Layering of IDoH: Loppie / Wien



Intersectionality: Layering of resilient and stress factors



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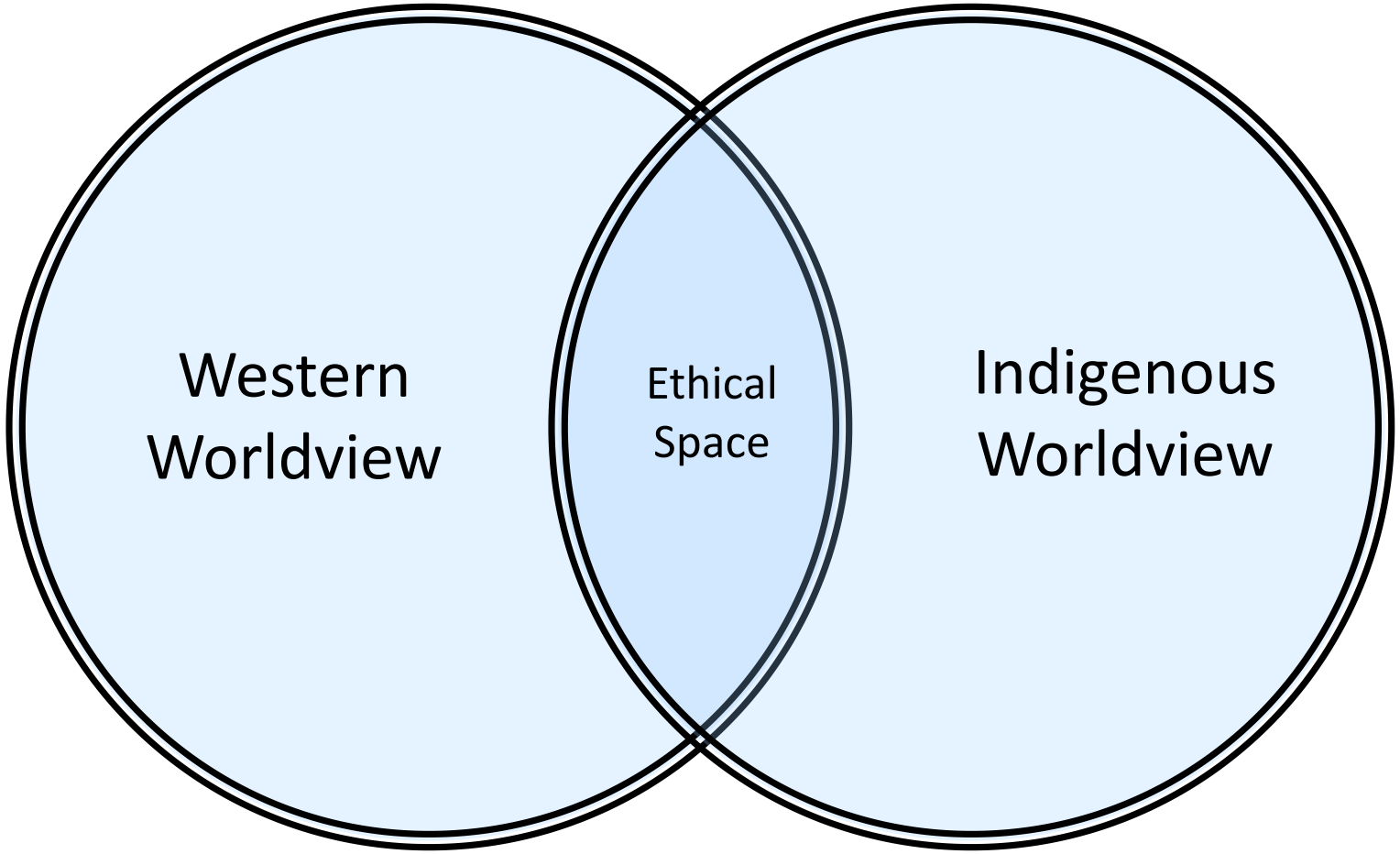
Ethical Engagement

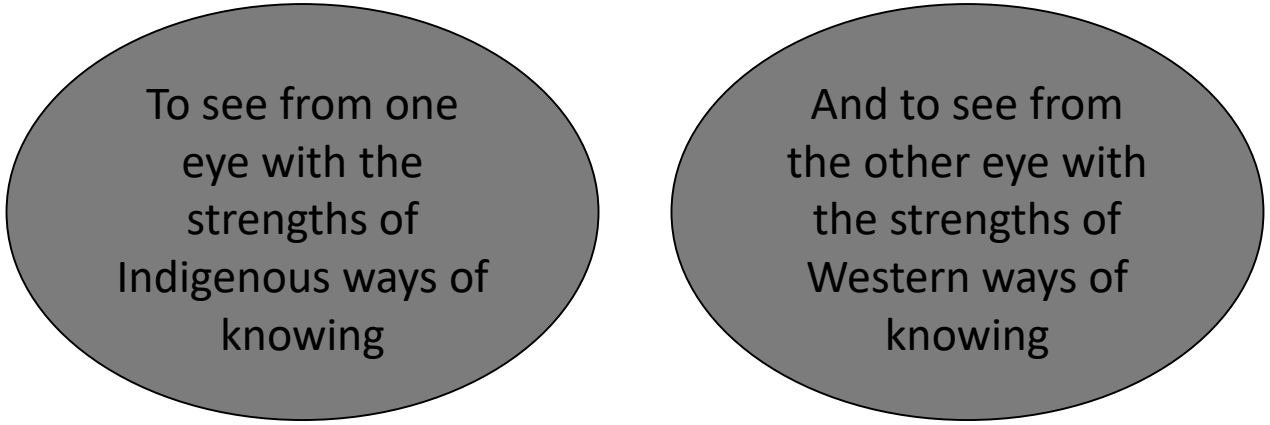
Ethical Space



Ermine W. 2004. *Ethical Space: Transforming Relations.* www.traditions.gc.ca/docs

Two-eyed Seeing: *Etuaptmumk*

The perspective of “two-eyed seeing”, as put forward by Mi’kmaq Elder Albert Marshall



and to use both of these eyes together.

Tri-Council Policy Statement 2, Chapter 9:

Research Involving the First Nations, Inuit and Métis Peoples of Canada

Key concepts / principles

- **Requirement of community engagement in Aboriginal research**
- Respect for First Nations, Inuit and Métis governing authorities
- Recognizing diverse interests within communities
- Respect for community customs and codes of practice
- Institutional research ethics review required
- Research agreements desirable, encouraged

TCPS2, Ch9: *cont'd*

- **Collaborative research – communities as partners**
- **Mutual benefits in research**
- Strengthening research capacity
- Recognition of the role of Elders and other Knowledge Holders
- Privacy and confidentiality
- Interpretation and dissemination of research results
- Intellectual property related to research
- *Collection of human biological materials involving Indigenous peoples*

Other resources

- CIHR Guidelines for Health Research Involving Aboriginal People (2007-2010): https://cihr-irsc.gc.ca/e/29134.html

- A Principled Approach to Research Conducted with Inuit, Métis, and First Nations People: Promoting Engagement Inspired by the CIHR Guidelines for Health Research Involving Aboriginal People (2007-2010): https://ojs.lib.uwo.ca/index.php/iipj/article/view/10635

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- https://www.queensu.ca/indigenous/decolonizing-and-indigenizing/indigenous-research/indigenous-community-research-partnerships

Moving Forward

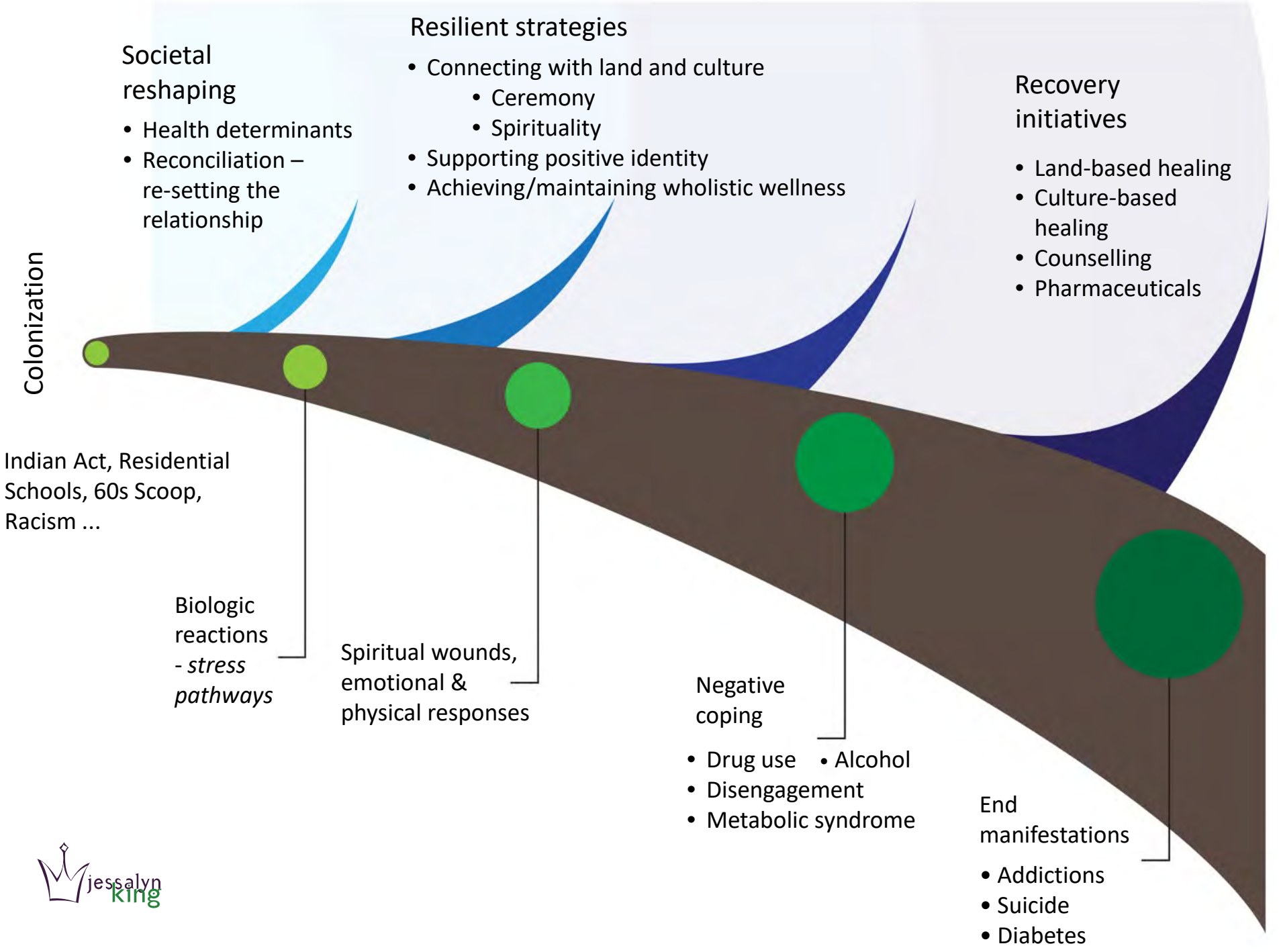
Decolonization

- Must address the “hegemonic basis of society’s values, practices, and institutions”:
  - Oppression
  - Colonialism/colonization
  - Racism
  - Privilege/Whiteness
- Ubiquitous across the institution and include all relevant systems, structures, policies and practices
- Must transcend health disciplines, institutions

Jones R, Crowshoe L, Reid P, Calam B, Curtis E, Green M, Huria T, Jacklin K, Kamaka M, Lacey C, Milroy J, Paul D, Pitama S, Walker L, Webb G, Ewen S. *Educating for Indigenous health equity: An international consensus statement.* Academic Medicine 2018.

Indigenous research methodologies

- Emerging, evolving, growing
- Creating ethical spaces where Indigenous Ways of Knowing/Doing coexist with Western Ways of Knowing/Doing
- Encompassing Indigenous worldviews, health systems and knowledge systems
- Need explicit recognition of Indigenous epistemologies and knowledges and explicit commitment to embracing Indigenous Ways of Doing
- Indigenous leadership essential


Societal reshaping
• Health determinants
• Reconciliation – re-setting the relationship
Resilient strategies
• Connecting with land and culture
• Ceremony
• Spirituality
• Supporting positive identity
• Achieving/maintaining wholistic wellness
Recovery initiatives
• Land-based healing
• Culture-based healing
• Counselling
• Pharmaceuticals
Colonization
Indian Act, Residential Schools, 60s Scoop, Racism ...
Biologic reactions - *stress pathways*
Spiritual wounds, emotional & physical responses
Negative coping
• Drug use • Alcohol
• Disengagement
• Metabolic syndrome
End manifestations
• Addictions
• Suicide
• Diabetes
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