An aging population and clinical, ethical and legal challenges to end of life choices, including Medical Assistance in Dying (MAID)
March 13, 2023

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Faculty/Presenter Disclosure

- **Faculty:** Lilian Thorpe

- **Relationships with financial sponsors:**
  - **Grants/Research Support: Nil**
  - **Speakers Bureau/Honoraria:** Canadian Association of MAID Assessors and Providers (CAMAP) for involvement in developing training guidelines for assessors and providers
  - **Consulting Fees:** Health Canada
  - **Patents**: Nil
  - **Other: Nil**

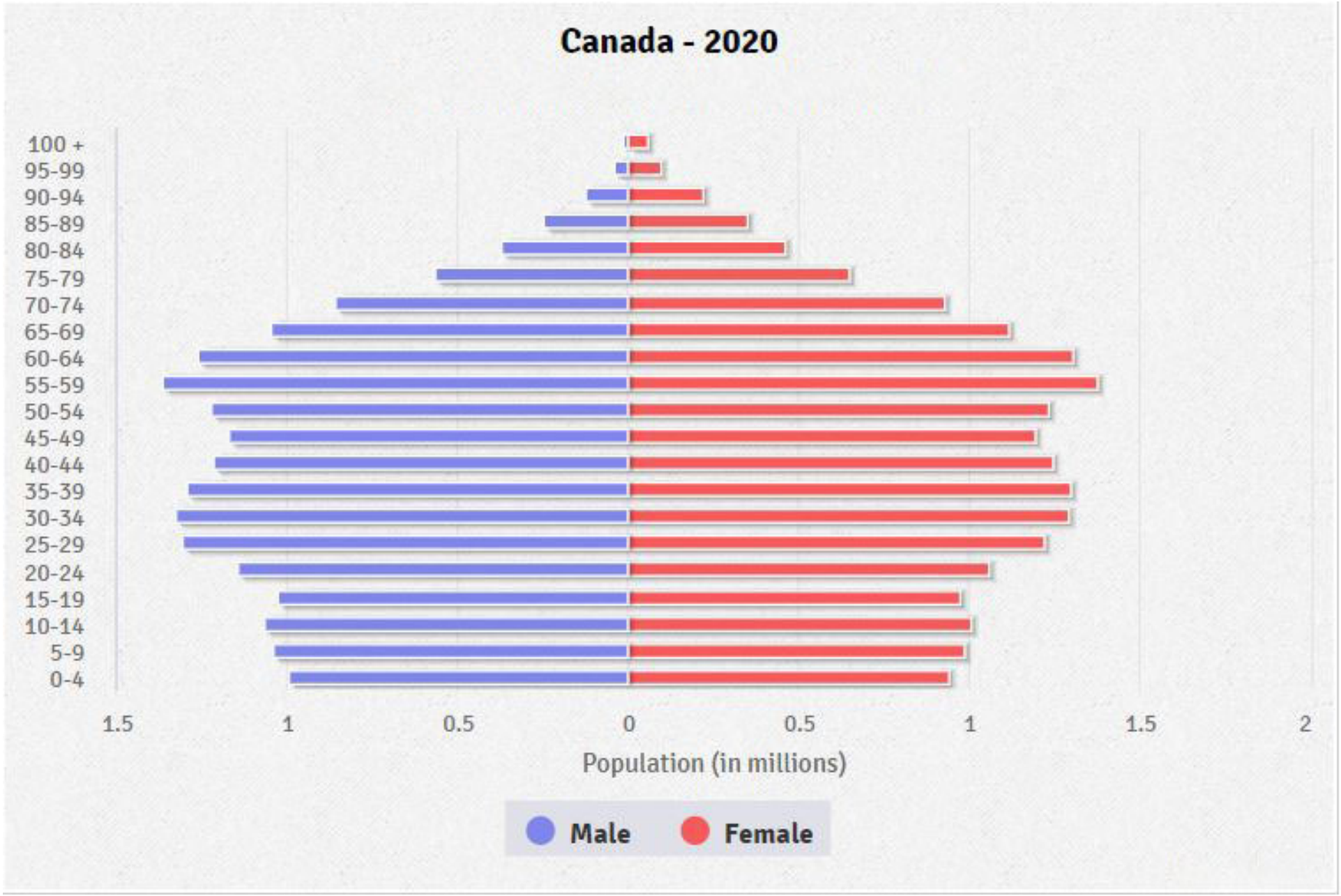
Biography

- Actively involved in MAID related clinical work, teaching, research graduate supervision.
- Member, Health Canada MAID Practice Standards Task Group, 2022-
- Member, Canadian Association of MAID Assessors and Providers (CAMAP) team developing national curriculum on assessing capacity and vulnerability, 2021-
- Member, CAMAP Guidelines Working Group on MAiD assessments for people with Chronic Complex Conditions 2021-
- Member and co-author, Canadian Association of MAID Assessors and Providers (CAMAP) Capacity Guidelines Working Group, April 2020
- Member, Saskatchewan Health Authority/Saskatchewan Cancer Agency Joint Ethics Committee, May 2, 2020 –
- Member of the (former) Saskatoon Health Region committee which developed the regional MAID policy, 2015-2016

Overview/Abstract

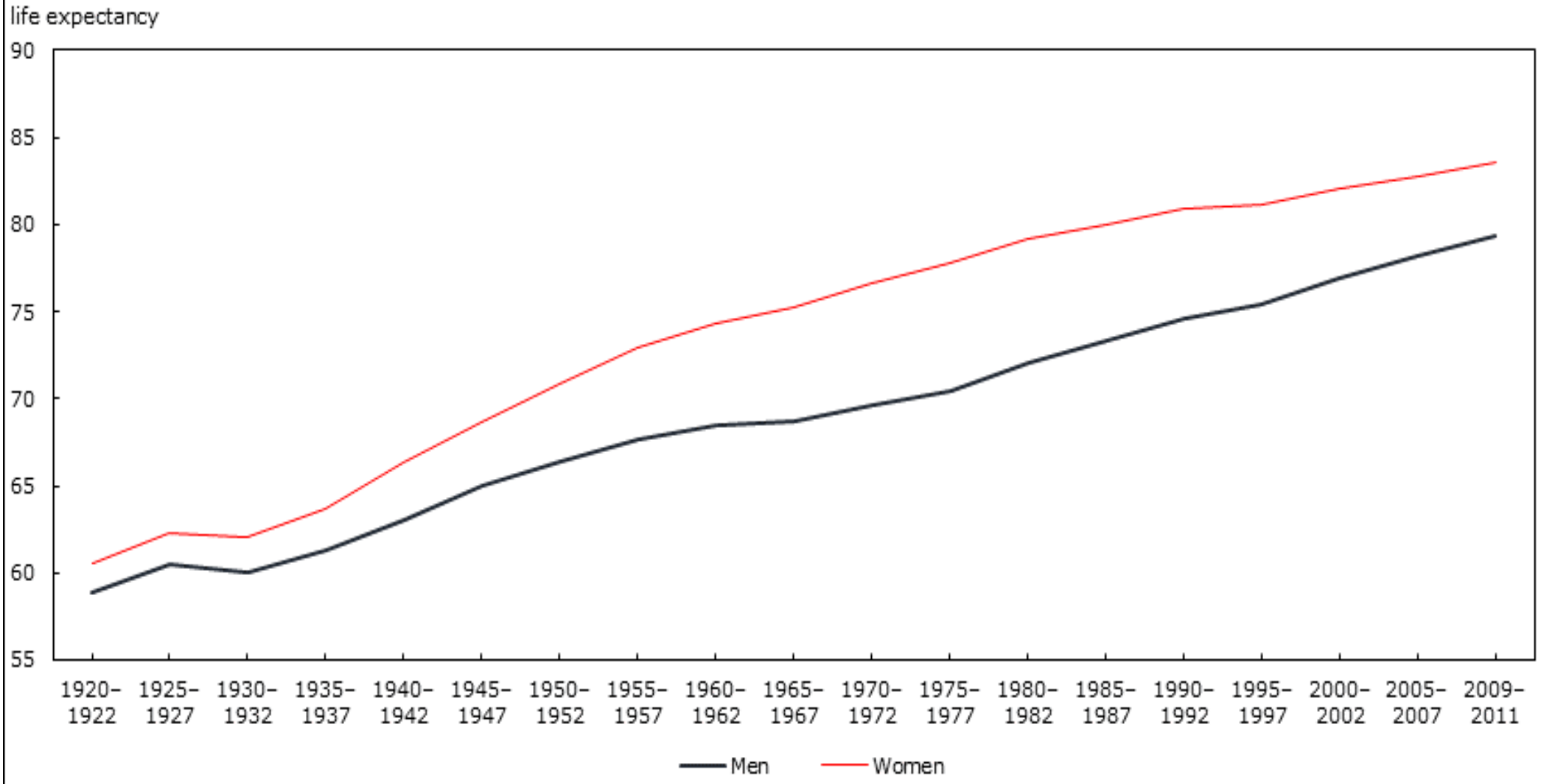
- As the population ages there has been increasing focus on the end of life, including discontinuation of interventions no longer bringing benefit, improving palliative care, and most recently allowing patients to access a medically assisted death.
- This has brought with it major clinical, legal, and ethical challenges, with highly polarized debate at many levels of society.
- This presentation from a geriatric psychiatrist will place MAID in the continuum of end of life care and explore the difficult balance between autonomy and protection of vulnerable people.

Canada's Population Pyramid



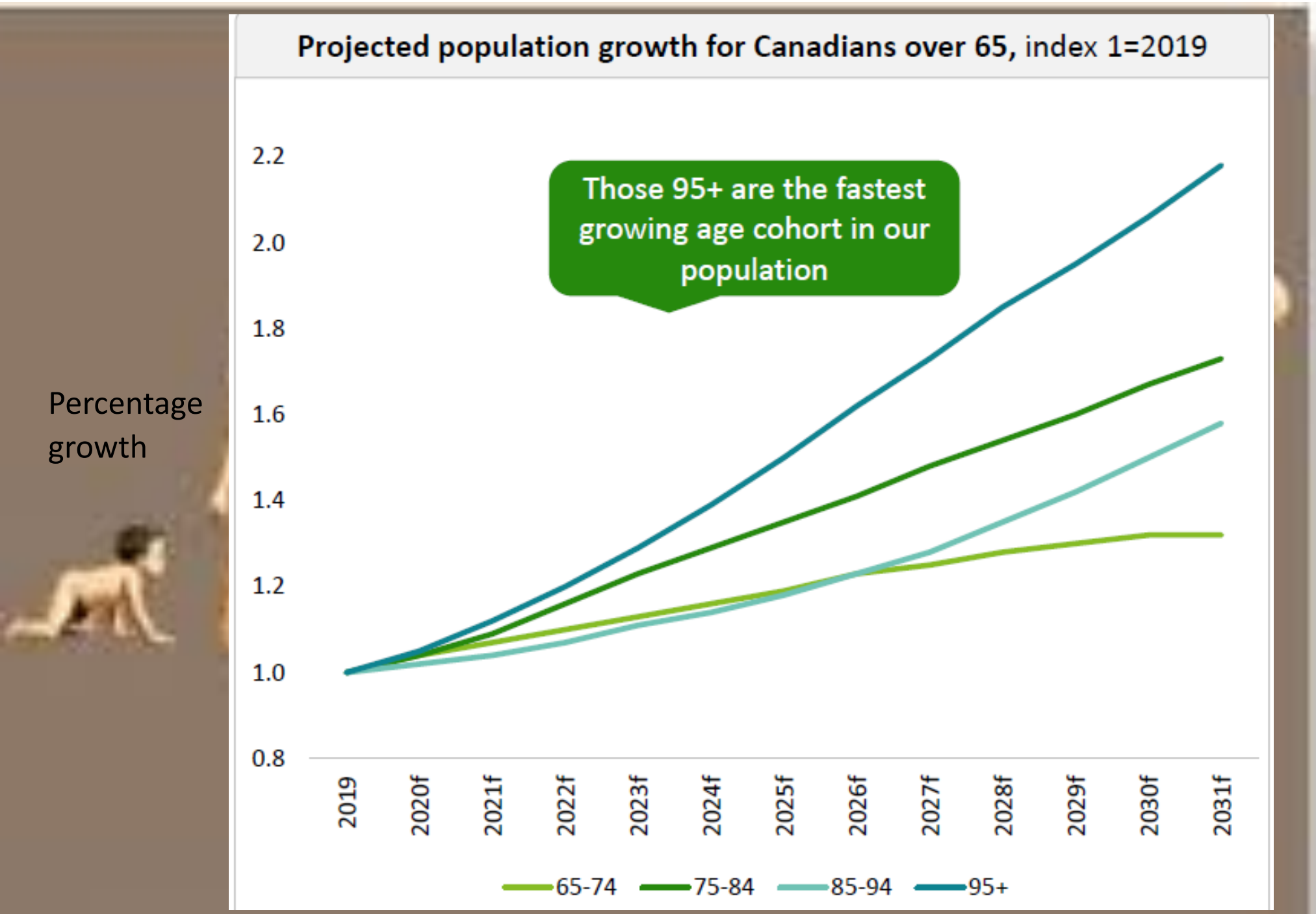
https://www.indexmundi.com/canada/age_structure.html

Chart 1
Life expectancy at birth by sex, Canada, 1920–1922 to 2009–2011



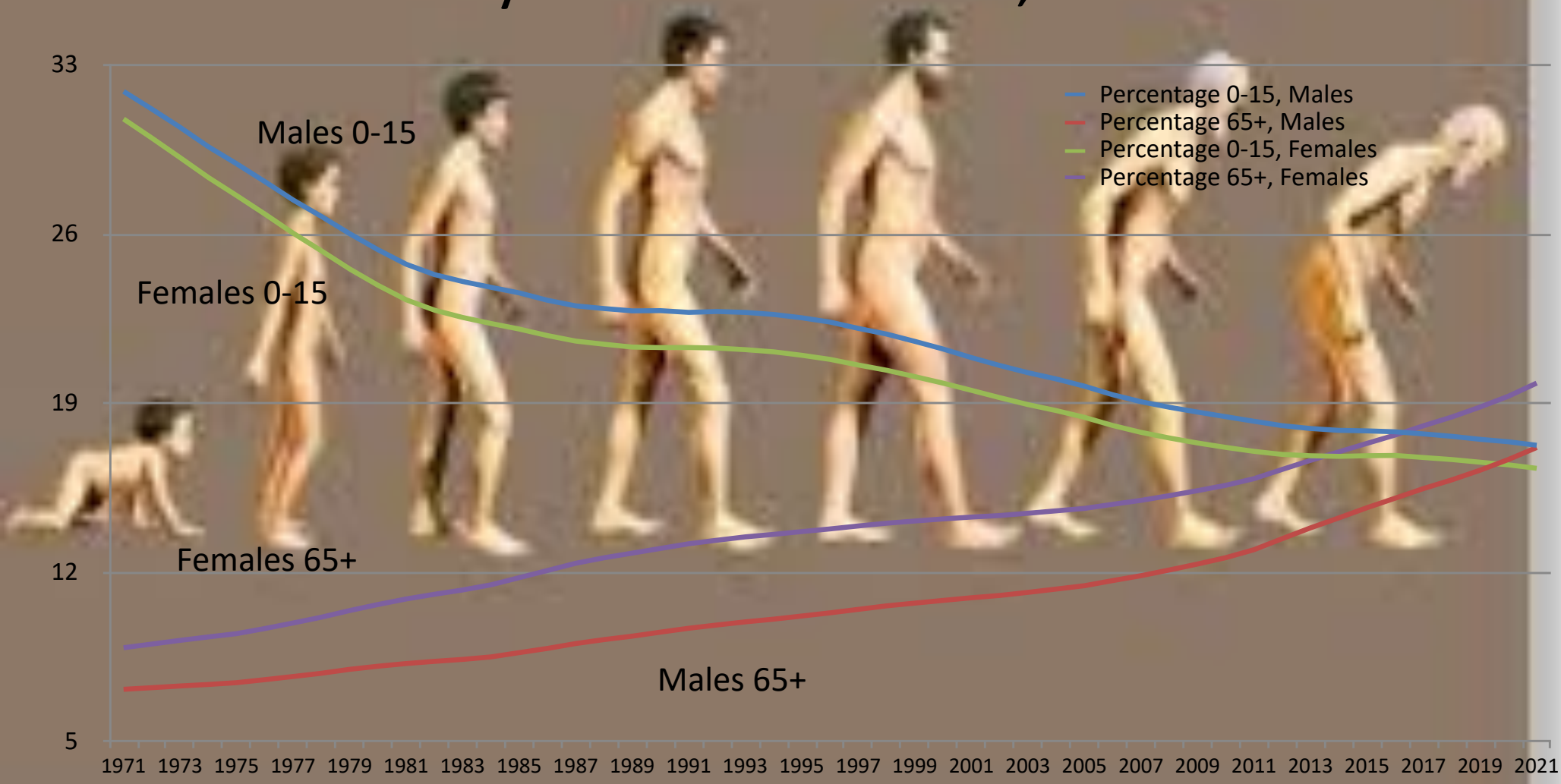
Sources: Nagunar, *Longevity and historical life tables*, 1920–1922 to 1965–1967.
Statistics Canada, *Report on the demographic situation in Canada, 2001*, 1970–1972 to 1990–1992.
Statistics Canada, *Life tables, Canada, provinces and territories*, 1995–1997 to 2009–2011.

https://www150.statcan.gc.ca/n1/pub/11-630-x/11-630-x2016002-eng.htm



Canadian Medical Association. Canada's elder care crisis: Addressing the doubling demand. March 25, 2021

Proportion of population aged less than 15 years old and 65 years old and over, 1971 to 2021



Statistics Canada. Table 17-10-0005-01 Population estimates on July 1st, by age and sex

“I'm not afraid of death; I just don't want to be there when it happens.” — **Woody Allen**

Leading causes of death, Canada, by sex, 2019

Percentage of total deaths, 2019	Males	Females
Diabetes mellitus	2.7	2.2
Alzheimer's disease	1.4	3
Diseases of heart	19.4	17.5
Cerebrovascular diseases	4.1	5.6
Influenza and pneumonia	2.2	2.6
Chronic lower respiratory diseases	4.4	4.7
Chronic liver disease and cirrhosis	1.6	0.9
Nephritis, nephrotic syndrome and ne	1.3	1.3
Accidents (unintentional injuries)	5.4	4.3
Intentional self-harm (suicide)	2.1	0.7
Assault (homicide)	0.2	0.1

Statistics Canada. Table 13-10-0394-01 Leading causes of death, total population, by age group

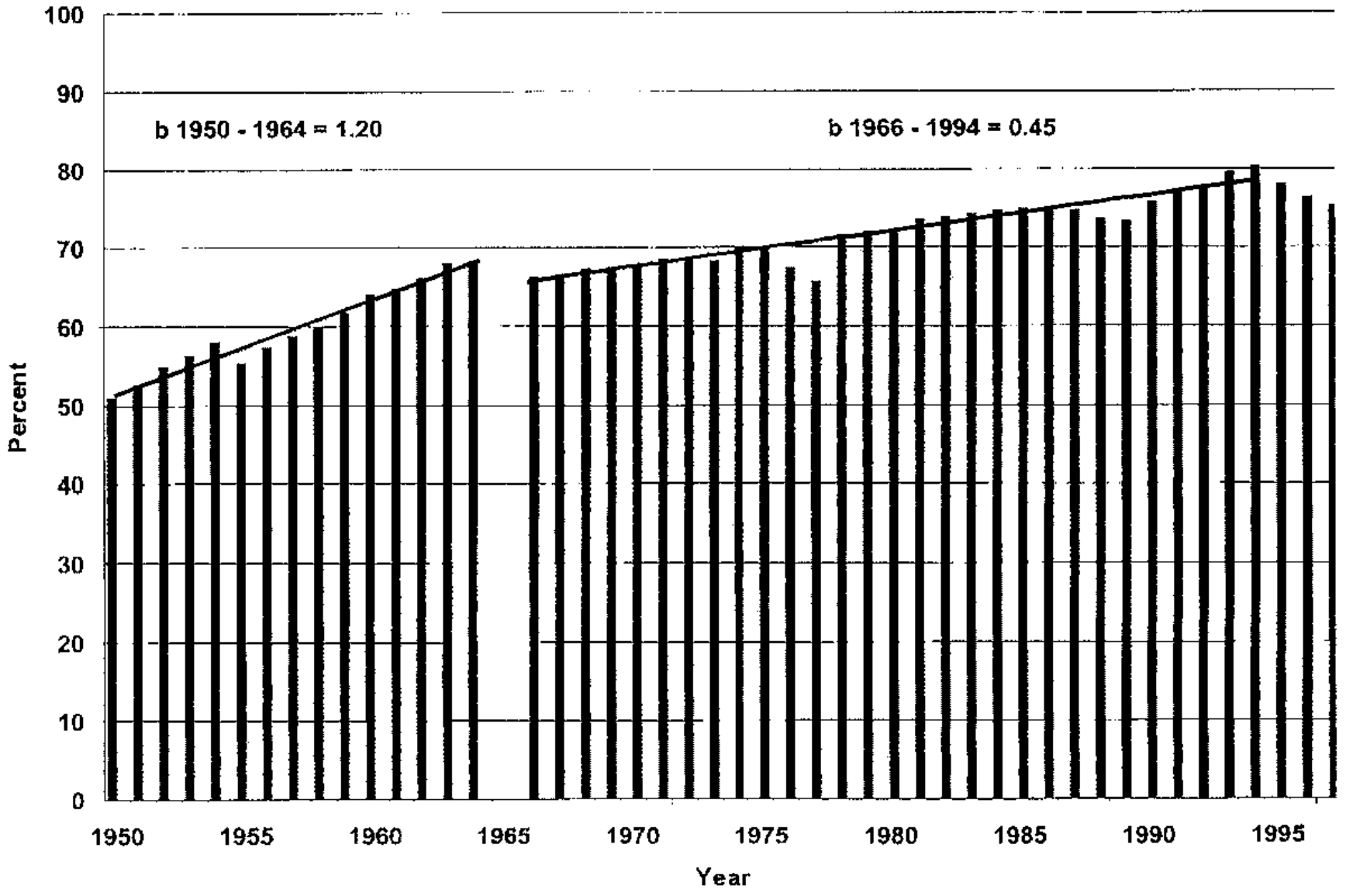
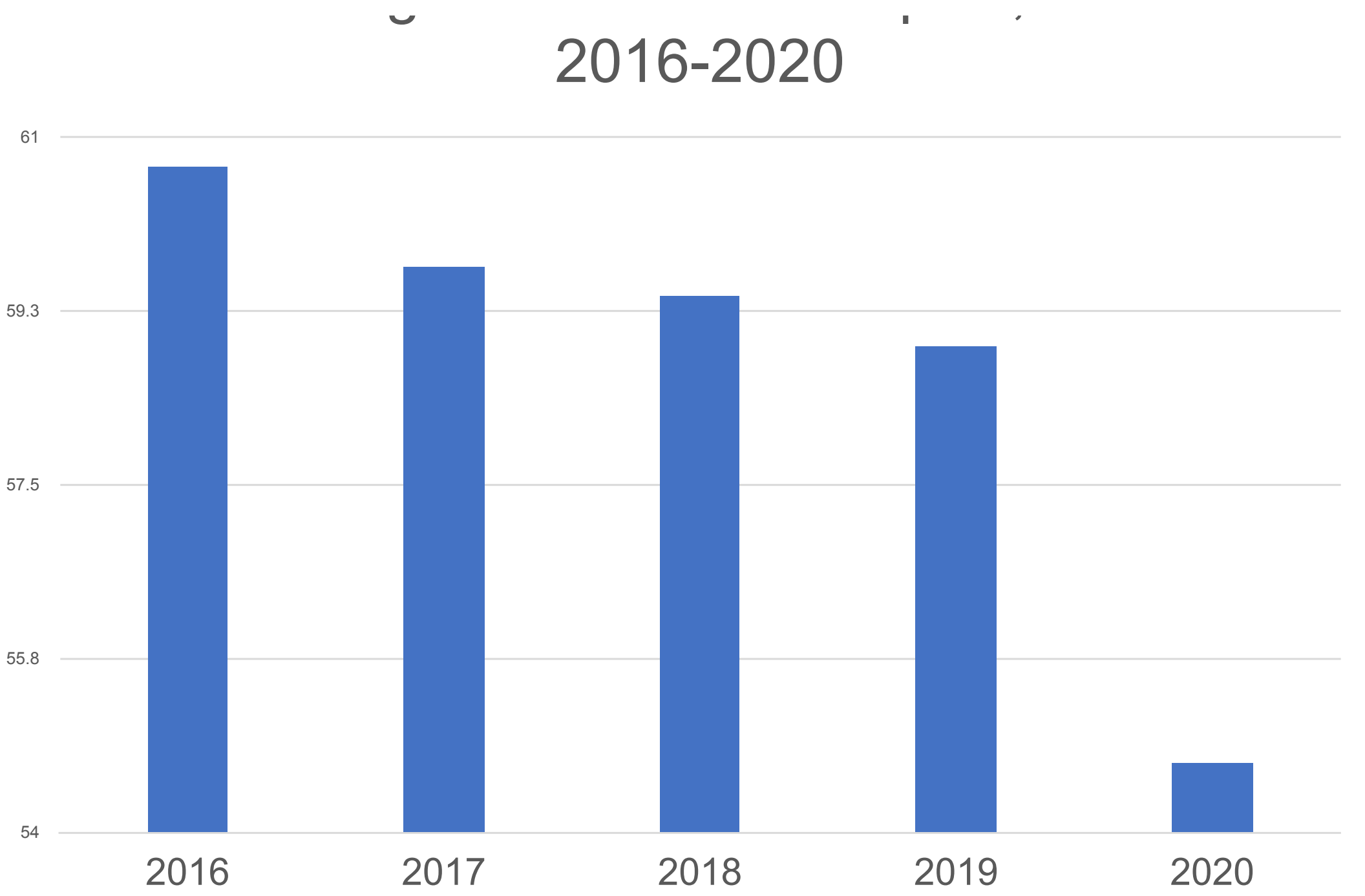
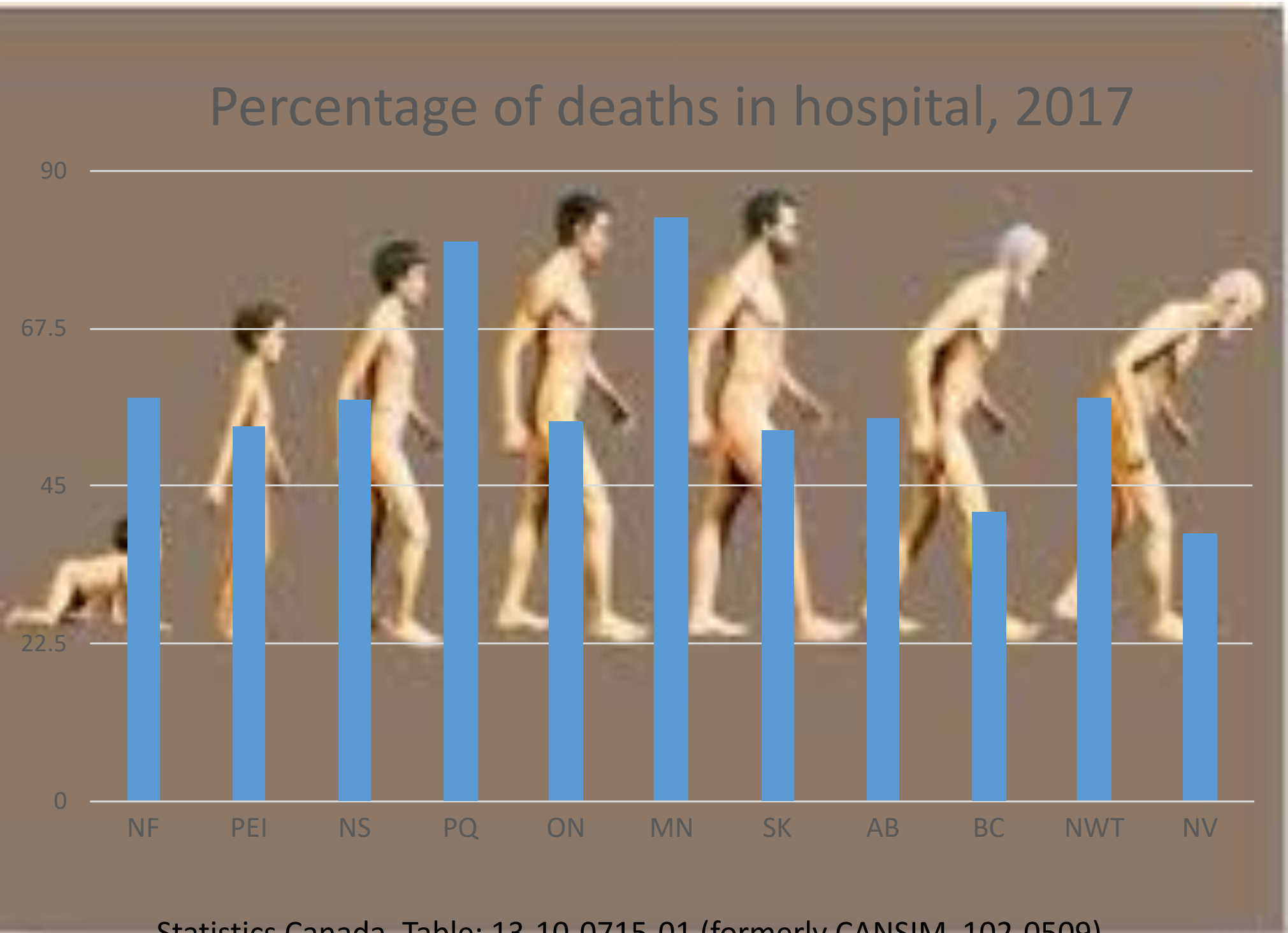


Figure 1: Hospital Deaths in Canada, 1950-1997

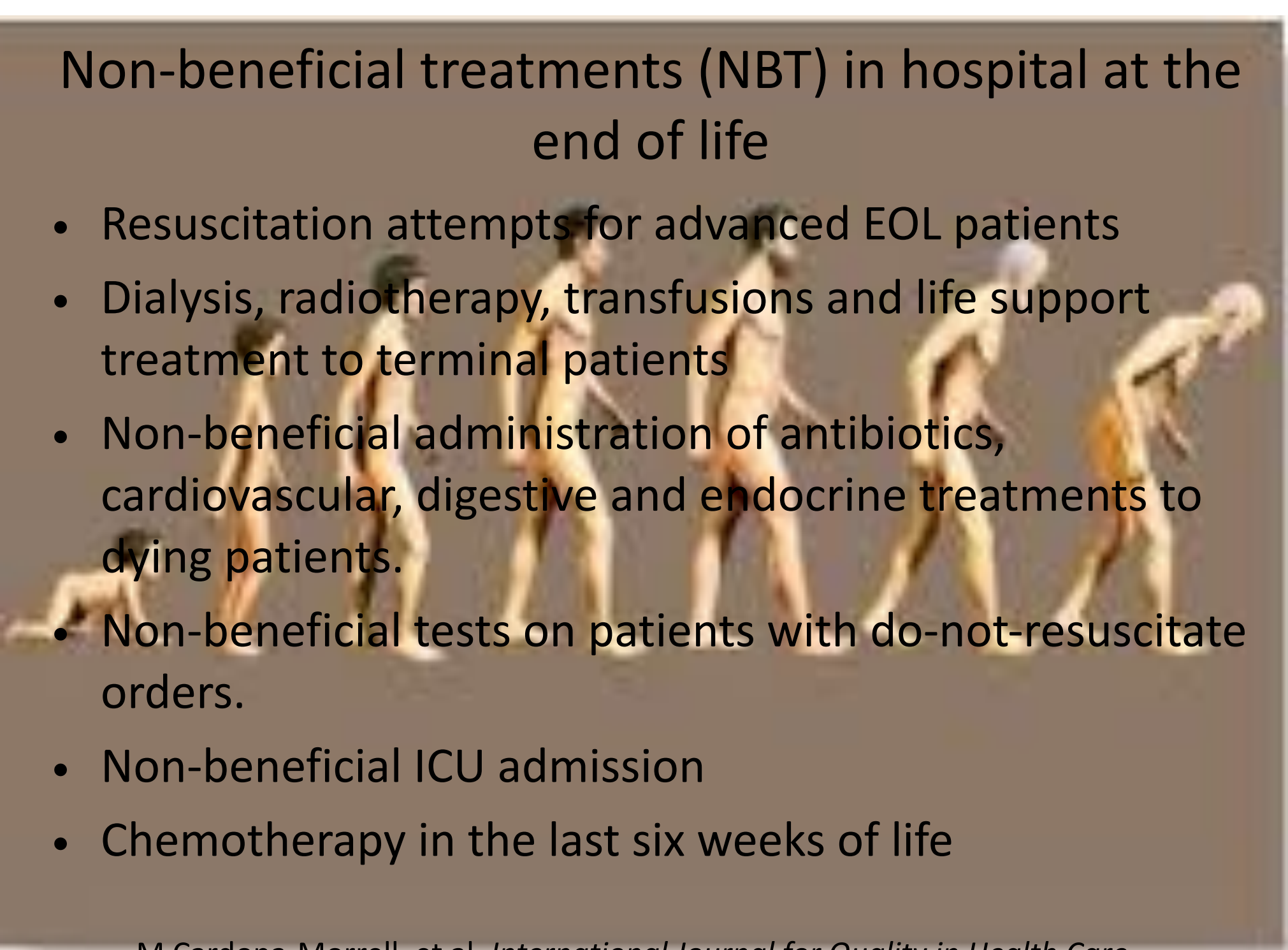


Statistics Canada. Table 13-10-0715-01 Deaths, by place of death (hospital or non-hospital)



Statistics Canada. Table: 13-10-0715-01 (formerly CANSIM 102-0509)

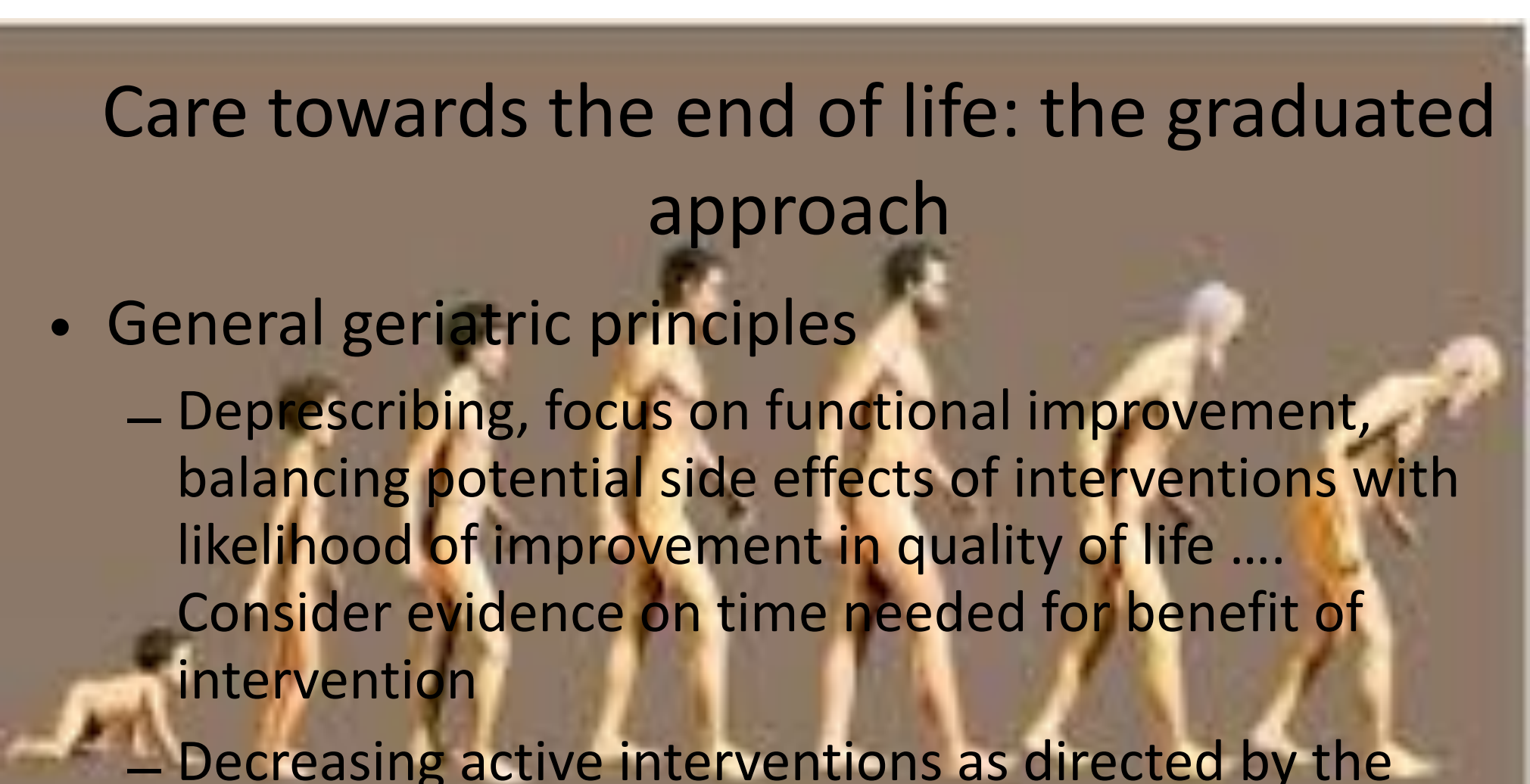
Non-beneficial treatments (NBT) in hospital at the end of life



- Resuscitation attempts for advanced EOL patients
- Dialysis, radiotherapy, transfusions and life support treatment to terminal patients
- Non-beneficial administration of antibiotics, cardiovascular, digestive and endocrine treatments to dying patients.
- Non-beneficial tests on patients with do-not-resuscitate orders.
- Non-beneficial ICU admission
- Chemotherapy in the last six weeks of life

M Cardona-Morrell, et al. *International Journal for Quality in Health Care*, Volume 28, Issue 4, September 2016, Pages 456–469,

Care towards the end of life: the graduated approach



- General geriatric principles
  - Deprescribing, focus on functional improvement, balancing potential side effects of interventions with likelihood of improvement in quality of life …. Consider evidence on time needed for benefit of intervention
  - Decreasing active interventions as directed by the patient (or substitute decision-makers) with the explicit acceptance of death approaching
- Palliative care
- Medical Assistance in Dying

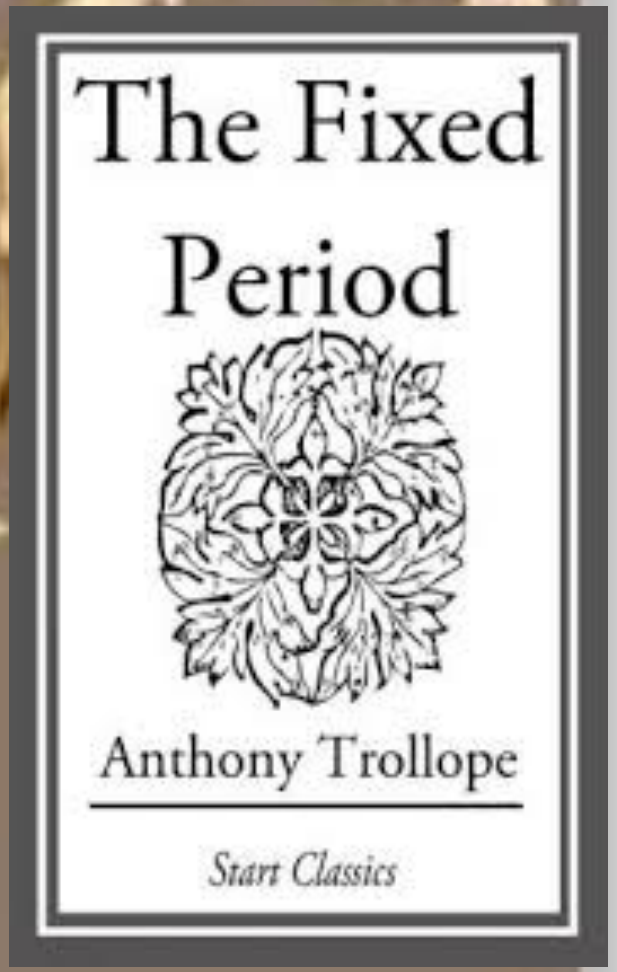
What is a good death?

- A good death is:
  - Free from avoidable distress and suffering for patient, family and caregivers
  - In general according with patient and families wishes
  - Reasonably consistent with clinical, cultural and ethical standards.

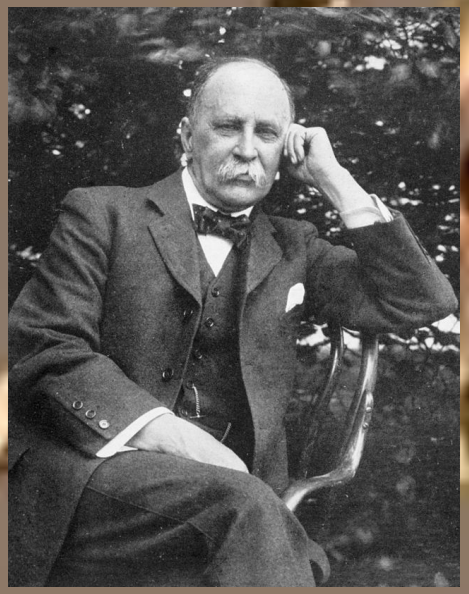
World Health Organization, 1997

Senicide in literature (The Fixed Period: Trollope, 1882)

- Citizens' lives were to be terminated at a fixed age to spare them undignified suffering and to help cut down on the state's expenditure on unproductive people.
- The age was fixed at 67, at which time a citizen's "deposition" was to take place, consisting of their removal to "The College", an institution situated in the town of Necropolis, followed by their "departure", and subsequent cremation, exactly one year later, at the age of 68

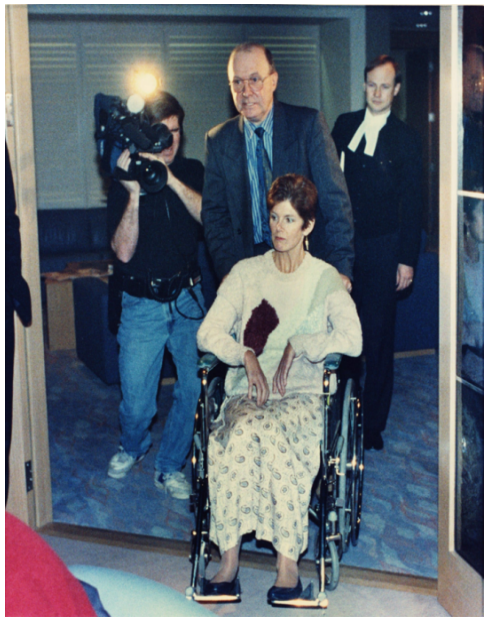


Sir William Osler



- The effective, moving, vitalizing work of the world is done between the ages of twenty-five and forty
- Take the sum of human achievement in action, in science, in art, in literature — subtract the work of the men above forty, and while we should miss great treasurers, even priceless treasures, we would practically be where we are today. . . . The effective, moving, vitalizing work of the world is done between the ages of twenty-five and forty."
- ..an institute be established to which men aged 60 years could retire for a year's quiet contemplation before a peaceful departure by chloroform

How Three Women Changed the Law



Sue Rodriguez (ALS)

August 2, 1950 – February 12, 1994

Died with the assistance of an anonymous doctor

Kay Carter 89Y with spinal stenosis Died in Switzerland 2010

Gloria Taylor (ALS) c. 1948 – October 4, 2012 Natural death

BILL C-14(June 2016)
Medical Assistance In Dying

Goal

- To balance individual autonomy over the end of life decisions involving suffering with protection of society.
- Concerns addressed about:
  - Vulnerable populations
  - The “slippery slope”

Care provider expectations

- No requirement to formally participate in MAiD
- Care providers may not abandon their patients and patients have to be allowed to seek their legal options.

https://laws-lois.justice.gc.ca/eng/annualstatutes/2016_3/fulltext.html

Eligibility Criteria (C14 and C7)

- At least **18 years old**
- **Capacity to make decisions** with respect to health
- **Eligible for publicly funded health care services** in Canada
- Make a **voluntary request** that is not the result of external pressure
- Give **informed consent** to receive MAID, meaning that the person has consented to receiving MAID after they have received all information needed to make this decision
- Has a **grievous and irremediable** medical condition:
  - serious and incurable illness, disease or disability (a mental illness cannot fulfill this criterion until March 17, 2023- *date now deferred*), and
  - advanced state of irreversible decline in capabilities, and
  - enduring physical or psychological suffering, caused by either the illness, disease or disability, or by the advanced state of decline in capabilities, that is intolerable to the person and cannot be relieved under conditions that they consider acceptable

C14 required reasonably foreseeable natural death (RFND)

- Natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining
  - *Based on Kay Carter with spinal stenosis in the initial successful court case, so likely a few years acceptable (except in Quebec)*

Origins of C-7: Truchon and Gladu v. Canada (Attorney General) and Quebec (Attorney General)

- On June 13, 2017, two plaintiffs challenged both Québec's and Canada's MAiD legislation.
- Jean Truchon and Nicole Gladu argued the laws violate their Charter rights because they are too restrictive, especially since the federal government requires that a person's natural death has become "reasonably foreseeable" and the Quebec legislation requires that a person be at the "end of life".
- Jean Truchon had cerebral palsy; Nicole Gladu has post-polio syndrome.

End-of-Life Law and Policy in Canada. http://eol.law.dal.ca/

Bill C-7: *An Act to Amend the Criminal Code (MAID)*

Eligibility Criteria

- Removal of reasonably foreseeable natural death (RFND)
- Temporary exclusion of mental illness until March 17, 2023

Procedural safeguards

- RFND
  - No mandatory waiting period, only one independent witness, can be care provider or other if no conflict of interest
  - Waiver of final consent
- Non-RFND
  - 90 day waiting period
  - Patient has to have been informed of the means available to relieve their suffering, including where appropriate, available, and applicable; counselling services, mental health and disability support services, community services and palliative care and has been offered consultations with relevant professionals who provide those service or that care
  - A practitioner with expertise in the condition causing the patient's greatest suffering has been consulted to consider with the patient the reasonable and available means to relieve the patient's suffering and the patient has given serious consideration to these means. The results of these consultations will be shared with the other assessing practitioners.

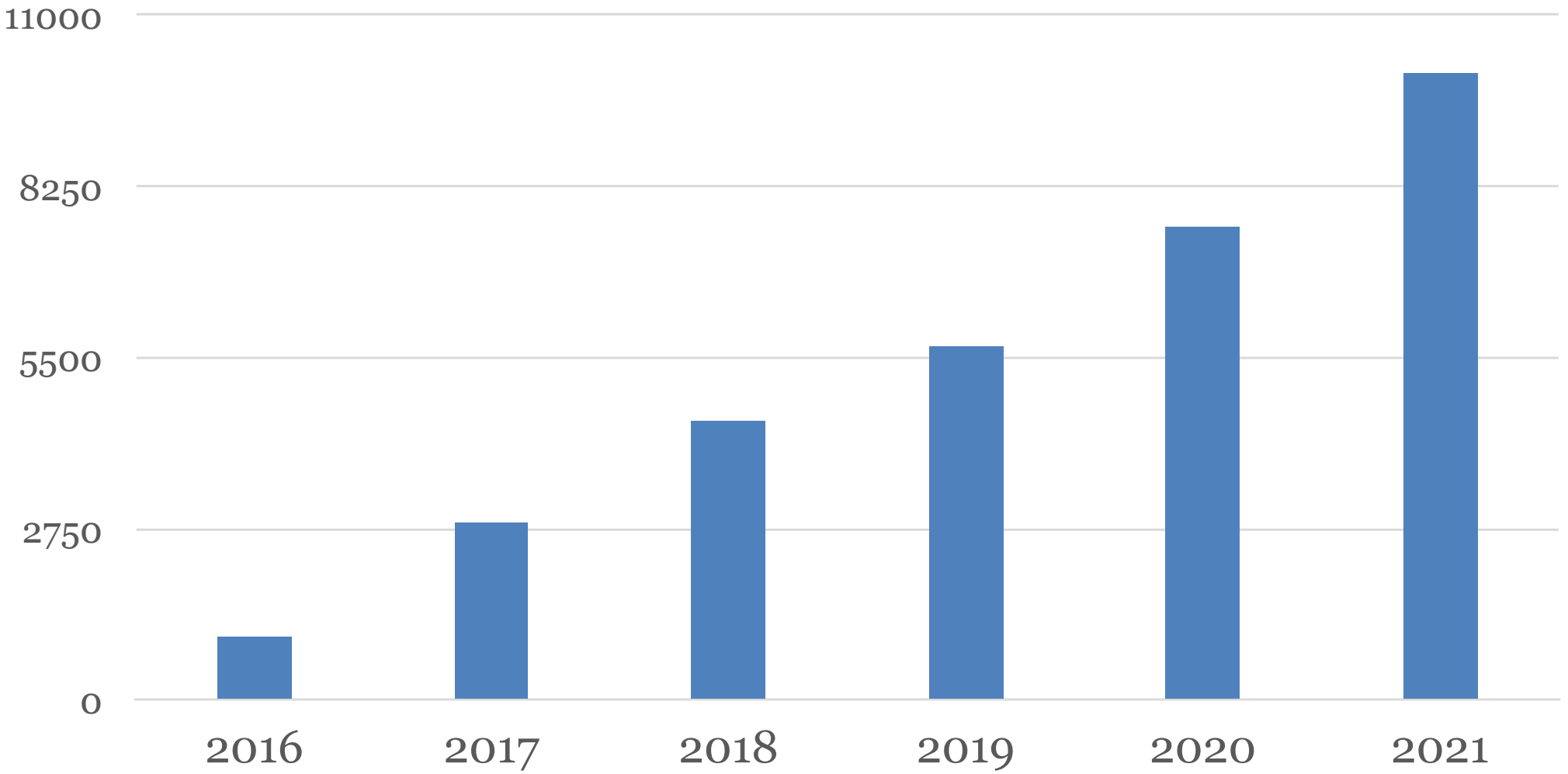
Reflection period and consent immediately before MAID

- RFND: No reflection period , final consent can be with a written advance waiver (some details apply)
- NRFND: 90 days reflection period (but this period can be shortened if the person is about to lose the capacity to make health care decisions, as long as both assessments have been completed)

Note:

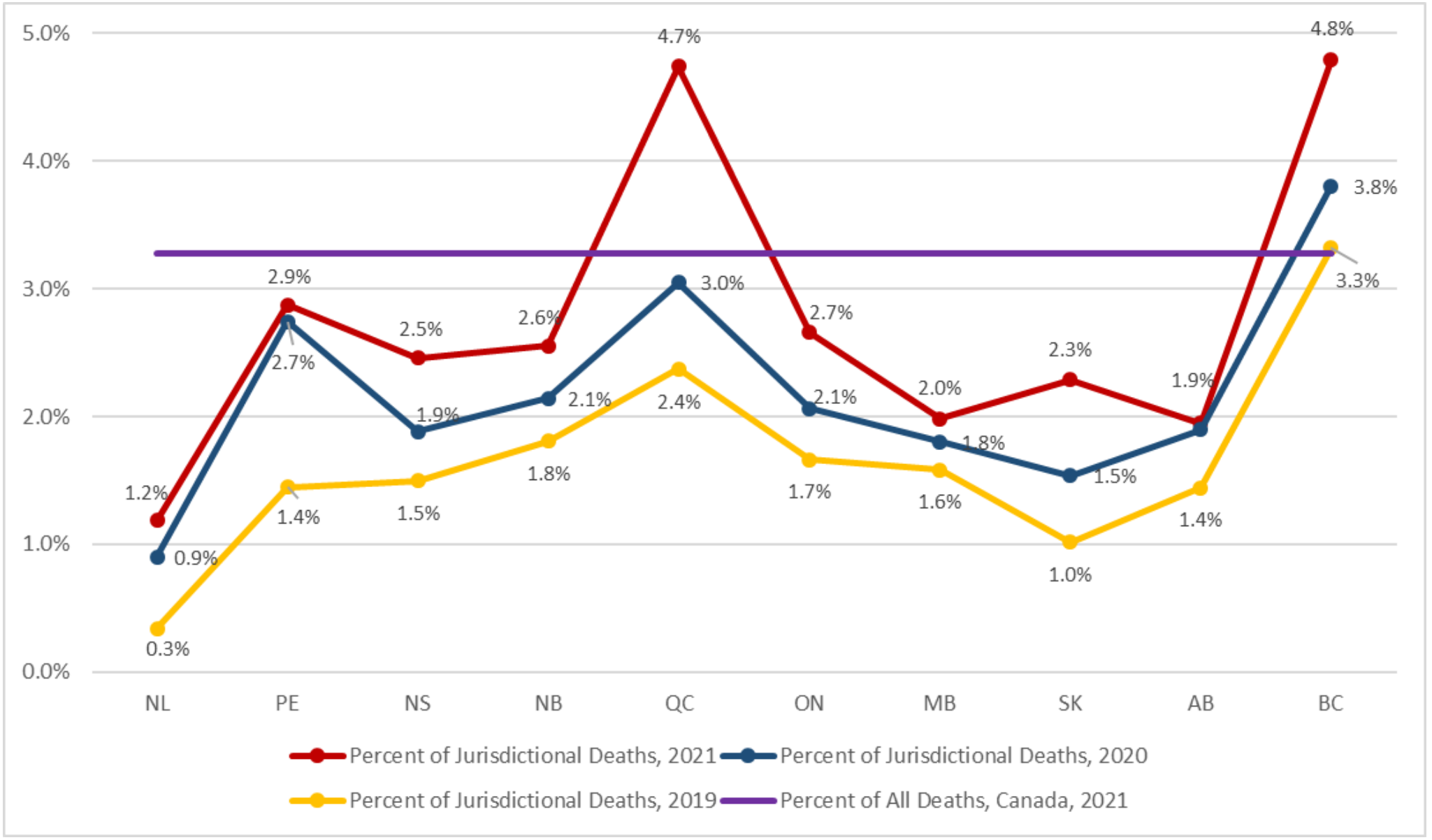
- The decision about eligibility does not have to be made immediately
- The reflection period is not written in stone and clinical judgment should inform all decisions

Total number of MAID deaths in Canada, 2016-2021

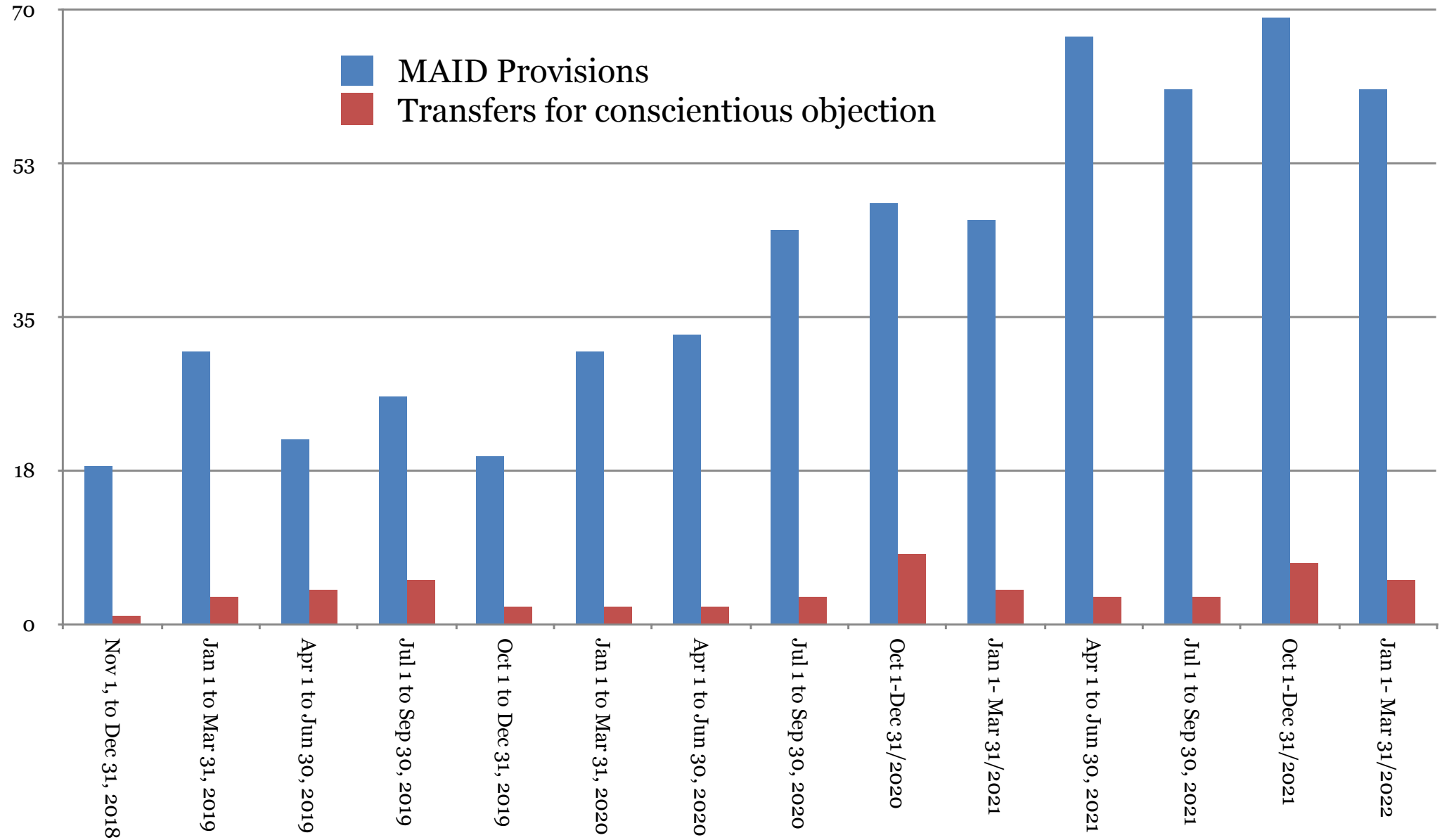


Third Annual Report on MAID, Health Canada

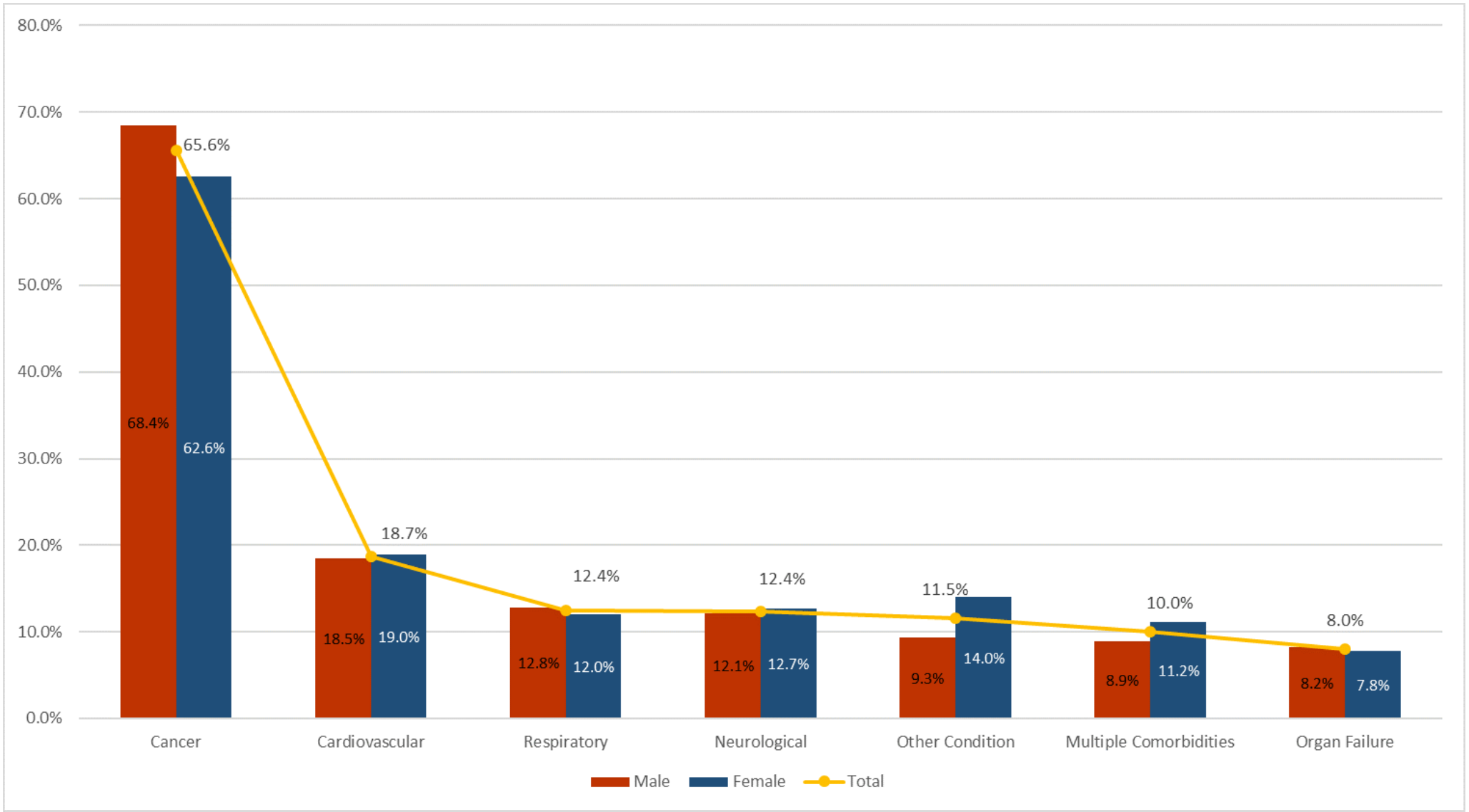
Percentage of Total Deaths Attributed to MAID by Jurisdiction, 2019 – 2021



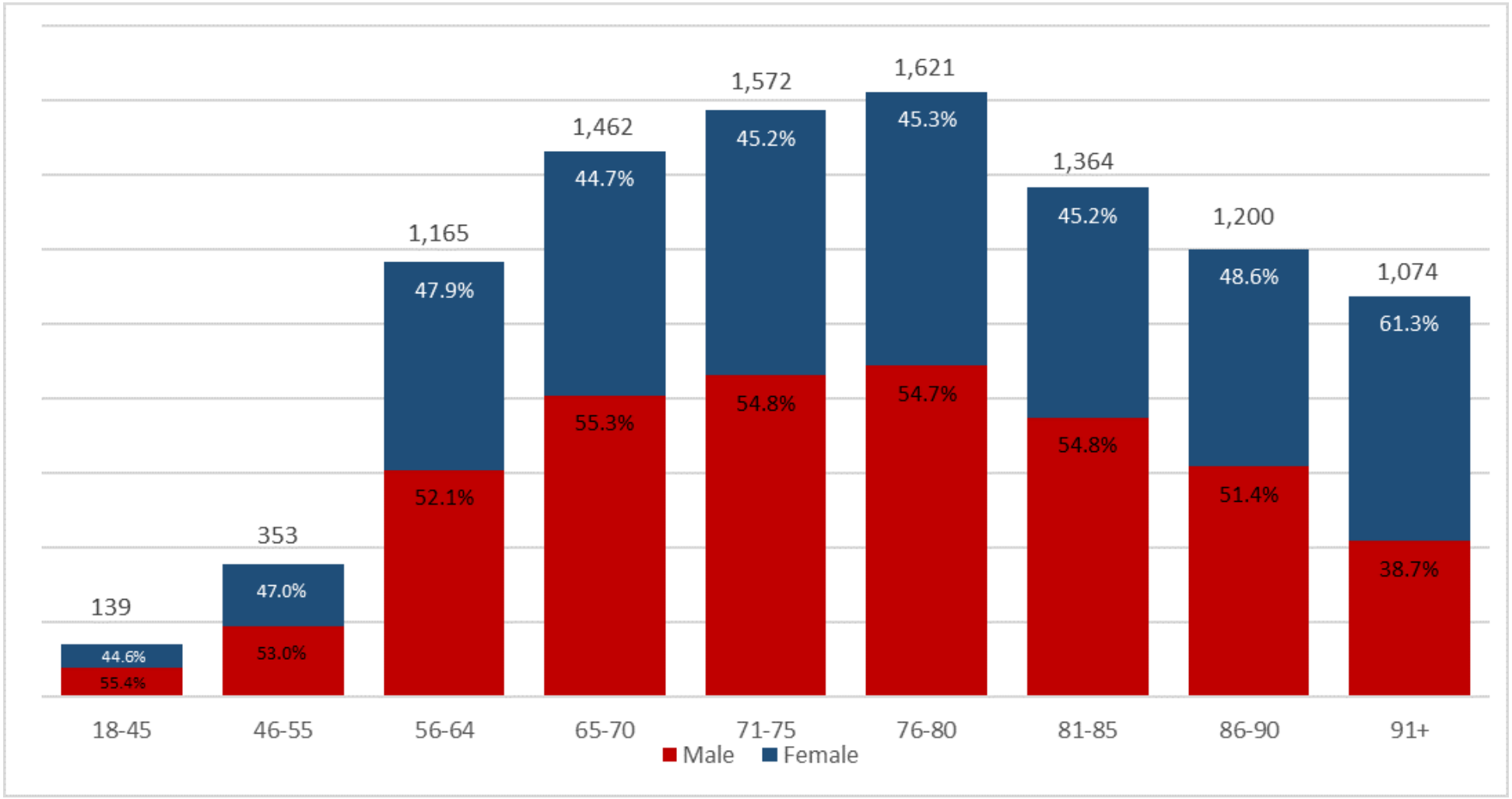
MAID in Saskatchewan November 2018 to March 31, 2022



MAID by Main Condition, 2021



MAID by Age Category, 2021



Suffering

Physical	Non-physical or existential
Pain	Loss of autonomy
Nausea, unable to eat or drink	Poor quality of life, isolation, loneliness
Aspiration/choking	Loss of dignity, meaning and sense of usefulness
Loss of control of bodily functions	Concern about burden to others
Decreased mobility	Worry about upcoming symptoms or inexorable decline
Dyspnea	Previous experience with difficult death

Patients asking for a medically assisted death

RFND
(Assisted dying)

- Cancer
- Other including CV, Respiratory, neurological (ALS, PD)

Not RFND examples
(Assisted suicide?)

- Morbid obesity
- Cerebral palsy, cystic fibrosis
- Spinal cord and other injuries
- Crohn's disease
- Tinnitus, vertigo
- Chronic pain
- Others

Special issues in those without RFND

- Frequent long-standing social isolation with disconnection from social and occupational networks
  - Decreased normative feedback from others about dysfunctional thinking patterns
  - Decreased knowledge about possible interventions and possible supports or mistrust of health system and treatments (i.e internet source of information)
- Increasing, long-standing demoralization and poor self-esteem
- Poor coping skills, impaired executive functioning
- Limited available supports in the community Frequent comorbid mental illness including personality disorders

MAID referral process

- Initiated by healthcare provider, patient, support person or family
- Pathway to MAID assessor
  - Through MAID program 1-833-473-6243
  - Directly to physician/nurse-practitioner known to person wishing assessment

The written request to be assessed for MAID

- Written request must be made after the person is informed by a medical practitioner or nurse practitioner that they have a "grievous and irremediable medical condition."
- One independent witness (including paid professional personal or health care worker)
  - Not a beneficiary under the will of the patient
  - A recipient in any other way of a financial or other material benefit resulting from the patient's death
    - i.e. not a spouse, children or grandchildren who would inherit after the death of the spouse, or in-laws who would benefit financially through their spouses
  - Not an owner or operator of a health care facility where the patient is receiving treatment or of a facility in which the patient resides

Written Request

PATIENT INFORMATION

Name (Last, First, Middle):		Phone Number:
DOB (yyyy-mm-dd):	HSN: Province of Issue: Saskatchewan	Gender: ☐ Prefer not to disclose ☐ Female ☐ Male ☐ Other
Home Address (Street, City, Province):		Postal Code:
Medical Diagnosis Relevant to Request for Medical Assistance in Dying:		

PATIENT REQUEST

I, , being at least 18 years of age, and having been informed by a physician or a nurse practitioner that I have a grievous and irremediable medical condition and am experiencing suffering; make a voluntary request to be assessed by two independent practitioners in order to determine my eligibility for medical assistance in dying, knowing I may change my mind at any time. I understand my health information will be collected, used, and disclosed for medical assistance in dying eligibility purposes.

PATIENT SIGNATURE: The witness must directly observe the patient or proxy physically sign the document.

Print Patient's Name:	Patient's Signature:	Date Signed (yyyy-mm-dd):

PROXY INFORMATION: The witness must directly observe the patient or proxy physically sign the document.

Proxy Declaration: If the patient **is physically unable to sign**, a proxy can sign on the patient's express direction and in the patient's presence. The proxy cannot be the listed witness, must be at least 18 years old, must understand the nature of the request for medical assistance in dying, and must not know or believe they are a beneficiary under the will of the patient, or a recipient in any other way of a financial or other material benefit resulting from the patient's death. Must be signed in front of the patient and the independent witness.

Print Proxy's Name:	Proxy's Signature:	Date Signed (yyyy-mm-dd):
Proxy's Home Address (Street, City, Province, Postal Code):		Phone Number:

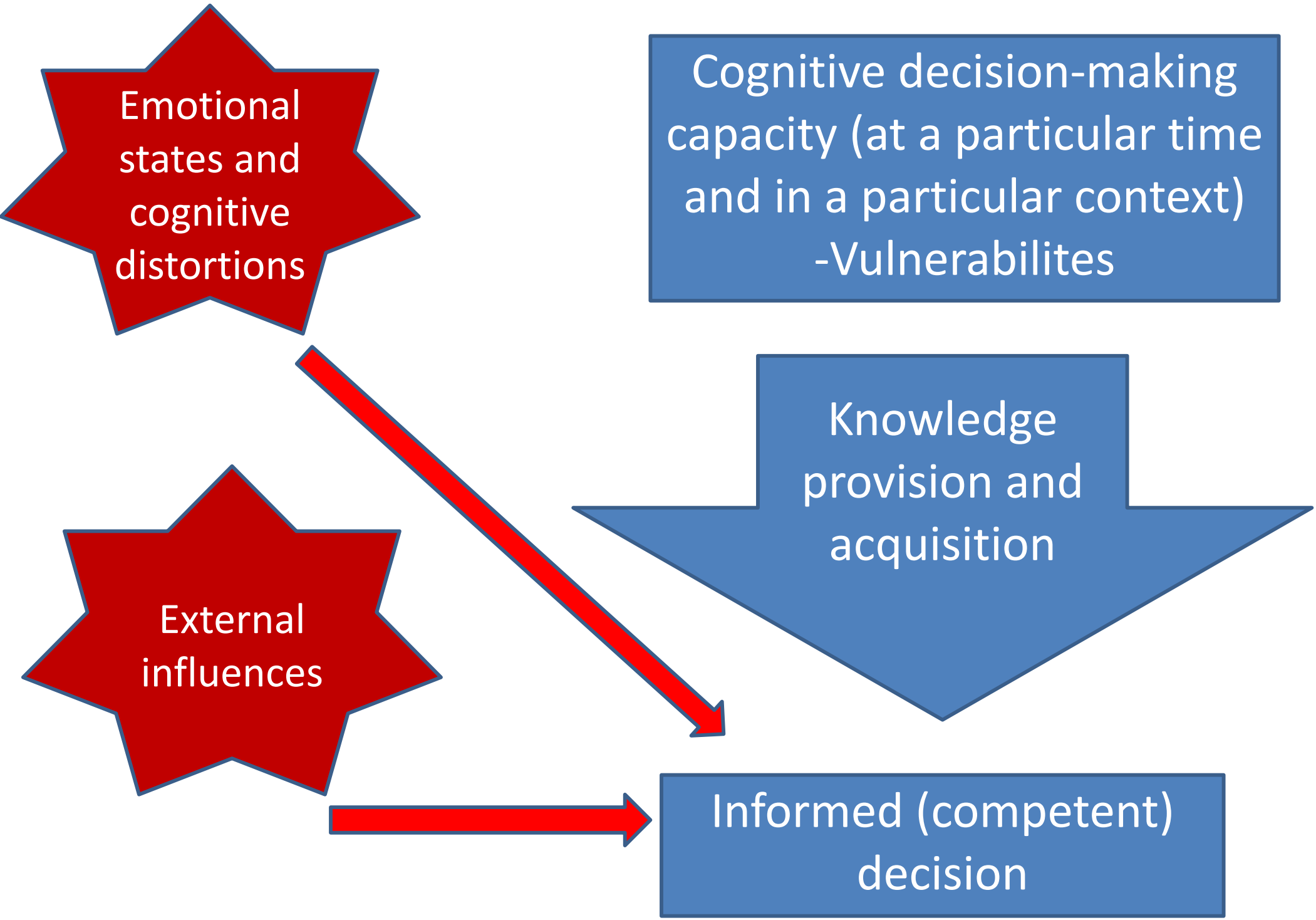
WITNESS INFORMATION: The witness must directly observe the patient or proxy physically sign the document.

The patient is personally known to me or has provided proof of identify. I am at least 18 years of age and I understand the nature of the request for medical assistance in dying. I do not know or believe that I am a beneficiary under the will of the patient or a recipient in any other way of a financial or other material benefit resulting from the patient's death. I am not an owner or operator of a health care facility where the patient is receiving treatment or of a facility in which the patient resides. The patient or proxy has signed this request in my presence on the date following the signature.

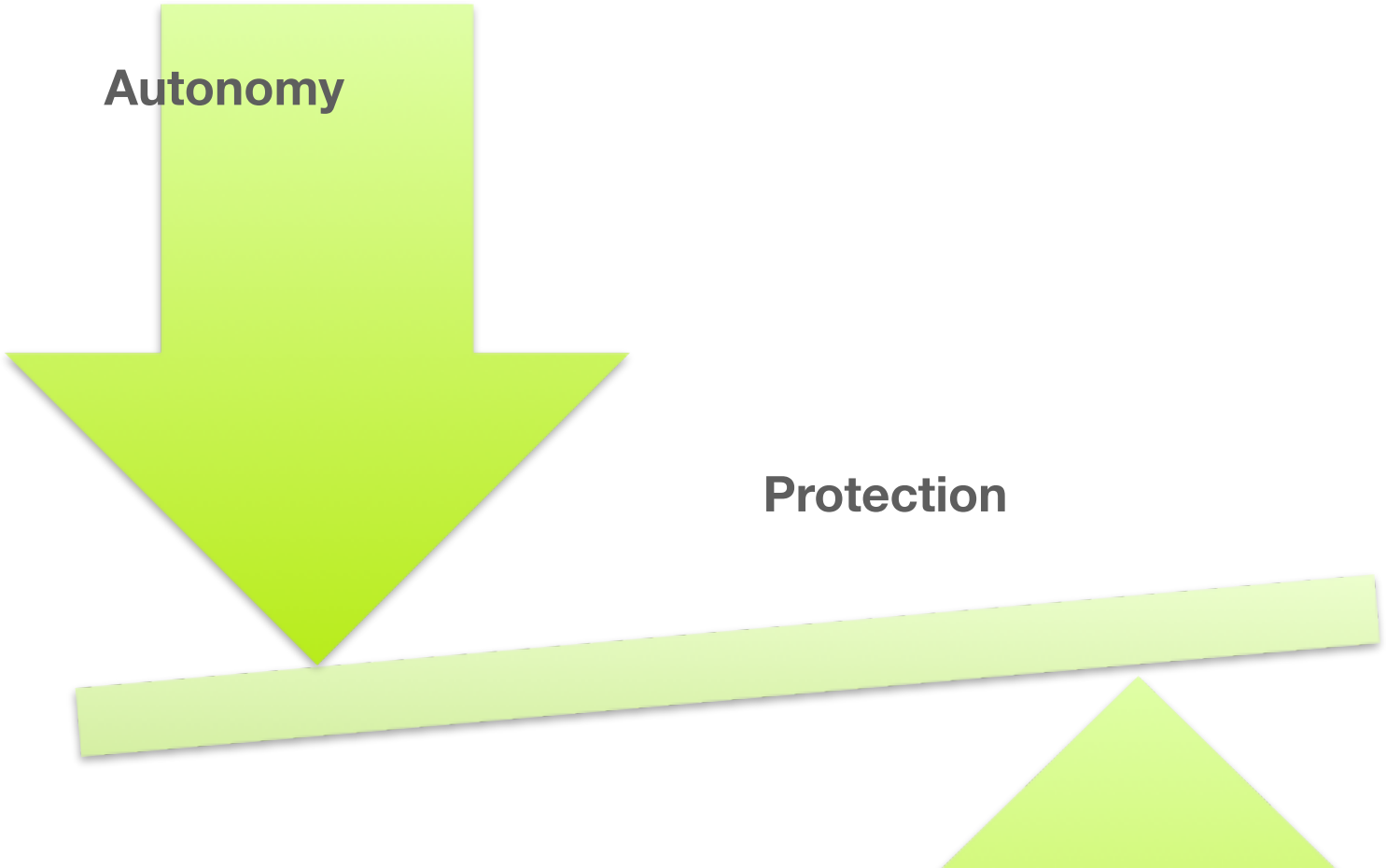
Print Witness's Name:	Witness's Signature:	Date Signed (yyyy-mm-dd):
Witness's Address (Street, City, Province, Postal Code):		Phone Number:

Assessments of eligibility

- Two independent practitioners have to agree that the patient is eligible for MAID, either under track I (RFND), or under track II, (not RFND).
  - The patient needs to be making a capable, well-informed, voluntary, and stable request about medical assistance in dying.
  - Assessment of eligibility might be straightforward and require only one visit, or it might require a number of visits when eligibility is borderline.
  - Assessors might involve others such as OT, SW, psychologist or psychiatrist in deciding whether a person has capacity to make this end of life decisions.
- If a patient is not found to be eligible by one or both assessors, another assessment might be requested by the patient. In some situations of unclear eligibility there might be a special meeting called between assessors to discuss further actions related to eligibility.


Emotional states and cognitive distortions
Cognitive decision-making capacity (at a particular time and in a particular context)
-Vulnerabilites
Knowledge provision and acquisition
External influences
Informed (competent) decision

Autonomy-Protection Continuum



Stringency of criteria for MAID

- Risks versus benefits: Number of potential years of life lost if qualifies
  - Potential shortening of life by three months in stage IV glioblastoma
  - Potential shortening of life by 30 years in patient with fibromyalgia, cerebral palsy or spinal cord injury
- Complexity of physical and mental health issues
- Complexity of psychosocial situation
- Potential impact on self and others

Preparation for MAID

- Further discussion about patient and family wishes.
  - Timing, location, and potential supports to be present during the event
  - Consider advance consent arrangement if likely to lose capacity and MAID provision wished in the near future
- Transfers
- Privacy-chart as usual

PATIENT INFORMATION (Advance Consent Arrangement Form-ACA)

Name (Last, First, Middle):		Phone Number:
DOB (mmmm d, yyyy):	HSN: Province of Issue:	Gender: ☐ Prefer not to disclose ☐ Female ☐ Male ☐ Other
Home Address (Street, City, Province):		Postal Code:

ACKNOWLEDGEMENTS / SAFEGUARDS

Initials	I have been assessed and approved for medical assistance in dying in accordance with all the applicable safeguards and eligibility criteria. In the event capacity is lost I give my consent in advance to receive medical assistance in dying on or before the specified date of _____, (*the specified date cannot exceed 90 days from the signing of this Advance Consent Arrangement*) which will result in my death.
Initials	I understand this Advance Consent Arrangement will become invalid if, on the "specified date" of medical assistance in dying provision, I express resistance or refusal with sounds, words, or gestures.
Initials	I understand this Advance Consent Arrangement is **NOT** an Advanced Care Directive.
Initials	If capacity is lost, I designate _____ (please print) to contact the Provincial MAID Program to enact a medical assistance in dying provision on or before the specified date of _____.
Initials	I acknowledge that this agreement does not create any obligation for the MAID providers named on the second page of this document to administer medical assistance in dying to me. The MAID provider may decide not to administer medical assistance in dying under all circumstances.
Initials	In the event I change my mind or the specified date has elapsed, this Advance Consent Arrangement becomes invalid.

ADDITIONAL TERMS (Optional)

The patient and the MAID provider may agree to additional terms of this arrangement (for example, specific conditions or circumstances under which medical assistance in dying could be provided on an earlier date). NOTE: Both the patient and the MAID provider must be in agreement and medical assistance in dying must be provided in accordance with the terms of this arrangement.

Patient's Initials	MAID Provider's Initials	Additional Terms:

PATIENT SIGNATURE

Print Patient's Name:	Patient's Signature:	Date Signed:

Day of MAID Provision

- Generally two providers present for mutual support (practical, medicolegal, emotional)
- Support to patient and family members
- IV administration of medications brought by MAID team
- Medical Certificate of Death completed by physician or NP
- Most responsible physician, family physician, palliative care (if applicable) and funeral home notified

(RFND) SECTION 1: BASIC INFORMATION (Consent for Medical Assistance in Dying)		
Patient Information		
Name (Last, First, Middle):	DOB:	HSN: Province of Issue:
Address (Street, City, Province):	Postal Code:	Gender: ☐ Prefer Not to Disclose ☐ Female ☐ Male ☐ Other
Provision of Consent		
I understand that I may, at any time, withdraw consent to medical assistance in dying or any other related matter. I confirm that the nature, benefits, risks, consequences, and alternatives of medical assistance in dying and related matters have been explained to me. I have been informed of the means that are available to relieve my suffering, including palliative care. I am satisfied with and understand the information I have been given, and consent to receive medical assistance in dying from the prescribing practitioner with the assistance of any other health care service providers as deemed to be appropriate. **I acknowledge this intervention will result in my death.**		
Intravenous Administration of Medications: Midazolam 10 mg IV, Lidocaine 40 mg IV, Propofol 1,000 mg IV, Rocuronium 200 mg IV		
Patient's Signature:	Time:	Date :
Patient has completed a Foreseeable Death: Advance Consent Arrangement form.		☐ Yes ☐ No
Proxy Declaration: If the patient **is physically unable to sign**, a proxy can sign on the patient's express direction and in the patient's presence. The proxy cannot be the listed witness, must be at least 18 years old, must understand the nature of the request for medical assistance in dying, and must not know or believe they are a beneficiary under the will of the patient, or a recipient of financial or other material benefit resulting from the death of the patient. Must be signed in front of the patient and the independent witness.		
Print Proxy's Name:	Proxy's Signature:	Date :

The Medications (in standardized kit from pharmacy)

- Midazolam
- Lidocaine
- Propofol
  Rocuronium

Distinction between administering and assisting.

- Only medical practitioners and nurse practitioners can administer the MAiD medications.
- This task cannot be delegated.
- Other health care workers may provide all other aspects of care.

The Medical Certificate of Death

- Cause of death:
  - a) Drug toxicity
  - b) Underlying medical cause precipitating MAiD request such as cancer
- Manner of death:
  - Unclassified

Follow-up

- Patients needing psychosocial support can be connected with appropriate services by the provincial MAID team social worker . Supports might include individual counseling or involvement in group grief therapy. This will depend on patient wishes and availability of resources

Ongoing challenges

Autonomy


I SUPPORT ASSISTED DYING
My choice.
right.
My right.
Dying With Dignity Canada

Beneficence and non-maleficence

Justice

- Should patients asking for MAID jump to the head of the line in health care?
  - Palliative care
  - Inpatient care
  - Long –term care bed
  - Home based 24/7 care when wanting to access MAID if not able to stay home

Winnipeg woman who chose to die with medical assistance said struggle for home care help led to decision

- … she had grown exhausted at her failed efforts to get more help with basic needs at home, and that is what drove her to access a medically assisted death.
- (Redacted) lived alone at home with her dog. She didn't want to give that up to live in a facility, said her friend (redacted).
- (Redacted) said the province and ALS Society advised that she would receive around the clock care were she to move into Riverview Health Centre. (Redacted) said she preferred to remain at home and that she knew others who died shortly after moving into long-term care.
- "It's really painful for me to think about the fact that she is gone because our society doesn't focus on giving people what they need."

Initiating the discussion of MAID

- If yes:
  - Might this be perceived as undue influence?
- If no:
  - Do people have the right to know their options ?

Voluntary stopping eating and drinking VSED and voluntary stopping personal care VSPeC to become eligible for MAID

- VSED and VSPeC make a person's death reasonably foreseeable (indeed certain).
- Should a person's reasonably foreseeable death caused by VSED or VSPeC be considered natural and then make them eligible for MAID?

Involvement of families

- Yes:
  - For collateral information about the person's previous wishes
  - For preparation for the person's death and alleviating family distress
- No:
  - Not legally required
  - Some family members might be adamantly opposed and cause distress to the patient

MAID requests after traumatic circumstances like traumatic spinal cord injuries (tSCIs)

- Suicidality is high for a few years after tSCIs
- People often adapt to changes in their circumstances over a number of years if provided the necessary supports
- People with similar experiences that have navigated their journey successfully are often able to provide the best information about the likely future of the patients' life and functioning

MAID for dementia

- Serious and incurable illness- Yes
- Advanced state of irreversible decline in capabilities- only later in the disease
- Capacity to provide informed consent- only early in the disease
- Enduring physical or psychological suffering- often disappears once awareness of dementia is lost

Medical Assistance in Dying- Sole Underlying Mental Disorder (MAID-SUMD)

ESTABLISHING INCURABILITY

ESTABLISHING IRREVERSIBILITY

- As with many chronic conditions, the incurability and irreversibility of a mental disorder cannot be established in the absence of multiple attempts at interventions with therapeutic aims.
- What if a person refuses evidence based treatments that would likely treat the disorder or suffering successfully?
- Bill C-14: "*enduring physical or psychological suffering, caused by either the illness, disease or disability, or by the advanced state of decline in capabilities, that is intolerable to the person and cannot be relieved under conditions that they consider acceptable*"

Health Canada, 2022. Final Report of the Expert Panel on MAiD and mental illness

Advanced requests for MAID

- Not legal yet
- Often wished for by patients wanting to avoid a lengthy dementing process

BUT

- Dementia results in loss of recognition of dementia itself and MAID wishes may disappear
- Patients may become highly resistive to any interventions including MAID
  - Practitioners will NOT want to provide MAID to a resisting patient even if this were legal
  - Medication administration would become verydifficult
-

Transfers from objecting sites

- Patients are often very distressed to be transferred out of a site that doesn't permit MAID
  - Should every location that is publicly funded allow MAID on site?
  - What about patients and staff who do not want to work in a site where MAID is occurring?

Discussion

MEDICAL ASSISTANCE IN DYING IN CANADA:
CHOICES FOR CANADIANS
Report of the Special Joint Committee on Medical Assistance in Dying

Hon. Marc Garneau and Hon. Yonah Martin
Joint Chairs

FEBRUARY 2023
44th PARLIAMENT, 1st SESSION

Recommendation 1

- That the Government of Canada, in partnership with provinces and territories, continue to facilitate the collaboration of regulatory authorities, medical practitioners and nurse practitioners to establish standards for medical practitioners and nurse practitioners for the purpose of assessing MAID requests, with a view to harmonizing access to MAID across Canada.

Recommendation 2

- That the Government of Canada, through relevant federal departments and in collaboration with relevant regulatory authorities, medical practitioners, and nurse practitioners, continue to address the quality and standardization of MAID assessment and delivery.

Recommendation 3

- That, every six months, Health Canada provide updates to the House of Commons Standing Committee on Indigenous and Northern Affairs and the Standing Senate Committee on Indigenous Peoples on its engagement with First Nations, Inuit and Métis on the subject of MAID.

Recommendation 4

- That the Government of Canada work with First Nations, Inuit and Métis partners, relevant organizations, such as the Canadian Association of MAID Assessors and Providers, regulatory authorities, and health professional associations to increase awareness of the importance of engaging with First Nations, Inuit and Métis on the subject of MAID.

Recommendation 5

- That the Government of Canada, through Correctional Service Canada, support approved track one MAID recipients being able to die outside a prison setting only for the event itself and any immediate preparatory palliative care that is required.

Recommendation 6

- That the Government of Canada, through relevant federal departments and respecting the jurisdiction of provinces and territories, consider increasing funding for the implementation of the Action Plan on Palliative Care: Building on the Framework on Palliative Care in Canada, and make targeted and sustained investments in innovative approaches and early-stage research aimed at improving health system performance and quality of care for people living with life-limiting illness and their caregivers.

Recommendation 7

- That, with the understanding that palliative care is not a prerequisite to access or receive MAID, the Government of Canada work in partnership with the provinces and territories on the following action items:
  - Continue the National Action Plan on Palliative Care: Building on the Framework on Palliative Care in Canada and look into innovative approaches and early-stage research aimed at improving health system performance and quality of care for people living with life-limiting illness and their caregivers.
  - Support the efforts of provinces and territories to develop initiatives aiming to improve home-based palliative care and culturally appropriate palliative care for underserved populations as well as access to this care.
  - Identify ways to improve access to high-quality, culturally appropriate, palliative and end-of-life care, in a timely manner by:
    - Supporting palliative home care
    - Supporting specialized paediatric palliative care; and
    - Supporting access to advance care planning.

Recommendation 8

- That the Government of Canada, in collaboration with the provinces and territories, work to develop data systems to collect disaggregated data for Black, Indigenous, racialized, disabled, and 2SLGBTQ+ communities beyond the regulations that went into force January 1, 2023.

Recommendation 9

- That Health Canada review the Special Access Program, other programs and policies, and relevant laws and regulations to determine whether there are ways to improve access to promising therapies, such as psilocybin, for both research purposes and for individual use as part of palliative care supports.

Recommendation 10

- That the Government of Canada continue to support persons with disabilities by implementing measures to reduce poverty and ensure economic security.

Recommendation 11

- That the Government of Canada, through the Department of Justice, and in consultation with organizations representing persons with disabilities, explore potential amendments to the Criminal Code that would avoid stigmatizing persons with disabilities without restricting their access to MAID. Options considered should include replacing references to "disability" in section 241.2(2) of the Criminal Code, with attention to the potential legal ramifications of such an amendment across Canada.

Recommendation 12

- That the Government of Canada convene an expert panel to study and report on the needs of persons with disabilities as they relate to MAID, similar to the Expert Panel on MAID and Mental Illness.

Recommendation 13

- That, five months prior to the coming into force of eligibility for MAID where a mental disorder is the sole underlying medical condition, a Special Joint Committee on Medical Assistance in Dying be re-established by the House of Commons and the Senate in order to verify the degree of preparedness attained for a safe and adequate application of MAID (in MD-SUMC situations). Following this assessment, the Special Joint Committee will make its final recommendation to the House of Commons and the Senate.

Recommendation 14

- That the Government of Canada undertake consultations with minors on the topic of MAID, including minors with terminal illnesses, minors with disabilities, minors in the child welfare system and Indigenous minors, within five years of the tabling of this report.

Recommendation 15

- That the Government of Canada provide funding through Health Canada and other relevant departments for research into the views and experiences of minors with respect to MAID, including minors with terminal illnesses, minors with disabilities, minors in the child welfare system and Indigenous minors, to be completed within five years of the tabling of this report.

Recommendation 16

- That the Government of Canada amend the eligibility criteria for MAID set out in the Criminal Code to include minors deemed to have the requisite decision-making capacity upon assessment.

Recommendation 17

- That the Government of Canada restrict MAID for mature minors to those whose natural death is reasonably foreseeable.

Recommendation 18

- That the Government of Canada work with provinces, territories and First Nations, Inuit and Métis communities and organizations to establish standards for assessing the capacity of mature minors seeking MAID.

Recommendation 19

- That the Government of Canada establish a requirement that, where appropriate, the parents or guardians of a mature minor be consulted in the course of the assessment process for MAID, but that the will of a minor who is found to have the requisite decision-making capacity ultimately take priority.

Recommendation 20

- That the Government of Canada appoint an independent expert panel to evaluate the Criminal Code provisions relating to MAID for mature minors within five years of the day on which those provisions receive Royal Assent, and that the panel report their findings to Parliament.

Family comments (*LT: believing their parent MUST be unhappy*)

- "[t]o be quite honest, I don't believe in [happy dementia]. Contented dementia amounts to symptoms of a disease being expressed. It's not that the person is content, but rather that brain plaques have disrupted their neurotransmitters, causing what appears to be expressions of joy"
- "The illness has not made her aggressive; she has remained gentle, she smiles, and sometimes she laughs. It is easy for a health care professional who assesses her once a year to perceive that she is comfortable with the disease. Yvette has what some call "happy dementia." Happy dementia is a trap. Yvette smiles, not because she is not in pain, but simply because the disease has not yet taken away her ability to do so"
- "I am working to calm my vanishing brain and my troubled heart. I feel a need to be reassured about my future so that I can do a better job of living out my remaining days and coping with the more frequent trials I will be experiencing"

Recommendation 21

- That the Government of Canada amend the Criminal Code to allow for advance requests **following** a diagnosis of a serious and incurable medical condition disease, or disorder leading to incapacity.

Recommendation 22

- That the Government of Canada work with provinces and territories, regulatory authorities, provincial and territorial law societies and stakeholders to adopt the necessary safeguards for advance requests.

Recommendation 23

That the Government of Canada work with the provinces and territories and regulatory authorities to develop a framework for interprovincial recognition of advance requests.