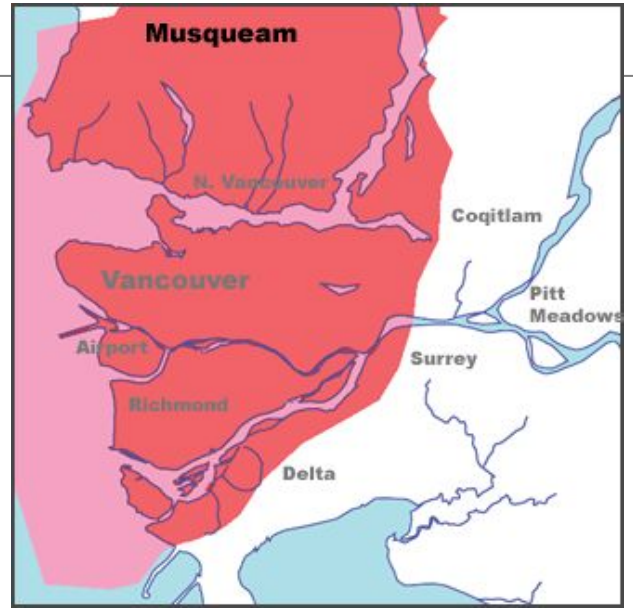
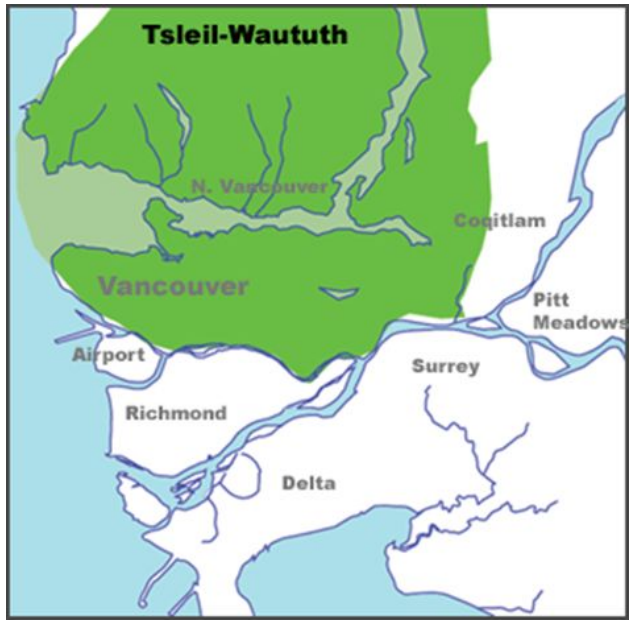
We would like to acknowledge that we are gathered today on the traditional territories of the Musqueam, Squamish and Tsleil-Waututh peoples.

Source: www.johomaps.net/na/canada/bc/vancouver/firstnations/firstnations.html





Living at Risk: ethical considerations when caring for older adults with diminished capacity

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Conflicts and Disclosures

- No conflicts of interest or disclosures

Objectives

1) Identify the ethical principles and tensions for patients with diminished capacity who wish to live at risk

2) Learn how an ethics framework can be helpful, using a case example

3) Recognize the possible risks and tradeoffs involved with enforced treatment on patient quality of life

4) Learn about relevant legislation, including the BC Adult Guardianship Act

Why are we talking about clinical ethics?

Sometimes **clinical expertise, evidence and facts** aren't enough to guide our decisions around a patient's care

Ethics adds important **values and principles** that can guide judgement

- When the most evidence-based option is not feasible or acceptable, or evidence is limited
- When the provider's and the patient's values do not align
- When there are significant harms expected with any available choice

Case Example - Mr. S

- 71M seen in SPH Elder Care clinic at request of GP for cognition

- PMHx
  - DM1 since age 27, multiple daily insulin injections – expert self-management
  - Minor neuropathy, no other complications, DKA etc…

- HPI
  - Increasing hypoglycemic events in the last year, which lead to transient confusion and verbal aggression until glucose normalized – 2 ED visits
  - Increasing conflict with his endocrinologist over tightness of control
    - Patient has a rigid of goal of glucs 4-7, which team feels to be too low
  - Occasional mild STM/word finding issues, but otherwise fully independent

Mr. S

- SocHx
  - Highly educated professor, independence very important to him
  - Ex-wife, daughter and son, all supportive and engaged
  - No substance use
  - Some financial resources
  - Still wanting to work on academic projects
- Assessment
  - MOCA 26/30, fully independent but “unusual beliefs about diabetes self-management”
  - Mild cognitive impairment
  - Follow up in 6-12 months

Mr. S continued

- Daughter brings him in 6 months later for medical and cognitive deterioration
  - 4 ED visits in the last month for hypoglycemia
  - ADLs are slipping, more cognitive decline, MOCA 19/30
  - Patient no longer able to call EHS or self manage lows
  - Family have 24hr Dexcom glucose reader sending info to family phones which alarm if gluc < 4 □ family calls paramedics
  - Increasingly emotionally labile
    - Fired by endocrinologist for verbally abusing staff
    - Threatens to “cut off” various family members and at times shuts off Dexcom transmission and refuses to speak to family
    - Refusing any offers of help (public/private supports, pharmacy, long term care)
- Assessment: dementia, depression, poor understanding of risks

Mr. S

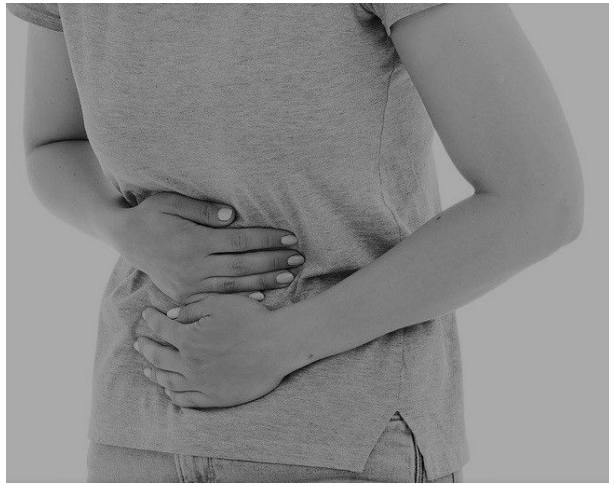
- How do we best help Mr. S?
  - Offer supports and medication and let him live at risk of potentially serious harm (and increase risk of harm to others
  - Admit him (potentially against his will), to assess risks and make a discharge plan (? LTC)

- Are there any other options that would satisfy his desire to live freely, while reducing risks to Mr. S and health care providers?
- What legislation in BC supports seniors to live at risk?
- What role does patient capacity have in making this decision?

Identifying Ethical Dilemmas

Ethical dilemmas arise when different **stakeholders** hold **divergent values** that lead to **opposing viewpoints** on what count as appropriate actions

They also arise when competing **ethical principles** support different goals or actions



Why are we talking about clinical ethics?

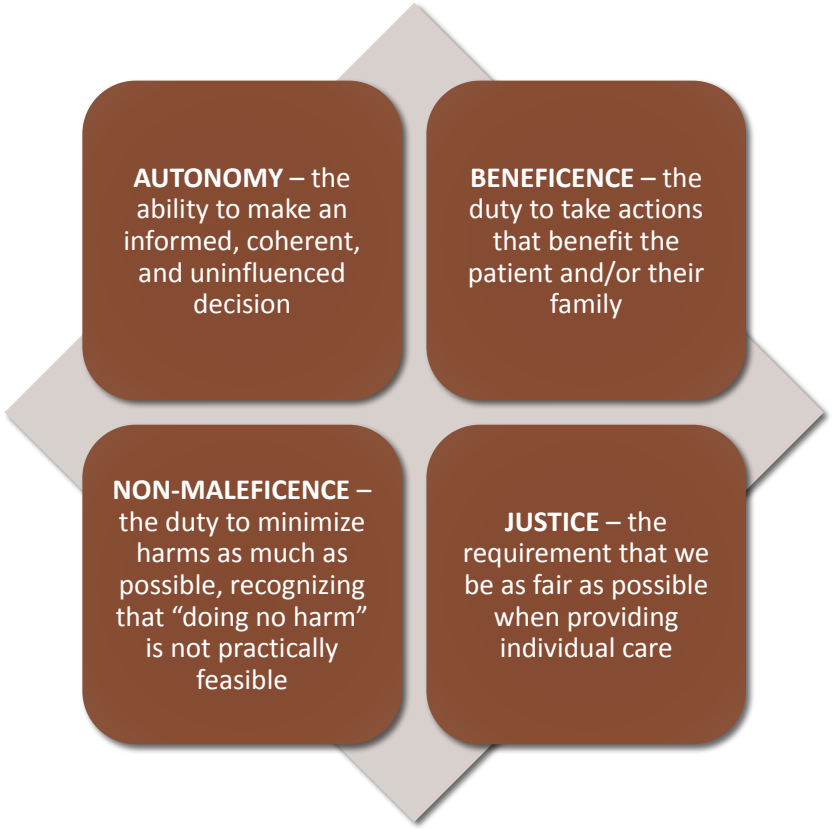
We need to also consider

- Values and goals (patient, family and care providers)
- Worldviews and biases
- Contextual features that make a case unique
- Resource availability

PHC ETHICAL DECISION MAKING FRAMEWORK

1. Identify the issues
2. Identify the stakeholders
3. Acknowledge biases, feelings and world views
4. Gather and clarify the facts:
   a) Medical Indications
   b) Patient Preferences
   c) Quality of Life Considerations
   d) Contextual Features
5. Analysis in light of ethical principles: Beneficence, Non-maleficence, Autonomy, Justice/ Fairness

1. Identify the Issue – Ethical Principles



2. Identify Stakeholders

- Patient
- Family
- Friends
- GP, case manager, home care workers
- Endocrinology
- Hospital team (physicians, SW, OT, PT, TST, leadership)
- Long term care
- Others?

3. Explore Biases and Worldviews

- Patients
  - Willing to accept **risk** to have **freedom**
  - Life experiences/personality/trauma/mental health issues that increase distress with more authoritative/institutional approaches

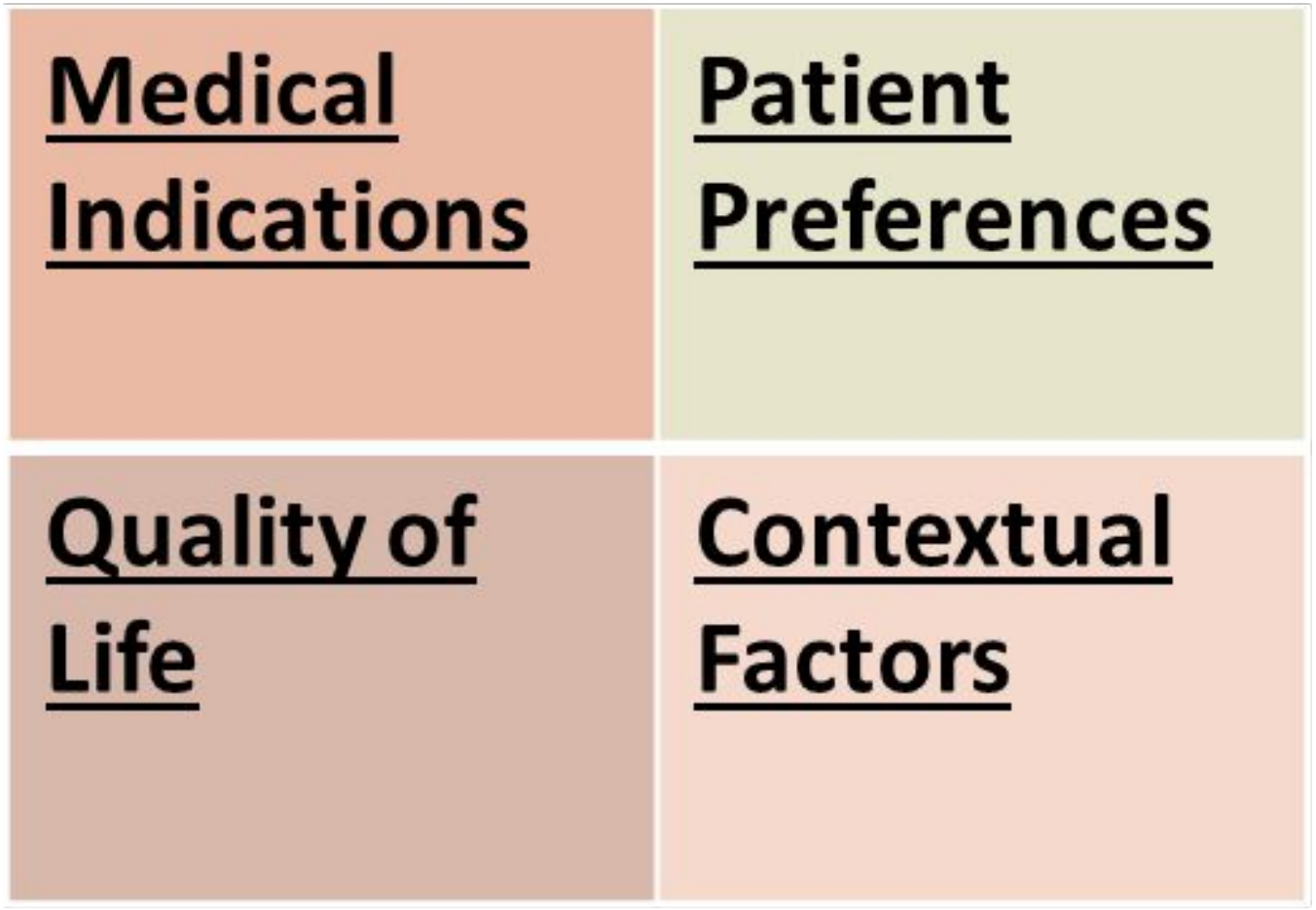
- Health care providers
  - Wanting to keep patients **safe = duty of care**
  - Duty to keep community members, HCPs safe
  - Pressured to find a durable DC destination (LTC can seem easier than community)
  - Cynicism due to limitations on time and resources
  - Medico-legal implications that favor safety over risk

Ageism and other Biases

- We may scrutinize an older person's "poor decision making" or assume impaired capabilities, simply because they are elderly
- We may not see the value of living in a way that is contrary to our own ideas of a "good life"
- We assume poor quality of life where a patient/family does not

Chasteen AL, Tagliamonte SA, Pabst K, Brunet S. Ageist Communication Experienced by Middle-Aged and Older Canadians. Int J Environ Res Public Health. 2022 Feb 11;19(4):2004.

4. Gathering Facts



Medical Indications ★	Patient Preferences
Quality of Life	Contextual Factors

Frailty and DC at Risk

- Approximately 30% of frail older adults are readmitted within 30 days of hospital DC
  - Increasing risk with cognitive impairment, polypharmacy, comorbids, falls

- No validated tools exist to predict with certainty which patients are at highest risk of readmission and adverse outcome

Kahlon S, Pederson J, Majumdar SR, Belga S, Lau D, Fradette M, Boyko D, Bakal JA, Johnston C, Padwal RS, McAlister FA. Association between frailty and 30-day outcomes after discharge from hospital. CMAJ. 2015 Aug 11;187(11):799-804.

Medical Indications	Patient Preferences ★
Quality of Life	Contextual Factors

The Incapable Patient

- 70% of hospitalized older adults are **incapable** and/or need assistance with decision making
  - Delirium
  - Dementia
  - Depression
- Increases with proximity to death

Bilanakis N *Clinical Practice and Epidemiology in Mental Health* 2014

Medical Indications	Patient Preferences
Quality of Life	Contextual Factors

What is a Medical SDM?

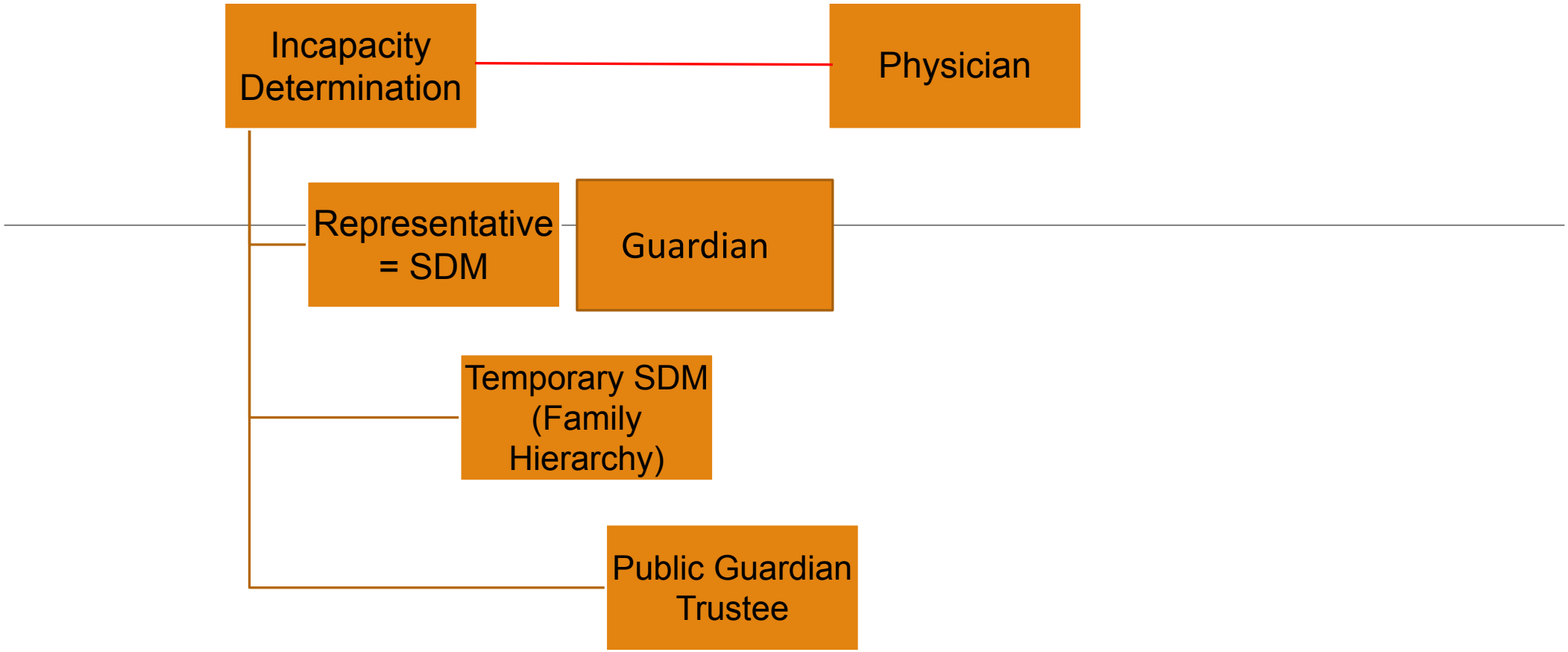
Empowered to make medical decisions for incapable patient

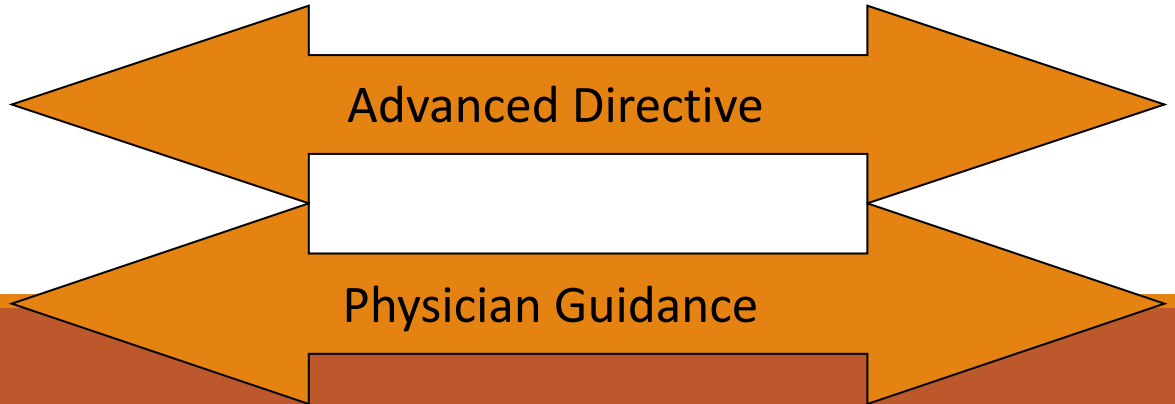
In theory:

- SDM should make the **same decision that the patient would make** if they had capacity

Extension of principle of autonomy

- “If your Dad could see himself now, what would he tell us to do about his healthcare?”





Health Care Consent and Facility Admission Act RSBC 1996 Act 288

Quality of life and changes of heart

Medical Indications	Patient Preferences
Quality of Life ★	**Contextual Factors**

- Subjectivity in QOL determination
  - What is acceptable QOL for you may not be acceptable for others
  - Acceptable QOL for others may not be acceptable to you
  - What a "reasonable person would want" may not be accurate for this patient

- Many patients become more (or less) willing to accept burdensome treatments
- States previously imagined to be intolerable may be tolerable (vice-versa)
- People that believe LTC "is a state worse than death" can eventually settle in

Auriemma CL, Nguyen CA, Bronheim R, Kent S, Nadiger S, Pardo D, Halpern SD. Stability of end-of-life preferences: a systematic review of the evidence. JAMA Intern Med. 2014 Jul;174(7):1085-92.

Harms of Force

- Useful thought experiment
  - If we were to force this patient to accept LTC/certain care, what would that look like?
    - Medications, physical force, confinement morbidity/mortality
    - Disruption and removal from sources of pleasure, meaning, quality of life
    - Triggering trauma from past experiences
    - Causing guilt and distress in family members
  - Acknowledging these harms are *possibilities, not guarantees*
  - *LTC may also provide benefit (regular care, meds, nutrition, social)*

Medical Indications	Patient Preferences
Quality of Life	Contextual Factors

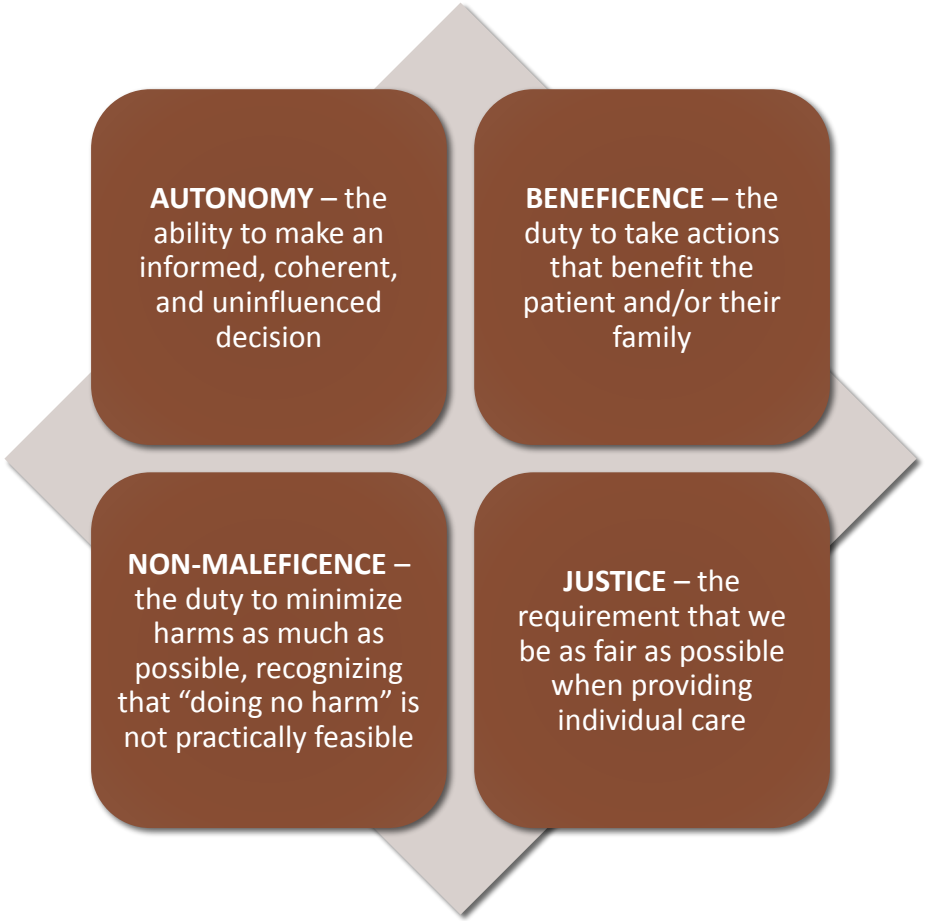
Adult Guardianship Act

- All adults can live in the manner they wish and accept/refuse supports :
  - They do not harm others
  - They are capable of making decisions (capable until proven otherwise)
- If they cannot care for themselves, and **are incapable, and harm is likely** (**ABUSE or SELF-NEGLECT**)
  - Ensure a plan for support and assistance is enforced to reduce risks
  - All efforts at support should be exhausted before enforcing restrictions against a person's will
- If concerns
  - Consult Public Guardian and Trustee

4. Summary - Gathering Facts

Medical Indications	**Patient Preferences**
Quality of Life	**Contextual Factors**

5. Analysis according to principles



6. Weigh Options

A) Perform a capacity assessment and organize a transfer to LTC via a SDM, even if sedation/force is required (hospital admission vs community)

B) Assess the patient and trial antidepressants/antipsychotics to see if patient's distress can be reduced, and increase willingness to accept supports

C) Continue to allow the patient to remain at home with whatever home supports he will accept, accepting a high risk of readmission and death

D) Explore palliative options in the community with a goal of symptom management and home death

E) Others?

7. Make a decision and implement

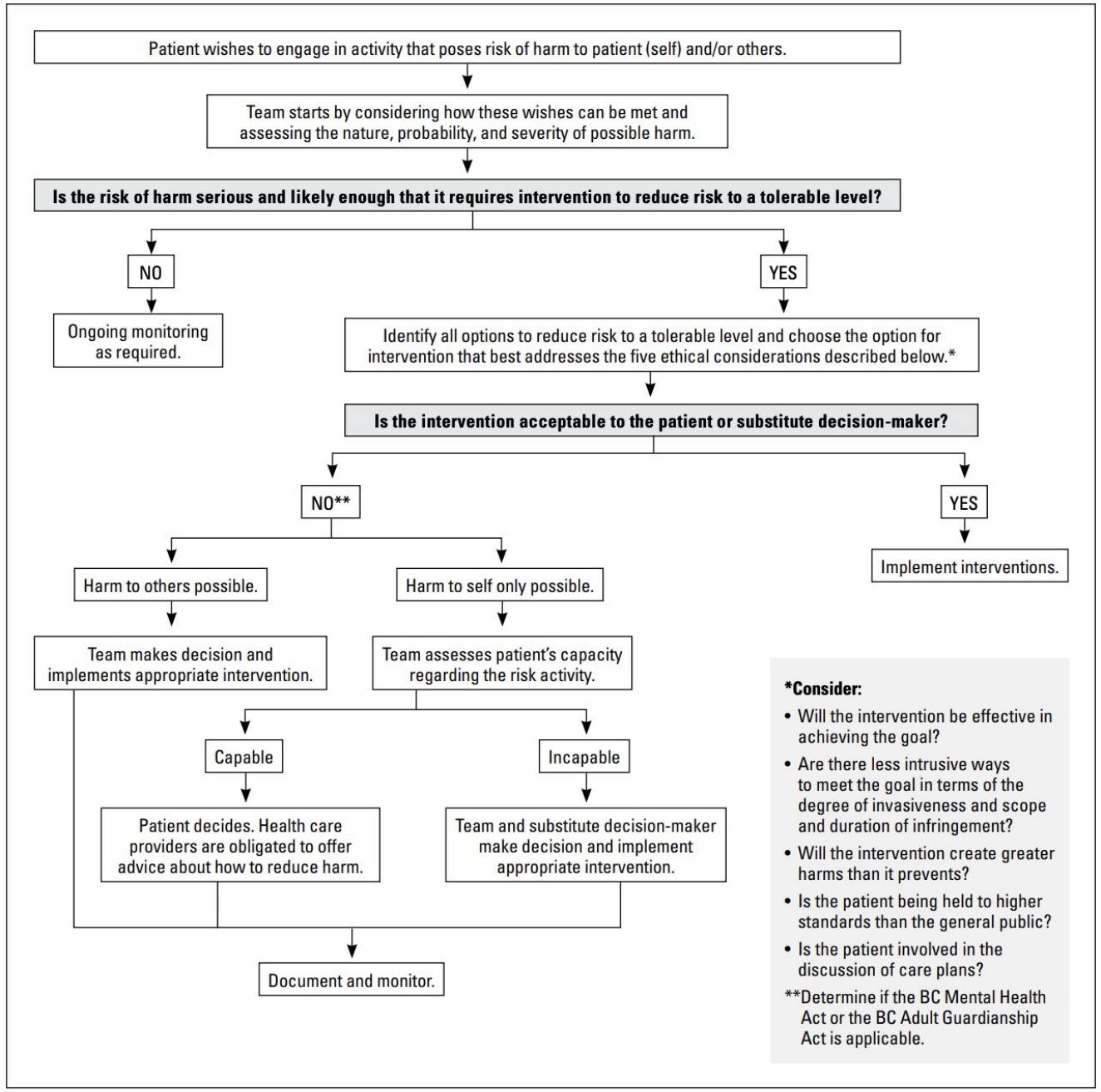
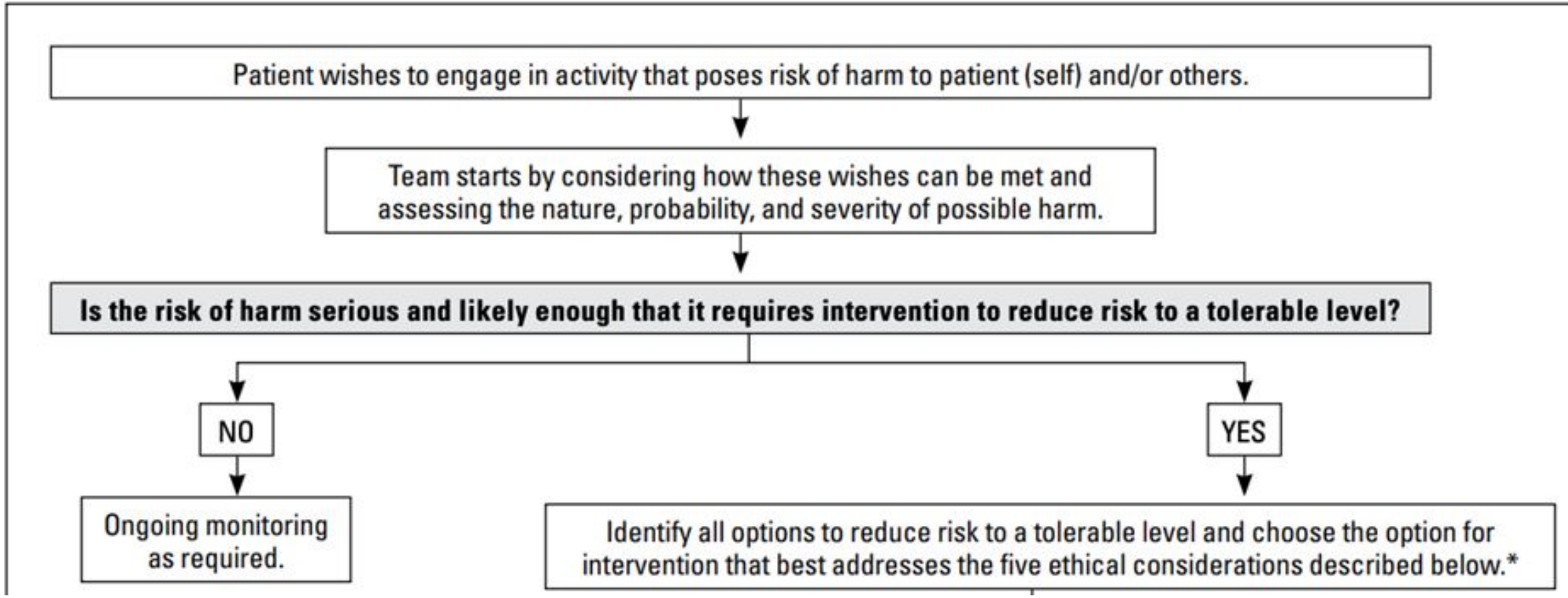


Figure. An ethical approach to managing patients choosing to live at risk.

Young, JM and Everett, B. 2018. When patients choose to live at risk: What is an ethical approach to intervention? BCMJ 60(6): 314-318


Patient wishes to engage in activity that poses risk of harm to patient (self) and/or others.
Team starts by considering how these wishes can be met and assessing the nature, probability, and severity of possible harm.
Is the risk of harm serious and likely enough that it requires intervention to reduce risk to a tolerable level?
NO
YES
Ongoing monitoring as required.
Identify all options to reduce risk to a tolerable level and choose the option for intervention that best addresses the five ethical considerations described below.*

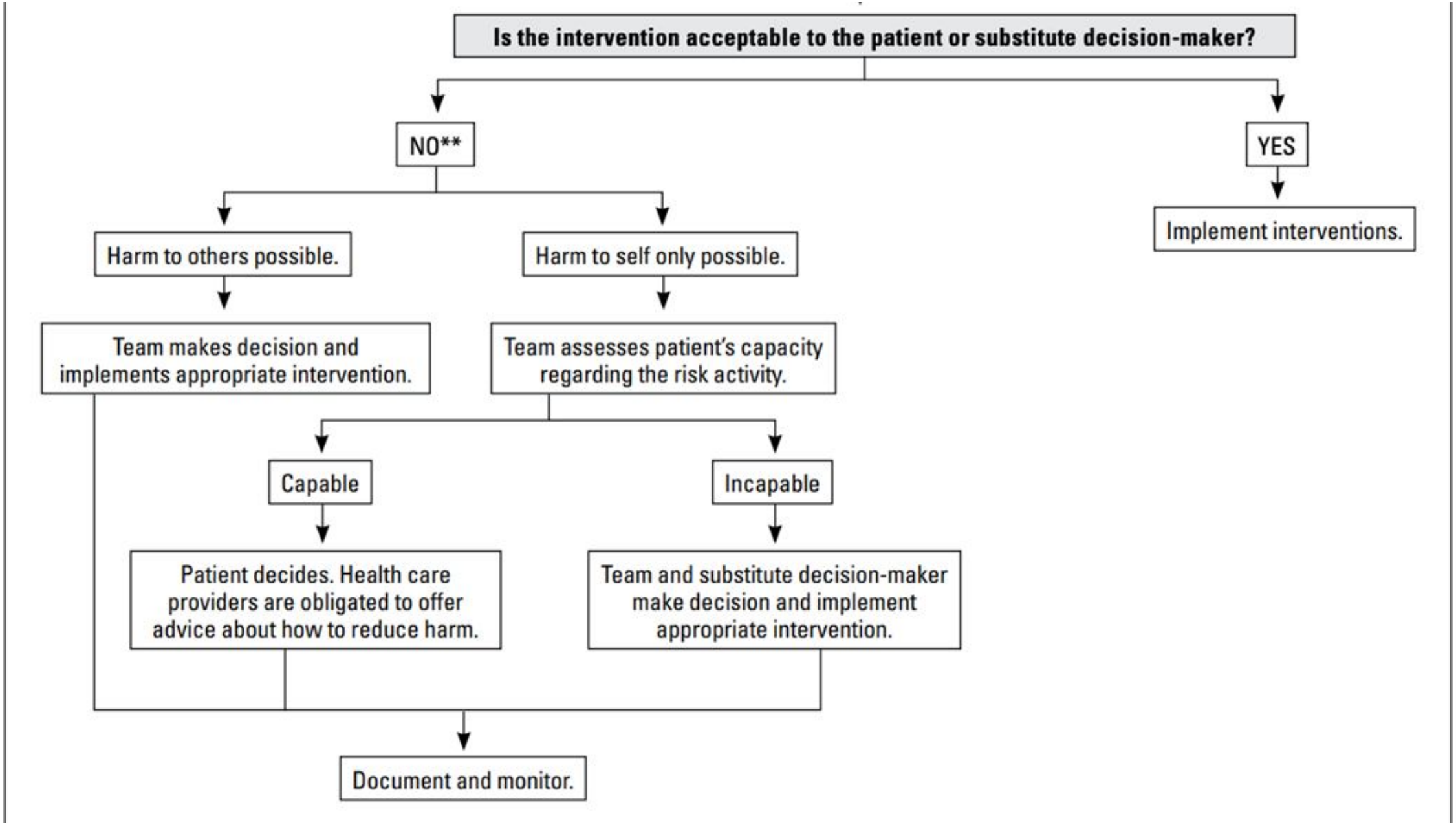
When considering whether to use force:

***Consider:**

- Will the intervention be effective in achieving the goal?
- Are there less intrusive ways to meet the goal in terms of the degree of invasiveness and scope and duration of infringement?
- Will the intervention create greater harms than it prevents?
- Is the patient being held to higher standards than the general public?
- Is the patient involved in the discussion of care plans?

**Determine if the BC Mental Health Act or the BC Adult Guardianship Act is applicable.

Young, JM and Everett, B. 2018. When patients choose to live at risk: What is an ethical approach to intervention? BCMJ 60(6): 314-318


Is the intervention acceptable to the patient or substitute decision-maker?
NO**
YES
Implement interventions.
Harm to others possible.
Harm to self only possible.
Team makes decision and implements appropriate intervention.
Team assesses patient's capacity regarding the risk activity.
Capable
Incapable
Patient decides. Health care providers are obligated to offer advice about how to reduce harm.
Team and substitute decision-maker make decision and implement appropriate intervention.
Document and monitor.

Case resolution - Mr. S

- Family meeting with SW (AGA), family, patient, collateral from GP/endo
    - Discuss risks of continuing on at home without any changes
        - Able to tell us he “might die”, but believes risks are exaggerated
        - Rejects help around insulin (private care, family, pharmacy)
        - Rejects options for LTC or private AL
        - Family concerned and burnt out, but **feel they cannot be responsible for “forcing him into a home” as he will “cut them off” and it is “his worst nightmare”**
- Initially, we continue to let him live at risk given his strong preference, with family monitoring glucose and calling EHS, acknowledging that decline and harms are inevitable

Case resolution - Mr. S

- 2 months later, on my evening CTU call shift, Mr. S brought in by paramedics for glucose 1.3, confusion
- Once resuscitated he is chatty, bright and up and around the ED
- ED doc plans to DC him
- I call the family who beg me to keep him in hospital
  - Increasingly he is cutting them off from communication
  - EHS has lodged a complaint against Mr. S
    - On last 2 occasions has physically assaulted EHS providers while confused
    - They may refuse to continue to provide service to him (!)
  - They are wondering if it is time to consider LTC (including use of force)

Case resolution - Mr. S

- Mr. S admitted, transferred to Geriatric Medicine
  - Assessed by Endo, Geripsych, family meetings incapable
  - Trials of different insulins, SSRI, antipsychotics
  - Patient allows staff to check sugars/give insulin without interference
  - Patient pacing unit 10hrs a day to drive down glucose, continues to exit seek
  - Will not agree to any supports at home but does not endorse a desire for a home death/palliative approach ("writing a book")
  - **Assessment – risks of DC are intolerable with no clear means to lower risks that are acceptable to the patient**
    - **Eventually transferred to private LTC with family providing consent**

Conclusions

- While we have a duty to offer care, patients will sometimes refuse care we feel is in their best interest, regardless of age, ability or capacity
- While we can never eliminate all risk, we are aiming to reduce risk to a “tolerable level” in a way that continues to respect the patient
- Main aspects to consider include:
  - Degree of harm (serious, imminent), harm to self, harm to others?
  - Have all options to reduce harm to a tolerable level been explored?
  - Can we find a risk mitigation option that will be effective and that the patient can accept?
  - Do we need to formally assess capacity (last resort)?
  - Should we invoke Adult Guardianship Act to facilitate assessment and support?

Thank You!