

REGISTRANT RESOURCE

Consent to treatment-equity considerations

Preamble

Consent is a fundamental component in the delivery of health care, and most care cannot occur without valid consent. For consent to be valid, it must be informed consent. Whether through the patient themselves, or through an alternate decision maker, everyone has the right to informed consent.

For consent to be informed, the patient must have been given an adequate explanation about the nature of the proposed investigation or treatment and its anticipated outcome, as well as the risks involved. Barriers can arise in obtaining informed consent, often when there are challenges with communication and comprehension, which can be caused by a variety of factors, both directly and indirectly.

The following consent considerations are not elaborated on in the practice standard; however, registrants should reflect on them to ensure they understand the unique circumstances of each patient's experience and approach care with an equity informed lens. Reflecting on the impacts that time, trust, power differentials and personal assumptions and biases can have on consent can provide for a more equitable approach to obtaining consent.^{1,2} It requires time, trust, and open discussion to fully obtain consent.

To understand the impact of inequities on the consent process, the College identified key patient groups that may face barriers to providing informed consent. These included: minors; those living with mental health challenges and/or substance use disorders; those experiencing homelessness; immigrants, migrants and refugees; and Indigenous patients. Through a process of interviews with registrants and other health-care providers working with the above-mentioned groups, the College identified the following considerations. While the principles were developed based on the needs of specific groups, they can be applied to any patient interaction based on their individual needs.

¹ <https://journalofethics.ama-assn.org/article/limits-informed-consent-overwhelmed-patient-clinicians-role-protecting-patients-and-preventing/2016-09>

² <https://www.sciencedirect.com/science/article/pii/S2352552521000852>

Definitions

health equity People are able to reach their full health potential and are not prevented from doing so because of their race, ethnicity, religion, gender, age, social class, socio-economic status, sexual orientation or some other socially determined circumstance.³

health inequity An avoidable or preventable health disparity that is considered unjust or unfair across one or more of these geographic, demographic and socio-economic dimensions.³

Principles

Understand patient values

It is important to understand what the patient's values and belief systems are and how they may impact their decisions for treatment, considering factors such as age, life experiences, cultural/spiritual values, etc. For example, patients who have come from a country experiencing state violence may feel indebted to Canada for accepting them and may be **reluctant** to express concerns about their care or the treatment being provided. Or, a teen patient may be reluctant to start chemotherapy due to changes in their physical appearance. Understanding values can allow for more open discussion and better-informed decisions.

Address barriers to communication and comprehension

Patients may not speak the same language as their physician or have limited understanding of medical terminology in that language. While patients may have someone whom they trust accompanying them to appointments, the use of professional interpretation ensures that the information is appropriately communicated, especially when there are complex medical terms. The use of family members may be convenient but can pose unintended risks of coercion. The use of other interpreters who may be conveniently present in a facility such as staff or hospital aids must be avoided as this may be deemed a serious breach of patient confidentiality.⁴ Registrants are to consider the unique circumstance and use professional judgment to determine when it is appropriate to use family members/others as interpreters rather than professional interpreting services. The use of translation can also be helpful for any written materials which aid in decision making.

Note: All registrants should have access to phone interpretation through Provincial Language Services. More information can be found [here](#). Additionally, it is a legal right for those who are deaf, deaf-blind or hard of hearing to have access to proper interpretation for publicly funded and medically necessary appointments.

Patients may also experience communication barriers for reasons such as a reduced capacity to process information quickly. Older adults, for instance, may experience slower processing

³ http://www.bccdc.ca/pop-public-health/Documents/Priority%20health%20equity%20indicators%20for%20BC_selected%20indicators%20report_2016.pdf

⁴ Bowen, S. (2015). The impact of language barriers on patient safety and quality of care.

and be deemed as incapable of making decisions. Allowing for more time in an appointment to provide information and give them ample time to process and ask questions may help in addressing this barrier. Finally, it is important to consider patients' literacy levels and how they best receive information.

It is helpful to discuss with patients how they best receive information and to understand their preferred learning modalities. Offering information in writing, video, verbally, etc. may help to meet patient needs. Written materials should always be made using plain language and have minimal medical jargon when possible and a patient's literacy levels should never be assumed.

Include children and youth in conversations about their care and treatment where possible, and their right to consent to treatment

As per the *Infants Act*, **there is no specific age in which a child or youth is deemed capable of providing consent.** Capacity of a minor is determined by assessing the extent to which the minor's physical, mental, and emotional development will allow for a full appreciation of the nature and consequences of the proposed treatment, including the refusal of such treatment. When a child or youth is deemed capable, discuss with them how they would like to involve their parents/guardian, if at all. When an adult is present with the patient, speak to the patient directly.

Children and youth may feel they want to be involved, even if they are not deemed capable to make bigger treatment decisions. Providing options, asking before touching, and explaining procedures in clear language they will understand may make them feel included in decisions about their bodies. It is important to respect their decision-making capabilities and autonomy as appropriate.

Be aware of family dynamics and consider assumptions about who is involved in the person's life and decision making

Family dynamics can impact a patient's decision-making process in positive and negative ways. Additionally, there can be complexities in determining who is the best person to act as the patient's temporary substitute decision maker, as it may not be reflected in the legislated hierarchy. For instance, patient's may be estranged from their family, or have complex relationships which could mean that if chosen, they would not act in the best interest of the patient.

For more permanent decision makers, it is important to always assess that they continue to act in the best interest of the patient, and to always continue to include the patient (when possible and appropriate).

Registrants working in pediatrics or with older adults may deal with other decision makers more often and with more complex cases. Ethics services, when available, are helpful with more complex situations. Registrants may also consider the following for these populations:

- Minors:
 - Being clear about who has the right to make decisions and who cares for the child/youth are important. There may be times when biological parents do not have capacity to make treatment decisions for their child. However, if they continue to play a role in the young patient's life, they should be included in consent conversations, even when they do not have the final say.

- There may also be challenges in the relationships between parents/guardians that may contribute to medical decision-making that is not in the best interest of the child/youth. This may require additional assessment and, potentially, consultation with other resources (e.g. experts in ethics, Ministry of Children and Family Development).
- Registrants should confirm if there are any court orders that could limit a parent's right to information regarding a child or youth's care. This may require obtaining a copy of any custody agreements or court orders as needed.
- Older adults:
 - It is helpful to be aware of the distinctions between power of attorney (POA) and representation agreement documents. An attorney specified in a POA may make legal and financial decisions on behalf of another person. The POA does not authorize the attorney to make personal health-care decisions on behalf of that person. A representative appointed in a representation agreement is authorized to make personal health care decisions and should be involved in all health care decisions that require informed consent.⁵

Gender-affirming care for children and youth, may have more specific considerations

Some of the options for gender-affirming care may require the patient to think about future decisions, such as fertility, which can be hard for them to fully comprehend. Additionally, there may be a higher proportion of young patients with underlying mental health diagnoses, including neurodiversity. Understanding how this may change their ability to consent at any given time demonstrates a need for frequent reassessment and open communication.⁶

It is important for there to be a robust process in how consent is obtained in this area of care, and a strong understanding of the patient as a whole, such as their home life. This requires continuous conversations with the patient and, if appropriate, the patient's family. There are times in which going forward with treatment may be detrimental to patient safety.

Assume capacity in adult patients

Registrants should assume all patients hold capacity unless proven otherwise, and that capacity can be fluid. Patients may also hold capacity in certain areas of their lives, or for certain decisions, even if they do not have complete capacity. Patient autonomy should be respected wherever capacity continues to persist.

When patients remain capable, speak directly to the patient, not to family members or others who may be with them in the room. Doing so can unintentionally influence the decision-making process, which may not always be in the best interest of the patient.

Overall, registrants should look at the entire patient picture and not simply the diagnoses. For example, some patients with dementia will still hold capacity for certain aspects of medical decision making.

⁵ <https://www2.gov.bc.ca/gov/content/health/managing-your-health/incapacity-planning>

⁶ Clark, A. & Virani, A. (2021). This wasn't a split-second decision: An empirical ethical analysis of transgender youth capacity, rights, and authority to consent to hormone therapy. *Bioethical Inquiry*. 18:151-164.

Consider the patient's physical and mental state

It is important to adjust consent conversations to ones that the patient has the capacity to make in the moment. This may mean one decision could require multiple appointments, or if in an inpatient scenario, involve multiple days of discussion. There are many factors which could impact a patient's physical and or mental state including, but not limited to:

- Pain
- Emotional status
- Basic needs not being met
 - Not having hearing aids on, dentures on, glasses on; opportunity to use washroom; thirst; hunger; temperature; clothing
- Trauma
- Active withdrawal/intoxication
- Bad news/new diagnosis
- Colonialism/intergenerational trauma

Note: patients should **never** be asked to consent for major life changing, non-emergency procedures, such as tubal ligation, during periods of duress, anesthesia, etc.

Understand the impacts of psychological trauma

A history of trauma can impact decision making and how one interacts with the health-care system. A patient may need further explanation of what could be seemingly basic tasks, or tasks that are often assumed to be implied consent. Trauma-informed principles become vital in these conversations. More information on trauma-informed practice can be found [here](#).

For many Indigenous patients and their families, consent was not historically obtained, whether it be in the residential school system, health-care system, court system or other oppressive system. It is important to reflect on how these events, and other aspects of colonialism and intergenerational trauma can impact informed consent

Focus on building trust and relationships first

Patients may feel apprehensive with a health-care provider for many reasons. Where complex decision making is required, more time may be needed to build a trusting relationship with the patient. This may mean setting up multiple appointments to get to know the patient or involving other care providers they trust.

Consider support systems

It is important to consider who the patient may need to help them navigate the health-care system and support them in consent conversations, especially for more in-depth or complex discussions and decisions. These support networks may be personal relationships, other health-care workers from the patient's local community that they trust, or Indigenous patient navigators within the health authorities. Informed consent may not be possible without these important supports.

However, while patients benefit from support from others, many do not have it. Patients, such as those experiencing homelessness, may be isolated from their families or other support

networks. Some patients may have friends or social relationships with people in their community whom they feel comfortable bringing to appointments. Other patients may benefit from peer navigators who may have common lived experiences and are typically associated with health authorities.