

Position Statement

Considerations for privacy and confidentiality in adolescent health care service delivery

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ABSTRACT

A hallmark of delivering quality adolescent health care services is the provision of confidential care. Key tenets when providing confidential care for adolescents include time alone with a health care provider, maintaining the privacy of health information, and securing informed consent for services without permission from a parent, guardian, or caregiver. While confidentiality is a basic principle for all health care encounters regardless of age, the unique considerations for capable adolescent patients are not always realized or appreciated. By ensuring appropriate quantity and quality of confidential care for adolescents, clinicians are better equipped to elicit a comprehensive history and physical examination, while empowering the adolescent involved to develop agency, autonomy, trust, and responsibility for their own health care decision-making and management.

Keywords: Adolescent; Confidentiality; Consent; Electronic health record; Privacy.

The importance of providing confidential care for adolescents cannot be overstated. Confidentiality is defined as an agreement between the patient and health care provider (HCP) that information discussed during medical encounters will not be shared with other parties without the patient's explicit consent (1). A comprehensive history and physical examination that includes sensitive personal information is often required for clinical decision-making involving adolescents. Full and truthful disclosure by individuals is essential to ensuring appropriate diagnostic testing and therapeutic management. Ensuring privacy and maintaining confidentiality is critical for effective, sensitive management of potentially stigmatizing health issues and enhanced quality care (2). Despite clear advantages, the delivery of confidential services remains suboptimal for adolescents in Canada (3).

The need for confidential care in all health-related encounters with adolescents has been endorsed by numerous international and national societies (4–7). Studies indicate that adolescents are more likely to access health care and disclose sensitive health information when confidentiality is assured (8,9). Concern regarding privacy is often cited as the primary barrier preventing adolescents from seeking health care services (9). In particular,

adolescents are less likely to openly communicate with HCPs around issues related to substance use, mental health, and sexuality when confidentiality cannot be guaranteed (10). Moreover, without confidential care, adolescents may decline routine services, such as sexually transmitted infection testing, or not engage in follow-up care (11).

Ensuring the proper provision of confidential care is also critical to the adolescent developmental trajectory. Time alone with HCPs fosters adolescent independence and the development of skills to better navigate both paediatric and adult health care systems (12). The autonomy and decision-making competencies nurtured by these interactions support age-appropriate developmental milestones essential for successfully transitioning to adult care (12).

LEGAL FRAMEWORK

In Canada, federal legislation such as the Privacy Act and the Personal Information Protection And Electronic Documents Act (PIPEDA) govern the collection, use, and disclosure of personal health information (13,14). These acts specifically recognize the right to privacy of all patients during medical encounters

but do not specify the age or circumstances to consider when determining the rights of young people to confidential care. Moreover, each Canadian province and territory has legislation regarding health record privacy protections, some of which takes precedence over PIPEDA. In most provinces and territories, responsibility is placed on the HCP to determine whether a particular adolescent's confidentiality should be maintained based on individual circumstances, with consideration of the patient's psychosocial development and maturity, behaviours, and family-related contextual factors. When an adolescent is deemed a 'mature minor' (i.e., is found to have the capacity and maturity to make health care decisions alone) and no risk to self is apparent, they may then consent to having their health records kept private (15). Two provinces diverge from the mature minor doctrine at the present time. In Quebec, the Act Respecting the Health Services and Social Services (16) specifically states that adolescents 14 years of age or older have the right to control access to their medical record. Similarly, Newfoundland and Labrador accord the right to privacy of medical information at age 16 (17). In both provinces, parents continue to have access to their adolescent's medical information before the ages specified by law.

Confidentiality versus consent

Confidentiality and consent are closely related but distinct concepts. While confidentiality focuses on keeping health information private, consent laws centre on the determination of decision-making capability. In general, informed consent requires that a decision-maker has the capacity to make a decision, is given all relevant information, and is making a voluntary decision freely, without coercion (18). There is no universally accepted, legally defined age of consent for health care decision-making in Canada. Therefore, just as with right to confidentiality, the capacity of adolescent patients to consent to a proposed treatment varies with age and circumstances and must be determined on a case-by-case basis. Similar to confidentiality laws, Newfoundland and Labrador (17) and Quebec (19) identify a specific age at which a minor can consent to low-risk treatments. All other provinces or territories in Canada function on the mature minor doctrine.

Limits to confidentiality

Even when the law explicitly protects the confidentiality of health information for adolescents, it may be permissible or even necessary to breach confidentiality in certain circumstances. Both the adolescent and the parent, guardian, or caregiver should be made aware of these circumstances by the HCP involved. Specifically, when an HCP deems that an adolescent is at risk of seriously harming themselves or others, confidentiality must be breached (20).

Furthermore, each province or territory has legislation requiring physicians (or other clinicians) to report to protective authorities when an adolescent is in need of protection. The provision includes reporting certain communicable diseases to public health, for example. HCPs may also be required to disclose confidential patient information due to a court order. HCPs must be aware of, and conversant with, the federal and provincial/territorial legislation affecting health care privacy and confidentiality in their jurisdiction.

FAMILY-BASED CONSIDERATIONS FOR CONFIDENTIAL CARE

Adolescent concerns

While adolescents may have a basic understanding of confidentiality, many are unaware of the specific protections that apply when they receive health services (21). HCPs should routinely counsel the adolescents they see regarding their right to confidential health care, along with any limits that may apply. Education on rights to privacy and confidential health care delivered through school-based or community health promotive programs could further alleviate concerns that might prevent adolescents from seeking health care. While some studies have shown that adolescents value confidentiality when interacting one-on-one with an HCP, others suggest that they can also experience discomfort during such encounters (22). Feelings of uneasiness around discussing sensitive information and concern about subsequent questions from parents or caregivers have been reported. Clear, routine discussions with adolescents and a parent or caregiver about the protections (and limits) of confidentiality before the medical encounter is initiated can help mitigate these concerns.

Beginning in early adolescence, spending at least part of each health visit alone with an adolescent patient, at regular intervals if not for every encounter, conveys the message that this is a routine practice and a valued part of health care. This private time provides opportunities for developing a trusting patient-provider relationship and invites discussion of sensitive health topics in an open and non-judgemental manner. Should a physician feel uncomfortable about being alone with a patient or reviewing certain sensitive topics, it is appropriate to consider a chaperoned discussion with another HCP present (23).

Parent or caregiver expectations

Studies suggest that parent and caregiver views on adolescent confidentiality are mixed, with physicians citing fear of parental resistance as a potential barrier to providing confidential care (24). While most parents and caregivers appear to acknowledge and recognize the benefits of adolescent confidentiality (25), they also report having concerns that confidentiality may promote risky behaviours or undermine their own protective role (22). Family members or caregivers might also believe that an adolescent feels comfortable discussing sensitive topics in their presence, and they may wish to be present to help intervene if something negative is impacting their adolescent's life.

To alleviate these fears, HCPs should consider communicating with parents early on around the developmental appropriateness—and the laws affecting—confidential health care for adolescents, and its demonstrable benefits. Posting notices in the waiting room to remind patients and families about the importance of confidential care may be beneficial. Also, confidential time should be presented to parents and caregivers as a routine part of the health care visit. HCPs are discouraged from asking in the presence of a parent or caregiver whether an adolescent would like time in private because the adolescent may feel uncomfortable with, or even reluctant, to agree.

In many circumstances, it is appropriate to encourage and support adolescents in discussing their health issues with a parent or caregiver. The Society for Adolescent Health and

Medicine (SAHM) and the American Academy of Pediatrics (AAP) encourage adolescents to discuss health issues with their parents while also supporting their right to privacy (5,26). This combined approach might involve discussion with adolescents about how they perceive a specific disclosure to parents, helping them to weigh the potential advantages of more open communication, and offering to facilitate communication with parents in ways that help the patient. Remember that some adolescents do not have parental support or, indeed, any meaningful connection with their families. In some cases, the disclosure of sensitive information to a parent or caregiver could put the adolescent at risk (e.g., of abuse, maltreatment, or being 'kicked out' at home). When clinicians encourage adolescents to communicate openly with their parents, it is essential to ask first about why they are reluctant to do so.

HEALTH SYSTEM CONSIDERATIONS

Technology

A fast-evolving issue related to the provision of confidential care for adolescents is the emergence and proliferation of health information technologies. While such platforms facilitate health care access and communication, they also create novel challenges to protecting the privacy of adolescents. Electronic health records (EHR) privacy controls cannot yet adequately address, let alone ensure, the confidentiality of adolescents. Patient portals available on most EHR platforms allow patients or caregivers to access to health information, including test results, diagnoses or problem lists, medications, and upcoming appointments. Few EHR platforms specifically protect confidentiality as a child moves into adolescence and becomes newly entitled to a private record. Moreover, sensitive health issues that an adolescent is not ready to disclose to others may be documented and accessed all too easily by other health professionals without explicit consent being given. Most EHR systems have not been designed to provide item-specific control over parental access and release of adolescent health care information. It is also costly for vendors to develop and maintain the levels of confidentiality mandated by law because they vary significantly according to jurisdiction (27). Clinicians are often left balancing their patient's need for confidentiality with creating an accurate and complete medical record.

The SAHM and the AAP have both advocated for improved EHR technology to address these unique challenges (28,29). EHR patient portals generally do not yet have the technical capacity to maintain or support the ability of minors to give consent for health care, or to protect their sensitive health care information (30). The optimal solution would be to develop a separate portal for adolescents when they are deemed mature minors, but such transitional technologies are not readily available. HCPs should advocate for EHR program development to block sensitive results from appearing on any patient portal.

Telemedicine and related technologies are rapidly transforming the way clinical care is provided. Telemedicine is defined as a two-way live communication between patient and provider at a distant site that includes audio or video equipment (or both) (31). Telemedicine can improve health care access and is likely to be an increasingly common option for medical

interactions because it allows flexible scheduling. However, several barriers to privacy protection exist when telemedicine is compared with in-person visits. The need to establish and guarantee a private environment is a leading priority for HCPs using telemedicine (32). In telemedicine visits, others may be present in-room but out of view, or sessions may be recorded without a patient's knowledge or consent. Moreover, adolescents do not always have a private, quiet space at home to transmit from. HCPs can encourage adolescents to sweep the room with their cameras to establish who is present, to use headphones, or to utilize chat functions to limit the ability of others to overhear medical conversations. At times, the best strategy may be to encourage the adolescent to find a secure location outside of the home (e.g., an office at school) to speak from.

Health care provider comfort level

There is wide range of understanding and practice regarding confidential care for adolescents in Canada (3). Paediatricians and family physicians alike report having insufficient knowledge of requirements and have identified the need for additional training and resources (33). Increasing education around privacy laws while reinforcing awareness of confidentiality concerns can improve knowledge gaps. Teaching on confidentiality should extend to all clinicians and front-line staff. Office staff should also be trained to welcome adolescents who present or call for an appointment on their own, and to safely relay test or other results.

Clinical setting

A broad range of facilitators and barriers to providing confidential care exist in different clinical settings (Table 1). Preventative health screening may be best addressed at routine health visits, but it is essential that HCPs create other opportunities to address confidential issues in various practice settings. Adolescents with higher levels of risk behaviours, (i.e., substance use or mental health issues) are more likely to use an emergency department (ED) as their primary source of care (34). Equally, adolescents with chronic health conditions engage in risk behaviours at similar or even greater rates than healthier peers (35), making tertiary care encounters another option for screening and risk prevention in this population.

Studies have shown that adolescent patients are interested in being screened and receiving information on safe sexual practices and other risky behaviours in both ED (36,37) and inpatient wards (38), regardless of gender, sexual experience, or relationship with primary care providers (39). Developing protocols to optimize confidential care in various settings can mitigate obstacles such as time constraints, space limits, and insurance practices that may compromise confidentiality.

SUMMARY

Adolescents have a right to confidential care and private time with their HCPs, and clinicians are legally and ethically obligated to provide routine, private, confidential care to adolescent patients. Clinicians providing adolescent care must understand the importance of confidentiality, its limits, and strategies to best facilitate the delivery of confidential care in the practice setting.

Table 1. Facilitators and barriers to providing confidential care for adolescents, by clinical setting

Clinical setting	Facilitators to confidential care	Barriers to confidential care	Strategies to improve confidential care
Outpatient clinic	<p>Long-term, continuous relationship with a primary care provider</p> <p>Flexible clinical environment (i.e., designing waiting rooms to maximize privacy or creating and providing pertinent reading material)</p> <p>Continuity of care from a young age allows for early, anticipatory discussions with parents around the need for one-on-one time for the adolescent and HCP</p>	<p>Long-term relationship between parents and the adolescent's primary care provider may cast doubt on privacy protections</p> <p>Long periods in a waiting room can increase feelings of self-consciousness and vulnerability, and may expose them to encounters with peers</p>	<p>Establish an adolescent-friendly environment (i.e., flexible hours, targeted reading material and artwork)</p> <p>Post prominent reminders respecting need for private, confidential medical care</p> <p>Establish a multidisciplinary health care team to integrate multiple services in one location and maintain a single medical record</p>
Emergency department (ED)	<p>High patient volumes allow for broad access to adolescents from different backgrounds</p> <p>Adolescents with higher levels of risk behaviours are more likely to use an ED as their primary source of care and flag positive when screened</p>	<p>Time constraints, long wait times, and lack of private spaces can lead to missed screening opportunities</p> <p>Triaging is often conducted in the presence of a parent or caregiver</p>	<p>Protocols to ensure routine screening for risk behaviours in a private setting at time of triage</p> <p>Tools for promptly screening risky behaviours (i.e., ASQ-S, CRAFT, HEADS-ED)</p>
Inpatient	<p>Patients typically spend several days on an inpatient unit, allowing time for in-depth screening</p> <p>Adolescents with chronic health conditions may not access primary care providers when hospitalized, making tertiary care physicians an alternate form of screening</p>	<p>Family-centred rounds are part of standard care, but discussions and decision-making at bedside are not private</p> <p>Certain hospital settings do not offer single patient rooms, further limiting private bedside discussions</p> <p>Large number of team members on clinical teaching units</p>	<p>Elicit and work to adolescent preferences regarding scheduling confidential discussions outside of rounds and including a parent or caregiver</p> <p>Schedule follow-up discussions with a smaller, more personalized team</p>

ASQ-S Ask Suicide-Screening Questionnaire; CRAFT Car, Relax, Alone, Forget, Friends, Trouble; HEADS-ED: Home, Education/Employment, Activities/peers, Drugs/alcohol, Suicidal Emotions/behaviours/thought disturbance, Discharge or current resources.

RECOMMENDATIONS FOR OPTIMIZING CONFIDENTIAL CARE WITH ADOLESCENTS

- HCPs must familiarize themselves with the federal and provincial or territorial legislation relating to health care privacy and confidentiality for their jurisdiction.
- HCPs should routinely counsel the adolescents they see in practice—and their parents or caregivers—about the meaning and importance of confidentiality, and any limits that may apply. These conversations ideally take place before the initial medical encounter to help mitigate any concerns.
- Beginning in early adolescence, HCPs should spend at least part of each health visit alone with an adolescent patient to convey that this is routine and valued health care practice. Clinicians should communicate to adolescents and their parents or caregivers the developmental importance of increasing autonomy and responsibility related to health care decision-making to facilitate better transition in navigating the adult health care system.
- HCPs are discouraged from asking in the presence of a parent or caregiver whether an adolescent would like time in private, because the adolescent may feel uncomfortable or reluctant to agree.
- Medical providers must be aware of their own EHR settings and limitations and should advocate for EHR program development to block sensitive results from appearing on any patient portal.
- Practice settings should review and revise their clinical procedures (including spacing limits, scheduling, charting) to ensure that adolescents' privacy and the confidentiality are fully protected. This could include posted documents describing patient rights and making sure families and clinical staff are familiar with and respect these rules.
- HCPs should have access to continuing education and training to ensure comfort and competence when providing confidential health care to adolescents at all stages in the patient journey. Teaching on confidentiality should extend to all front-line staff to ensure quality care for this population.

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