

Assessing and supporting adolescents' capacity for autonomous decision-making in health-care settings

A tool for health-care providers



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Abbreviations and acronyms

HCP	health care provider
WHO	World Health Organization

Glossary

Adolescent. WHO defines adolescents as people aged 10–19 years (7).

Adolescent-friendly health care and services. The WHO “quality of care” framework (2) sets five criteria for health services to be considered adolescent friendly:

- accessible: adolescents can obtain the available health services;
- acceptable: adolescents are willing to obtain the available health services;
- equitable: all adolescents, not just selected groups, can obtain the available health services;
- appropriate: the health services are those that adolescents need; and
- effective: the right health services are provided in the right way and make a positive contribution to health.

To be considered adolescent friendly, services must adhere to the eight WHO global standards to improve the quality of health-care services for adolescents (7).

Anticipatory guidance: Generally defined as discussions and counselling to anticipate and prepare parents or legal guardians, children and adolescents for significant developmental changes (physical, psychological, emotional, social) that may occur between health care visits. Includes all actions to promote progressive autonomy and self-management by adolescents and to help parents or legal guardians to support the autonomy of their child or adolescent. The capacity to express one’s point of view and to make decisions requires specific skills. Every health professional has a duty to support children and adolescents in the acquisition of such skills from an early age. Each contact with a child or adolescent is thus an opportunity to provide anticipatory guidance.

Attitude: A person’s values and beliefs about a process or person, which influence their behaviour (7).

Competence: A legal concept referring to the right to make an autonomous decision (i.e. a decision taken without authorization by a third party, e.g. parents or guardian). The age of competence depends on the national legal framework. In some high-income countries, minor adolescents are considered competent as long as, in a given situation, their health-care providers consider that they are capable of decision-making. In many other countries, competence is defined legally according to age.

Confidentiality: The right of an individual (e.g. adolescent) to privacy of personal information, including health-care records. Adolescents have the

right to privacy during consultations, examinations and treatments. Thus, confidential care is an essential component of the health care of adolescents and supports their autonomy. Health-care providers (HCP) should be able to inform adolescents and their parents or legal guardians about confidential care and its limits. In applying confidentiality, it is also essential to ensure effective communication with parents or legal guardians, as appropriate.

Decision-making capacity: While competence is a legal concept, capacity is a clinical concept that refers to the individual psychological or cognitive ability to make a decision. Usually, four dimensions are considered to contribute to the capacity for making decisions (3): how people understand information about their condition and the available options, how people compare the options by balancing risks and benefits and can discuss the potential consequences of a decision, how people discuss the relevance of the options for their own situation and how people can express a choice and argue it in the light of previous discussions.

Evolving capacity: The capacity of an adolescent to understand matters that affect changes in their life and health with age and maturity (7). The more an adolescent knows, has experienced and understands, the more the parent, legal guardian or other persons legally responsible for him or her can transform direction and guidance into reminders and advice, and later into exchange on an equal footing (4).

In health care, evolving capacity means that, as the adolescent matures, his or her views have increasing weight in choices about care. The fact that the adolescent is very young or in a vulnerable situation (e.g. has a disability, belongs to a minority group, is a migrant) does not deprive them of the right to express their views, nor does it reduce the weight given to the adolescent’s views in determining their best interests (5) and, hence, choices on aspects of care.

Informed choice: A choice made by an adolescent on the elements of his or her care (e.g. treatment options, follow-up options, refusal of services) as a result of adequate, appropriate, clear information for understanding the nature, risks, alternatives to a medical procedure or treatment and their implications for health and other aspects of the adolescent’s life. If there is more than one possible course of action for a health condition or if the outcome of a treatment is uncertain, the advantages of all possible options must be weighed against all possible risks and side-effects. The views of the adolescent must be given due weight according to his or her age and maturity (5).

Informed consent: A documented (usually written) agreement or permission based on full, clear information on the nature, risks and alternatives of a medical procedure or treatment and their implications, before the physician or other HCP begins the procedure or treatment. After receiving this information, the adolescent (or a third party authorized to give informed consent) either consents to or refuses the procedure or treatment. The procedures and treatments that require informed consent are stipulated in national laws and regulations. Although many procedures and treatments do not require informed consent, the adolescent should be supported to make an informed choice and give assent if they wish.

Rights: Adolescents' health-related rights include at least the following (1):

- Care that is considerate, respectful and non-judgemental of the adolescent's unique values and beliefs. Some values and beliefs are commonly held by all adolescents or community members and are frequently cultural and religious in origin. Others are held by the adolescent alone. Strongly held values and beliefs can shape the care process and how adolescents respond to care. Thus, each health-care provider must provide care and services that respect the different values and beliefs of adolescents. Also, health-care providers should be non-judgemental with regard to adolescents' personal characteristics, life-style choices and life circumstances.
- Care that is respectful of the adolescent's need for privacy during consultations, examinations and treatments. Adolescent privacy is important, especially during clinical examinations and procedures. Adolescents may desire privacy from other staff, other patients and even family members. Staff members must appreciate the needs of adolescent clients for privacy and respect those needs.
- Protection from physical and verbal assault and other forms of degrading and inhuman treatment. This responsibility is particularly relevant to very young and vulnerable adolescents, those who are mentally ill and others who cannot protect themselves or signal for help.
- Information that is confidential and protected from loss or misuse. The facility respects information as confidential and implements policies and procedures that protect information from loss or misuse. Staff respect adolescent confidentiality by not disclosing their information to a third party unless legally required and by not posting confidential information or holding client-related discussions in public places.
- Non-discrimination, which is the right of every adolescent to the highest attainable standard of health and quality of health care, without discrimination of any kind, irrespective of the adolescent's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status of his or her parents or legal guardian.
- Participation in care. Unless decision-making capacity is delegated by law to a third party or the adolescent lacks decision-making capacity as assessed by the relevant authority,¹ the adolescent decides on all aspects of care, including refusing care. The adolescent also decides which family member and friends, if any, participate in the care process. Adolescents' involvement in care is respected, irrespective of whether the adolescent has the legal capacity for decision-making. An adult's judgement of an adolescent's best interests cannot override the obligation to respect all rights of adolescents as stipulated in the Convention of the Rights of the Child (6). This includes the right of an adolescent who is capable of forming his or her own views to express those views freely in all matters that affect him or her and having those views given due weight in accordance with their age and maturity (1,5) (see also *Evolving capacity*). The facility supports and promotes adolescent involvement in all aspects of care through related policies and procedures.

Shared decision-making: Based on the premise that both the patient and the HCP are experts and work together in making a medical decision. This concept, which moves away from a unilateral, paternalistic view of decision-making, is now widely acknowledged as an essential component of patient-centred care (7). There are many models of shared decision-making. Most include the following components: describing treatment options, tailoring information, exploring patient preferences (concerns, goals, beliefs and values) and deliberation (seeking a consensual decision) (8).

¹ In many countries, health-care providers have the authority to assess whether an adolescent has decision-making capacity; in some circumstances, a decision is taken in court.

1. Introduction

Background and purpose

The right to participate is a fundamental right stated in the International Convention of the Rights of the Child. The definition of “child” in the Convention is children aged 0–18 years. Therefore, all adolescents should be able to participate and freely express their views on any decisions regarding their health, no matter their decision-making capacity. The weight given to their views and their degree of autonomy depend, however, on their decision-making capacity, which in turn depends on their biological maturity (for which age is a proxy measure) and their social, psychological and cognitive maturity, which depends to some extent on age but is also shaped by factors such as social networks, access to education and family context. Evaluation of decision-making capacity is therefore not straightforward for HCPs, many of whom lack training and tools in conducting such evaluations, and age is often used as the sole indicator of maturity.

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