

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

A tool for health-care providers

Web Annex. Algorithm for
health-care providers

Assessing and supporting adolescents' capacity for autonomous decision-making in health care settings: a tool for health-care providers. Web Annex. Algorithm for health-care providers

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This publication forms part of the document entitled *Assessing and supporting adolescents' capacity for autonomous decision-making in health care settings: a tool for health-care providers*. It is being made publicly available for transparency purposes and information.

Purpose of the tool

This tool is meant to help health-care providers in assessing the capacity and supporting the ability of adolescents to make autonomous decisions.

Introduction

The right to participation is one of the fundamental rights stated in the International Convention of the Rights of the Child. The definition of “child” in the Convention covers people aged 0–18 years. All adolescents must be able to participate and freely express their views on any decision regarding their health, no matter their level of decision-making capacity and the country they live in. Participation is therefore an integral part of the universal definition of quality of care for adolescents.

Although the universal framework defines the right of adolescents to participate actively in their own care, application of these guidelines varies widely among countries according to their legal and cultural contexts. The weight given to adolescents' views and their degree of autonomy depend on their decision-making capacity in some countries and on their age or other factors in others. In countries where adolescent participation is not supported, health-care professionals (HCPs) should advocate for their rights to be heard and to participate in decisions on their health.

Assessment of an adolescent's decision-making capacity is not straightforward for most HCPs. The factors that must be taken into consideration include the adolescent's developmental stage, the role of their parents or legal guardians, providers' attitudes, and important legal and ethical issues. The aim of this tool is to support HCPs in promoting the health of adolescents.

Scope of use according to the social and legal context of the country

Adolescents for whom a **decision on their health** must be made and on which they disagree with their parents or guardians and/or their HCP.

Examples:

- taking or stopping a medication or other treatment (including contraception)
- undergoing surgery
- undergoing examinations, laboratory tests, other investigations
- admission to hospital (including psychiatric hospitals)
- providers' attitudes

Adolescents who request care and do not wish their parents or guardians to know. *Examples:*

- a 15-year-old adolescent who smokes cannabis;
- a 14-year-old girl who wishes to take birth control pills;
- a 17-year-old adolescent with a diagnosis of HIV.



How this tool should be used

General guidelines

The process comprises several main steps, and the tool allows them to be navigated sequentially or non-sequentially, e.g. going back directly from step 3 to step 1.

The steps described in this tool should be fully integrated into the health-care process rather than applied separately.

The necessary, appropriate time should be taken for each step. It is strongly recommended that at least two consultations be planned, unless an urgent decision is required.

The HCP should spend the necessary time on each step according to the characteristics and complexity of the decision to be made.

Practical use of the tool

- Read the general considerations.
- Let the overview diagram guide you through the process.

Each step is numbered

1

For each step, a detailed description is given in a section with the same number.

- Each description consists of two parts:
 - The theoretical basis (**plain text**)
 - Concrete tips (**coloured boxes**) for use by the HCP in practice



General considerations

This section introduces the conceptual frameworks and definitions necessary for using this tool. It describes the integration of legal and ethical perspectives and defines the framework for use of the tool according to the age of the adolescent. The section also describes the main ways in which adolescents are supported and not only assessed in making decisions.

Reliance on children's rights and principles

This tool is an integral part of an approach to respect for children's rights (Convention on the Rights of the Child, 1989) and for fundamental principles.

Child's best interests and dignity

The best interests of children and respect for their dignity shall be primary considerations in all actions concerning them.

Participation

The Convention on the Rights of the Child states the right of the child "who is capable of forming his or her own views to express those views freely in all matters affecting the child". This implies that adolescents' participation in their care should be "respected irrespective of whether or not adolescents have a legal capacity for decision-making".

According to the concept of evolving capacity, their views should be given increasing weight because their capacity to understand matters that affect their health increases with maturity. Participation thus implies an evolution from childhood to adulthood that goes beyond the age of legal majority and for which the sole criterion of age is not sufficient to decide how to involve adolescents in their care.

Competence vs capacity

Competence is a legal concept, which refers to the right to give an opinion or to make an autonomous decision.

Capacity is a clinical concept, which refers to the individual psychological and cognitive ability to understand information, reason and deliberate to make a decision.

In some countries, minor adolescents (< 18 years) are considered competent if, in a given situation, their health-care provider and health-care team deem them so.

Considerations of age

The tool is specifically designed for use with minor adolescent clients. The legal definition of "minor" differs by setting. In most countries, minors are individuals under the legal age of majority (usually 18 years). The tool is designed for use with adolescents from the time they show significant cognitive capacity to make certain independent decisions (usually from the age of 10–12 years). Although the tool is applicable mainly to individuals aged 10–18 years old, younger children should still be involved in their own care and invited to express their views.

Assessing vs supporting decision-making capacity

This tool is designed to move from a vertical, unilateral view of an "assessment" of decision-making capacity to support a more active process, in which HCPs help adolescents to gain maturity in their decision-making capacity. The adolescent is seen as a partner, at the centre of the process that puts the adolescent rather than the disease at the centre of care. The practitioner's role is to support adolescents, with or without their families, to make decisions based on all the important elements.

The bioethics perspective

- Although ethical principles (respect for autonomy, beneficence, non-maleficence and justice) must be taken into consideration in making decisions, difficulties arise when they conflict (e.g. respect for autonomy conflicts with non-maleficence)
- No one principle is more important than another; therefore, when two or more principles conflict, their application should be based on the context of each situation and inform a decision that is in the best interests of the child in that particular situation. The role of the practitioner is to support the adolescent and/or parent or guardian in applying their values to a specific decision.
- The deliberative process described in this tool will provide reasons for weighing one value against another.





Overview of practical steps to assess adolescent capacity and support adolescents' autonomous decision-making

This section gives an overview of all steps at a glance. For details, click on the corresponding step.



Empathetic,
trustful and
respectful
climate

1

Joint exploration of the situation and options

With the adolescent. Consider involving the family and/or other significant persons at each step.

1a

Exploration of the **psychosocial context**, including resources and vulnerability factors



Adolescent



Family and/or other
significant persons



Health care
provider

1b



Information and common **understanding** of the situation and options



Comparison of the available options



Appreciation of the relevance of available options for the personal situation



Expression of choice by the adolescent

2

Common synthesis of the situation

With the adolescent. Consider involving the family and/or other significant persons at each step.

Summary of the main issues

Consensus building

3

Decision point – for one situation, at a given time

Capacity for autonomous decision-making present?

Yes

No or
questionable

Risk-benefit ratio in
light of the adolescent's
need for protection

Questionable
or unfavourable

Favourable

4a

Adolescent's
autonomous decision
Organization of follow-up

4b

Deferral of
decision for further
exploration and
support of capacity



Framework
of care to
support
autonomous
decision-
making





Empathetic, trustful, respectful climate

This section describes fundamental interviewing skills and attitudes for successful use of the tool.

Adolescent-friendly health care

The use of this tool should be embedded in an approach to care that is adolescent-friendly and respects adolescents' rights. The WHO "quality of care" framework lists five criteria for defining health services as adolescent-friendly:

- **Accessible:** adolescents are able to obtain the health services that are available.
- **Acceptable:** adolescents are willing to obtain the health services that are available.
- **Equitable:** all adolescents, not just selected groups, are able to obtain the health services that are available.
- **Appropriate:** the right health services (i.e. the ones they need) are provided to adolescents.
- **Effective:** the right health services are provided in the right way and make a positive contribution to health.

HCP may also rely on the WHO "global standards to improve quality of health-care services for adolescents".

Fundamental attitudes of adolescent health-care providers to support autonomous decision-making

- Treat every adolescent as an individual, with respect for their rights, needs and choices.
- Approach adolescents in a non-discriminatory and non-judgemental manner.
- Demonstrate empathy, reassurance, non-authoritarian communication and active listening.
- Demonstrate awareness of one's own attitudes, values and prejudices that may interfere with the ability to provide quality health care.
- Approach adolescent health care as a process, not as a one-off event.

A few general tips



- See the adolescent as a partner who can express choices; avoid a "paternalistic" approach.
- Accept that the adolescent has at least some capacity for autonomous decision-making.
- Focus on and support adolescents' strengths and resources
- Take as much time as necessary, over a few consultations if required.
- Give the adolescent some time alone during the consultation so that they can reflect on the information and discussion.

A few communication tips

- Use language that is developmentally appropriate.
- Explore the situation with an open mind, using open-ended questions.
- Be alert to verbal and non-verbal behaviour that may make the adolescent feel judged.
- Listen actively: reformulate/reflect, clarify, summarize, pay attention to the pace of the discussion.
- Recognize and help the adolescent to name the emotions they may be expressing.

Throughout the process, HCPs are encouraged to use features of **motivational interviewing** (<https://motivationalinterviewing.org>).





Framework of care to support autonomous decision-making

To support decision-making capacity, promote self-empowerment and autonomy through shared decision-making, confidential care and information delivery to your client +/- adult of reference.

Principles of shared decision-making

In shared decision-making, both the client and the HCP are experts, and they work together in making a medical decision. This concept is an essential component of client-centred care. Concretely, it consists of describing treatment options, tailoring information, exploring client preferences (concerns, goals, beliefs and values) and deliberation (seeking a consensual decision).

Confidentiality in adolescent health care

- Adolescents have the right to privacy during consultations, examinations and treatments.
- Protection of confidentiality is an essential component of health care for adolescents, because it enhances their engagement in care.
- Ensure confidentiality while supporting effective communication between adolescents and their parents, guardian or other caretakers.
- **Situations in which to consider breaking the confidentiality of adolescents, even if they are competent**, and reporting issues to the appropriate authority (**according to the legal context**):

Not exhaustive

- Disclosure of previous or current sexual abuse
- Disclosure of current or recent suicidal plans or significant self-harming behaviour
- Disclosure of imminent and credible homicidal intent.

Inform yourself about the legal framework

- What is the legislation in your country or area for adolescents' rights: right to consent to or refuse treatments, right to confidential care, access to confidential contraception and sexual health services, access to abortion, etc.
- Be aware of the fundamental rights stated in the CRC: participation, privacy, best interests, non-discrimination, etc.



Inform adolescents about their rights

- *Example:* "You have the right to be heard and to be involved in all aspects of your care. You can express yourself at any time, and we will always take your opinion into account."

Inform adolescents about how you share decision-making

- *Example:* "If you have to make a decision about your health, we will work **together** to understand your concerns. We will assist you in **understanding** your options. We aim to **agree** on the decision that will serve your best interests."

Inform the adolescent about how you manage confidential care and the involvement of parents or legal guardians

Examples:

- "You have the right to **privacy**. This means that, unless you report a serious condition that threatens your life or that of other people, you have the **right to confidential care**."
- "We still strongly encourage you to **share some information with your parents or guardian**."
- "At the end of the consultation, we will **agree** on the way to give **feedback** to your parents or guardian."



Exploration of the psychosocial context, including resources and vulnerability factors

Exploration of both the psychosocial context and the emotional state of your client is essential to assess conditions that influence the capacity for decision-making.

Resources*

- Purpose in life, plans for the future
- Problem-solving skills
- Spiritual beliefs
- Strong family connectedness
- Positive family climate
- Sound relationship with one or more adult(s)
- School or professional integration
- Good relationships with teachers and schoolmates
- Significant friendships (on- and offline)
- Social and creative activities

**These lists include examples and are not exhaustive*

Vulnerability factors*

- Chronic illness or pain
- Isolation
- Mental distress or illness
- Risk-taking behaviour (e.g. substance misuse, unprotected sexual intercourse, poor adherence to treatment, juvenile delinquency)
- Parent(s) or guardian(s) with vulnerability factors (e.g. psychiatric illness, substance use disorder, unemployment)
- Significant family conflicts
- Social vulnerability (e.g. poverty, homelessness)
- School or work drop-out
- Violence (psychological, physical, sexual, neglect)
- Peer pressure

Developmental considerations. Impact of the emotional context

The capacity to foresee the consequences of a decision may be influenced by the emotional state, especially among adolescents because of specificities in their brain development. Thus, reasoning capacity and decision-making might be altered in situations of high emotional arousal ("hot cognition") versus low emotional arousal ("cold cognition"). It is essential that the HCP be aware of these aspects and provide a safe, calm atmosphere for optimal reasoning, to enhance decision-making capacity.

Possible questions for assessing resources and vulnerability (based on a modified HEEADSSS)



Attention:

Remember **not to** use these questions as a "check-list" and to pay attention to communication aspects



See more examples of questions on the [next page](#)

→ Strengths and interest

Tell me what you're most proud of.

→ Health condition

How do you feel about your health condition?

→ Home

What are relationships like at home?

→ Education and employment

What is your current occupation?
How is it going?

→ Activities

What do you and your friends do for fun?
(with whom, where, and when?)

→ Drugs

Do you or your friends use tobacco, alcohol or other drugs?

→ Sexuality

Have you ever been in a romantic relationship?

→ Suicide, self-harm and depression

Do you feel sad or down more than usual?
Are you "bored" or tired all the time?

→ Safety

Do you witness violence around you or have you ever been victim of violence?



Exploration of the psychosocial context, including resources and vulnerability factors

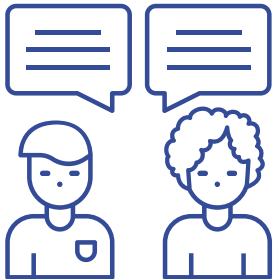
(Continued)

Possible questions for assessing resources and vulnerability (based on a modified HEEADSSS)



Attention:

Remember **not to** use these questions as a “check-list” and to pay attention to communication aspects



For a more complete HEEADSSS interview:
<https://www.yphsig.org.uk/resources-1/app>

→ Strengths and interest

How would you describe yourself? Tell me what you're most proud of. How would your best friends describe you? Do you have spiritual beliefs?

→ Health condition

How do you feel about your health condition? How are you dealing with your medication? Who helps you with your medical care?

→ Home

Where do you live? Who lives with you? What are relationships like at home? Who can you rely on when you have a problem? Have you ever been involved in or witnessed violent situations within your family?

→ Education and employment

What is your current occupation? How is it going (grades, relationships with friends and teachers etc.)? What are your future education, employment plans or goals?

→ Activities

What do you and your friends do for fun? (with whom, where, and when?) Do you have a “best” trusted friend? How much time do you spend on screen/ Internet and for what purpose?

→ Drugs

Do you or your friends use tobacco, alcohol or other drugs? Characterize the exploratory vs risky nature of substance use.

→ Sexuality

Have you ever been in a romantic relationship? Are you attracted to boys? Girls? Both? Have you ever been forced or pressured into doing something sexual that you didn't want to do? How do you protect yourself?

→ Suicide, self-harm and depression

Do you feel sad or down more than usual? Are you “bored” or tired all the time? Does it seem to you that you have lost interest in things that you used to really enjoy? Do you find yourself spending less and less time with friends? Are you having trouble getting to sleep? Have you thought a lot about hurting yourself or someone else? Have you ever thought of committing suicide? Do you have concrete plans to commit suicide?

→ Safety

Have you ever been seriously injured? How? Do you always wear a seatbelt in a car or use a helmet when biking or riding a motorbike? Have you ever ridden with a driver who was drunk or high? Do you sometimes text (mobile phone) while driving? Do you witness violence around you?



1b

Exploration of decisions and options with the adolescent

Exploration with the adolescent of the available options in four steps.

In a discussion on a decision, four main areas, derived from the MacCAT-T tool (assessment of adult decision-making capacity), should be explored with the adolescent.

1. **Understanding:** sharing information and exploring understanding of the situation and options and that a choice has to be made. Information should be provided in comprehensible, developmentally appropriate language.
2. **Reasoning:** comparing the options by balancing risks and benefits and discussing the potential consequences of a decision
3. **Appreciation:** discussion of the relevance of the various options for the personal situation
4. **Expression:** expressing a choice after arguing it in the light of previous discussions

N.B. In this section, the term may refer to: taking or stopping a treatment; request confidential care; accept or refuse an intervention, etc.

Remember that the phrasing of questions should be developmentally appropriate.

Information and common understanding of the situation and options



Provide detailed information in clear, developmentally appropriate language

- What have you been told about your condition and your current treatment?
- Have I or other professionals explained it well enough? What other information do you need?
- What is your illness, condition or situation, and how does it affect your health?
- What treatments or investigations are necessary and why? Why is confidential care necessary?
- When is the treatment or investigation to be done?
- What does this option or decision mean to you, and how will it affect your life (in the short, middle and long term)?
- What will be the impact of your condition and your option or decision on you and on your family, school and friends?

Comparison of the available options (reasoning)



- Do you understand the consequences of this option or decision for your present situation?
- Do you have in mind an alternative to this option or decision?
- Can you describe or explain the pros and cons of this option or decision?
- Can you describe or explain the pros and cons of the alternative option(s)?

Appreciation of the relevance of available options for the personal situation



- Do you think that this option or decision is the best for you? Could you tell me why?
- Do you think that your prior experience has influenced your decision? How?
- What does this option or decision mean to your parents or legal guardian?
- Why do you think your parents or legal guardian should or should not be involved in the decision?
- How have you taken important medical or other decisions in your family?

Expression of choice



- What option would you choose? What decision would you take?
- How have you ended up with this option or decision?
- Does this option or decision feel right to you?
- (In the absence of a decision) Why is it so difficult for you to reach a decision?
- Is there anything we can do to help you reach a decision?
- Is there anyone you trust who would help you make a decision? Should they be present? Why or why not?



2

Common synthesis of the situation

After the first step of exploration, the second important step is to synthesize the overall situation with the adolescent +/- parent(s) or legal guardian and other significant people.

Then, a decision should be taken on whether the adolescent has the capacity to make an autonomous decision. If they have the capacity, given that the tool is applied to minor adolescents, the HCP should further reflect and weigh the situation to decide on the need for protection, depending on the legal context of each country.

Key questions for synthesis and consensus-building on the decision



- What are the **characteristics of the situation and of the decision to be made** (complexity, short and long-term impact, invasiveness)?
- Are there **vulnerability factors** that put the adolescent at risk according to the decision to be made? What **resources** can be used to minimize this risk?
- What factors support or hinder the ability of the adolescent to **freely express and make an autonomous choice**?
 - At what point is the adolescent free to express their own choices and opinions?
 - How do their relationships with their parents or legal guardian and with the HCP influence their choice?
 - At what point is the adolescent capable of maintaining their choice in the face of conflicting views (parents, legal guardian or HCP)?
- What is the **emotional state** of the adolescent, and how much does it influence their decision-making capacity?
- What is the **influence of your own beliefs, values and representations as an HCP** on the perception of the situation?
 - What are your attitudes and emotions in this situation?
 - How do you interpret these in light of your own experience?
 - How do your own beliefs, values and representations influence your perception of the situation?

- **Who else should be involved** in supporting the adolescent's decision-making process? *(to be discussed with the adolescent)*
 - Adolescents' parents or legal guardian?
 - Another trusted adult relative? Friends?
 - Other professionals who know the adolescent well (e.g. teacher, educator, mental health provider, social worker)



3

Decision point

You may use the following practical visual diagram to help you synthesize the situation and reach consensus on the decision

IMPORTANT: This diagram is an aid for synthesis and orientation and not a tool for deciding whether an adolescent is capable of making autonomous decisions. It should be used flexibly and be integrated into the overall process.

Select levels as appropriate:	High impact/risk	Low impact/risk
Characteristics of the situation	Highly invasive	Not invasive
Level of vulnerability in light of the decision to be made	High vulnerability	Low vulnerability
Level of resources and strengths	Low	High
Key elements of decision-making capacity		
Ability to understand the situation and options	Low	High
Ability to reason about the different options	Low	High
Ability to appreciate the relevance of options for the personal situation	Low	High
Ability to freely express a choice and argue it in the light of the discussion	Low	High

Key questions to integrate the bioethics perspective into the synthesis:



- What are the main issues at stake?
- Who is responsible for making the final decision with the adolescent?
- Which ethical values are emphasized by each option?
- What are the conflicts between the different values?

Do not remain alone

Consider involving a third party or/and an ethics expert



- Discuss the situation with a colleague who is not emotionally involved or on your team, as appropriate
- In complex situations and when available, consider involving an expert in bioethics (e.g. bioethics consultant)



4a Adolescent's autonomous decision / Organization of follow-up

Decision-making capacity is constantly evolving and will be enhanced by anticipatory guidance. Follow-up is necessary whether the adolescent has or has not the capacity for decision-making, either to evaluate the decision taken or to promote capacity where the adolescent could not make their own decision.

Anticipatory guidance

Generally, anticipatory guidance is considered to be the set of discussions and counselling actions carried out with the aim of anticipating and preparing for significant developmental changes (physical, psychological, emotional, social, etc.) that occur between health care visits.

The capacity to express one's point of view and to make decisions requires the acquisition of progressive autonomy and self-management for the adolescent as well as actions to help parents and guardians to support the autonomy of the child or adolescent. Every health professional has the duty to support children and adolescents in acquiring such skills from an early age. Thus, each encounter is an opportunity to provide anticipatory guidance.

Remember that decision-making capacity and medical conditions evolve over time. Therefore, any important decision requires follow-up, planned in consultation with the adolescent +/- parents or legal guardian.



Set the conditions and framework for further follow-up (including the place of parents, legal guardian or gatekeepers)



- **Schedule follow-up visits as appropriate.**
- **Discuss at each visit:**
 - Implementation of the decision: barriers to implementation, impact on clients and parents or legal guardian
 - Evolution of the medical condition
 - Needs of the client and parents or legal guardian
 - Psychosocial context and well-being
 - Is consensus still reached?
 - › YES: continuing follow-up
 - › NO: repeat the whole process

Provide anticipatory guidance focused on decision-making capacity

- **Promote progressive adolescent autonomy and self-management by:**
 - Providing time alone during follow-up visits
 - Proactive involvement in any decision from childhood (help children to express their choices and make decisions before entering adolescence)
 - Dealing with adolescents first for any discussion about their health and follow-up (e.g. lab result, scheduling appointments)
 - Promoting adolescent health literacy (e.g. developmentally appropriate didactic material)
 - Supporting adolescents in expressing their choices in their daily lives
- **Support parents, legal guardians or gatekeepers in promoting the autonomy of the child or adolescent:**
 - Explain the benefits of progressive autonomy and self-management for their child or adolescent
 - Discuss with the adolescent and parents or legal guardian concrete progressive steps to promote self-management (e.g. *daily medication management, going to follow-up visits alone*)



4b

Deferral of decision for further exploration and support of capacity

When capacity for decision-making is not present or questionable OR when consensus is not reached because of worries about the adolescent's need for protection, the final decision should be deferred if possible in order to take sufficient time to explore the reasons. The goal is therefore to go through the steps of the process again in order to find solutions together with the adolescent (+/- their parents or legal guardian) in order to reach consensus.

In summary, it is about answering the question “**WHY** consensus was not reached and **HOW** can we reach it?”

- Schedule subsequent visits – Allow as much time as possible for the interaction
- Involve at least **another professional** (third party and/or ethics expert)
 - At least, discuss the situation with a colleague who is not emotionally involved or on your team, as appropriate.
 - In complex situations and when available, consider involving an expert in bioethics (e.g. bioethics consultant).
- Explore with the adolescent +/- family or legal guardian why consensus was not reached, and explore together what support is necessary to reach one (see table on the right).



Examples of questions (WHY)	Possible actions (HOW)
Did the adolescent have all the necessary information about their medical situation and available options to make a decision?	Ask the adolescent to make a list of questions, check for understanding, and provide the necessary information in developmentally appropriate language.
Is there anything that puts the adolescent in an emotional state that impairs their capacity to make a decision?	Support the adolescent by providing the appropriate conditions to explore the issues.
Does the adolescent have the support necessary to make a decision?	Discuss with the young person whether other people should be involved in the discussion or if they have a trusted person with whom they can talk.
Are there any vulnerability factors that you are concerned about that would cause you to disagree with the adolescent's choice, even if they are competent to make this decision?	Identify these concerns with the adolescent, and explore together the resources that can be mobilized to minimize the risks.
Does the adolescent's current health status (e.g. pain, intense psychological distress) prevent them from making a decision in this situation?	Provide specific support as appropriate.
How do personal and familial prior experiences, beliefs, values and representations influence the decision-making process? What influence do relationships within the family have? Any coercive influence?	Schedule subsequent visits to explore the issues with the adolescent alone. Consider scheduling a meeting with the family or legal guardian as appropriate.
Have you explored in depth how your own experiences, values and representations influence your judgement of the situation?	Ask yourself these important questions again. Discuss the issues with at least one other colleague or on your team.



