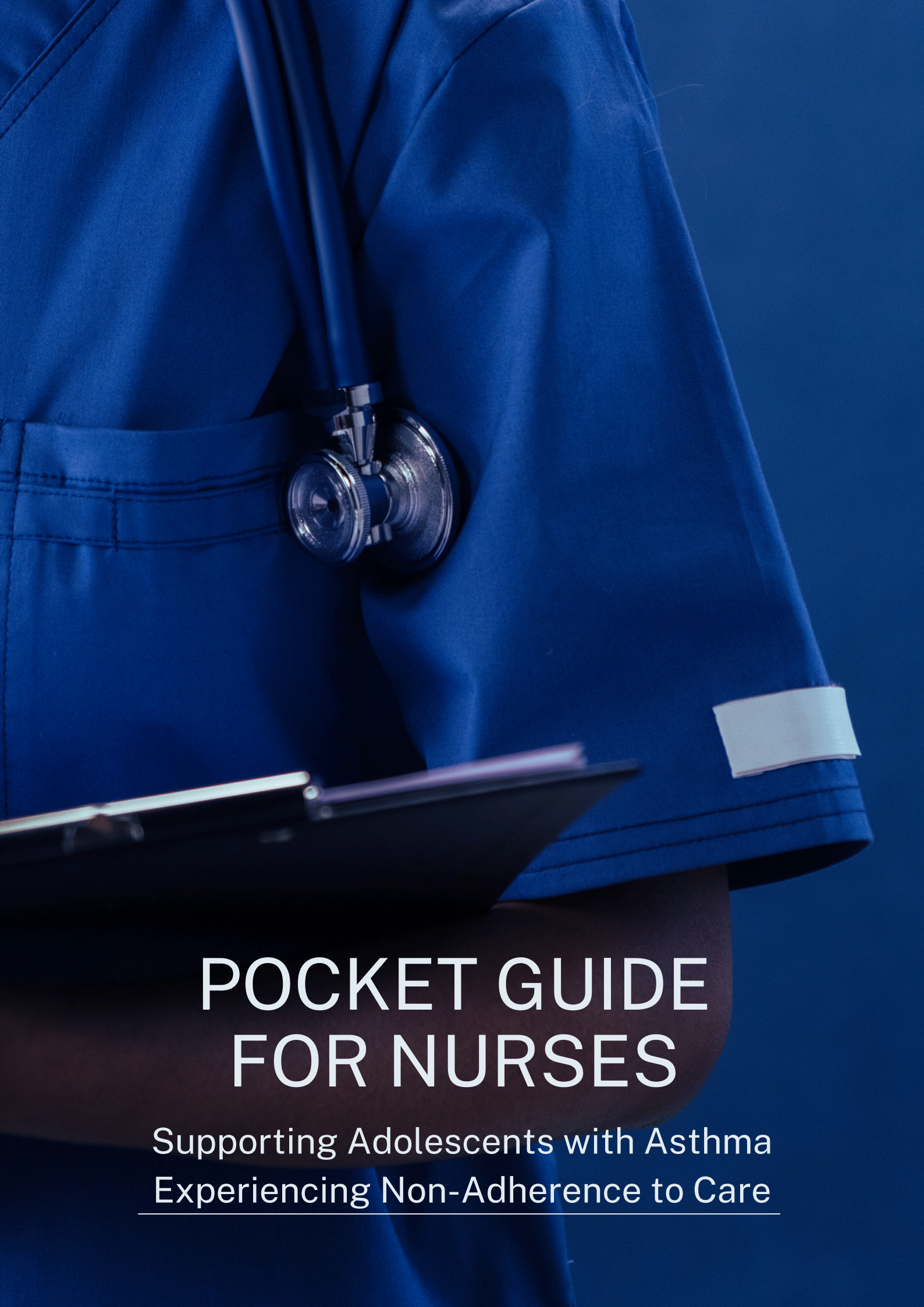


POCKET GUIDE FOR NURSES

Supporting Adolescents with Asthma Experiencing Non-Adherence to Care

SUMMARY

1. Context & Objectives

Adolescence is a critical period, marked by a search for autonomy, psychosocial vulnerability and, for adolescents with asthma, the additional burden of managing a chronic disease.

In asthma, treatment non-adherence affects **more than 50% of adolescents** (Bender, 2016) and compromises their health.
It is multifactorial, involving the search for autonomy, stigmatisation, difficulties accepting the disease, and disruption in the relationship with healthcare professionals (Holley et al., 2018).

Hospital nurses play an essential role in supporting the transition toward autonomous self-management.

Objectives of the Guide:

- Provide nurses with a screening and targeted intervention protocol to improve adherence to care among adolescents hospitalised for asthma.
- Promote nursing care tailored to adolescents experiencing non-adherence.
- Provide practical tools to strengthen adherence and support transition.

Target audience: Hospital nurses working in paediatric settings.

2. Care Pathway

a. Identification of the Risk of Non-Adherence

When should non-adherence be suspected?

Clinical criteria	YES/NO
Repeated missed treatments	□ / □
ACQ score < 15 (poorly controlled asthma)	□ / □
Recent hospitalisation for an asthma attack	□ / □
Statements minimising or rejecting asthma	□ / □
Inhaler not used at school	□ / □
Reluctance to attend or absence from medical or nursing consultations	□ / □

TYPICAL PROFILE OF A NON-ADHERENT ADOLESCENT :

- Trivialised perception of the disease
- Low motivation or feelings of incompetence
- Stigmatisation related to treatment (e.g. using an inhaler in public)
- Lack of therapeutic education or family support
- Hidden anxiety or depressive symptoms

*If the patient presents ≥ 1 clinical criterion and/or a typical profile, it is recommended to further investigate by administering the **MARS scale**, which assesses medication adherence by identifying non-adherent behaviours. Subsequently, the care pathway should be initiated.*

2. Care Pathway

b.Structured Nursing Assessment

Objective: To collect clinical, psychosocial and educational information in order to develop a personalised support plan.

- **Clinical situation:**
  - Collect medical history, frequency of exacerbations and recent hospitalisations.
  - Identify known triggering factors.
  - Assess asthma control using the **ACQ scale.**

→ Tip : Asking the adolescent to describe their last asthma attack or most recent missed treatment often helps initiate a non-judgemental dialogue.

- **Factors influencing adherence:**
  - Observe the adolescent's behaviour in hospital (e.g. avoidance of treatment administration, intentional omission, verbal opposition).
  - Explore their perceptions of the disease ("What does asthma mean to you?") and of treatment using tools such as the **B-IPQ** or illustrated vignettes.
  - Identify personal barriers (fear, shame, forgetfulness, side effects).
  - Identify emotional and contextual factors such as family stress, school pressure and peer influence using the **HEADSSS assessment** tool.
  - Explore autonomy, the adolescent–parent relationship and the adolescent's role in decision-making.
  - Assess the level of digital health literacy (**eHEALS**).
  - Identify environmental factors such as family conflict, school environment, social and economic vulnerability.

→ Note: Adolescence is a period of identity development. Opposition or trivialisation of risks may sometimes represent a form of self-assertion.

2. Care pathway

b. Structured Nursing Assessment

- **Understanding and knowledge of treatment:** *self-management skills*
  - Check whether the adolescent understands the purpose of their maintenance treatment, how it works, and the difference between maintenance and rescue treatment.
  - Verify whether they know how to use the inhaler device by asking them to demonstrate it.
  - Ensure that they recognise warning signs and know how to respond appropriately.

→ *Examples of questions : "Can you tell me what this medication is for?" ; "When do you usually take it?"*

- **Relationship with caregivers and relatives:**
  - Who is involved in the daily management of the adolescent's asthma?
  - Are the parents informed and supportive, or conversely overwhelmed or overly intrusive?
  - What level of autonomy does the adolescent want? And how is this perceived by the parents?
  - Are there tensions or misunderstandings regarding treatment?

→ *Tip : Reconcile perspectives by encouraging mutual listening through both joint and separate discussion sessions.*

- **Educational and support needs:**
  - Identify preferred learning methods (visual, verbal or practical).
  - Assess the need for a structured therapeutic patient education (TPE) programme.
  - Identify internal resources (motivation, personal goals) and external resources (family, school and peer support, etc.).
  - Determine the need for referrals (psychologist, paediatrician, etc.).

2. Care pathway

c. Nursing Approach

Objective : To build a relationship of trust and attentive listening from the very first contact.

Fundamental principles:

- The nurse acts as a supportive, stable, and non-judgemental figure, which is essential during a period of identity instability.
- Respecting the adolescent's pace is essential: avoid rushing and allow space for free expression.
- Every intervention should be adapted to the adolescent's level of maturity, knowledge, perceptions of the disease and educational preferences.

Good practices:

- Use active listening and regularly rephrase information to ensure understanding.
- Avoid overly technical terms and favour clear, visual and interactive communication methods such as videos, comics or games.
- Encourage decision-making autonomy through open-ended questions:
- "What do you think about this treatment?" ; "What makes it difficult for you to take this medication every day?".
- Integrate emotions into the approach (e.g. fear, shame, anger) without minimising or judging them.
- Ensure a non-patronising approach by co-constructing care with the adolescent, recognising them as a partner in care.
- Show genuine interest in their hobbies, habits and daily life (e.g. sports, school, social media, etc.).
- Respect confidentiality (within legal limits) in order to strengthen trust.

→ *This approach is based on a patient–parent–healthcare professional partnership that recognises the adolescent's experiential knowledge.*

2. Care pathway

d. Nursing Strategies

Concrete, flexible and adaptable strategies are necessary to address the complexity of non-adherence among adolescents with asthma.

INDIVIDUALISED THERAPEUTIC EDUCATION

- Carry out practical demonstrations validated by the adolescent: “Show me how…” rather than “Tell me how…”.
- Use age-appropriate visual materials (videos, games, etc.), such as “De bien mystérieuses traces” by the Ligue Pulmonaire (2012).
- Provide education in short, repeated sessions over several days to reinforce learning.
- Offer a blended educational approach combining engaging digital tools and personalised educational consultations, allowing adolescents to ask questions, express their feelings and develop practical self-management skills.
- Co-construct a personalised action plan with the adolescent: “What would you do if you experienced this symptom?” (See Checklist for Adolescents with Asthma).
- Encourage tripartite communication with dedicated one-to-one discussion times.
- Train parents to adopt a gradual supportive role while avoiding excessive reminders that may create frustration.

SUPPORTING AUTONOMY

- Suggest the use of mobile monitoring applications (e.g. AsthmaMD) with medication reminders.
- Strengthen self-esteem through positive reinforcement: “You handled that really well today.”
- Implement a personalised follow-up chart (paper or digital) with weekly goals.
- Clarify with parents the role they wish to play and encourage a gradual reduction in parental control whenever possible.
- Establish longitudinal nursing follow-up through regular interviews to support transition and improve adherence.

2. Care pathway

d. Nursing Strategies

INTEGRATION OF PSYCHOSOCIAL DIMENSIONS

- Identify the adolescent's concerns: "What is the most difficult thing for you right now (apart from asthma)?".
- Use assessment tools such as the HEADSSS interview or the PAQLQ.
- Observe indirect signs such as irritability, withdrawal or contradictory statements,...
- Encourage emotional expression through emotion cards or non-verbal tools (e.g. pictograms).
- Rephrase feelings empathetically: "You may be feeling overwhelmed by all of this?".
- Consider the impact on school life: "Does your asthma affect your classes, sports or friendships?".
- Collaborate with the school nurse.
- Encourage adolescents to identify their own solutions for balancing social life and asthma management.
- Strengthen family relationships and involvement by highlighting the adolescent's efforts in front of their parents.
- Clarify roles: "How could your parents support you without making you feel constantly monitored?".

TRANSITION

- Assess maturity using the Good2Go scale.
- Structure a transition pathway (see Nursing Transition Protocol).

INTERDISCIPLINARY COLLABORATION

- Organise multidisciplinary meetings involving the physician, healthcare team and psychologist when necessary.
- Refer to a paediatric specialist nurse or advanced practice nurse when the clinical situation exceeds first-line interventions (persistent non-adherence, comorbidities, educational difficulties).
- Include the specialist nurse in multidisciplinary meetings and care plan development.
- Communicate key information to the healthcare network: school nurse, family physician, physiotherapist.
- Offer outpatient educational follow-up or post-hospitalisation nursing consultations.

2. Care pathway

d. Nursing Strategies

MOTIVATIONAL INTERVIEWING

The aim is to strengthen intrinsic motivation for behavioural change.

Core principles (Miller et Rollnick, 2023)**:**

- Express empathy through active, non-judgemental listening.
- Reinforce change talk by reflecting and reformulating statements that support change.
- Roll with resistance rather than directly confronting barriers.
- Support self-efficacy by highlighting the adolescent's successes and abilities.

Good practices :

- Choose a calm, interruption-free environment that feels safe and reassuring.
- Adopt an open and approachable body posture.
- Allow moments of silence and avoid trying to convince the adolescent at all costs.
- Use visual tools to illustrate the potential benefits of change.
- Co-construct an eco-map and a genogram with the adolescent to gain an overview of their resources → useful as an intra- and interdisciplinary communication tool.
- It is recommended to assess the importance of change, confidence and motivation using **Likert-type scales** (from 0 to 10), commonly used in motivational interviewing.

Motivational interviewing can be used briefly (5–10 minutes) during an informal conversation or within a more structured framework.
It naturally fits into an educational approach centred on the adolescent's active participation.

Examples of questions :

- "What do you like about not having to take your treatment? And what bothers you about this situation?" → open-ended question
- "On a scale from 0 to 10, how ready would you be to try taking your inhaler regularly? What would help you move to a higher number?" → assessment
- "You're telling me that you're tired of asthma... and that you don't really see the point of the treatment. Would you like us to try to understand this together?" → reflective statement and invitation to explore without imposing

3. Healthcare network

Geneva / Vaud (Canton of Vaud)

In Geneva :

- **HUG – Paediatric Pulmonology Unit**

Tailored inpatient and outpatient care for adolescents with asthma. Age range: from 0 to 18 years. Individualised follow-up, action plans, allergy assessments and school coordination.

- **Centre for Allergies and Asthma (CAAT – Geneva)**

Paediatric and allergy consultations for children and adolescents. Age range: from 4 years to adulthood. Multidisciplinary team including pulmonologists, allergists and educators.

- **Ligue pulmonaire genevoise – Workshops and support groups for families**

Sessions adapted for young people, including individual and group therapeutic education.

- **OneDoc – Pulmonologists for adolescents**

Network for booking appointments with pulmonologists, including specialists trained in paediatrics and adolescent care. Age range: up to 16 or 18 years depending on the practice. Community-based follow-up possible with links to HUG if required.

In Lausanne / Vaud :

- **CHUV – Asthma School (Department of Women, Children and Adolescents)**

Age range: from 5 to 16 years (children and adolescents). Educational sessions including demonstrations and explanations about treatments and asthma attacks. Parental participation encouraged.

- **CHUV – Severe Asthma Consultation**

For adolescents with difficult-to-control asthma or complex treatments. Age range: from 12 years to adulthood. Coordination with paediatric services when necessary.

- **EHNV – Asthma School (Yverdon / Nord Vaud)**

Therapeutic education modules linked with CHUV. Age range: from 5 to 16 years. Partnership with parents and school structures.

- **aha! Swiss Allergy Centre**

Provides holiday camps, helplines and educational resources for young people with asthma. Age range: from 8 to 18 years (specific programmes available).

4. Algorithm for the Management of Non-Adherence

Initial Identification

- Frequent missed treatments
- School absenteeism
- Minimising discourse or treatment refusal
- Irregular attendance at consultations
- Recent hospitalisation for an asthma attack

Nursing Clinical Assessment

- MARS scale
- Observation of behaviour towards care and treatment
- ACQ scale
- Good2Go questionnaire
- Identification of cognitive, social and emotional barriers
- Assessment of family and school support: HEADSSS assessment tool

Confirmed non-adherence

- Age-appropriate therapeutic patient education (TPE)
- Co-constructed SMART goals
- Use of a mobile application (e.g. “Living with Asthma”)
- Development of a personalised action plan
- Positive mirroring (e.g. testimonies from other adolescents)
- Interdisciplinary collaboration with the school nurse / family physician
- Strengthening self-esteem

>>> Integration into the support programme

Confirmed adherence

- Regular reassessment
- Tripartite collaboration: adolescent–parents–nurse
- Strengthening communication between the healthcare professional and the adolescent
- Clarification of roles: what the adolescent does and what the parent does
- Encouraging shared decision-making
- Valuing progress and achievements

Progressive Adherence

The adolescent :

- progresses towards the defined goals
- uses a diary or an app to monitor treatment intake
- gains confidence
- expresses their needs during consultations

The healthcare professional becomes a “temporary guide”.

Long-Term Follow-Up

- Patient partnership approach
- Remote nursing follow-up
- Regular reassessment and adjustment
- Access to additional resources: suggestion to join a support or discussion group
- Easy access to healthcare professionals if needed
- Preparation for transition to adult care

5. Additional Information

Additional resources

- Checklist for adolescents with asthma
- Nursing transition protocol for adolescents with asthma
- Personalised care plan template
- Comic book
  - **“De bien mystérieuses traces” by the Ligue pulmonaire suisse (2012),** available for download in PDF format and in the three national languages.
    https://www.liguepulmonaire.ch/materieldinformationcHash=0ae174c9e6b34985bee99ee2fefdc313&tx_pubshop_pi1[page]=3&tx_pubshop_pi1[action]=index&tx_pubshop_pi1[controller]=Publication&f[0]=topics%3A163&f1]=topics%3A175&f[2]=topics%3A552&page=2
- YouTube videos for adolescents to raise awareness about asthma *(French-language educational video)*
  - **L'asthme | TiDoc | Zone Jeunesse**
    https://www.youtube.com/watch?v=-9qqrx-dE5s
  - **“respire” la mini série qui t'aide a respirer**
    https://www.youtube.com/watch?v=Oy1Y2ZRL8FY
  - **"L'Ado qui n'écoutait pas son Asthme" - Film d'animation par la GPFD**
    https://www.youtube.com/watch?v=QghEU4mnETw
  - **"La chaise vide" - Gregory Pariente Foundation - Prévention de l'Asthme chez l'adolescent**
    https://www.youtube.com/watch?v=RRlK5xLNrDo

6. APPENDICES

1. MARS Scale
2. ACQ Scale
3. HEADSSS Tool
4. eHeals Scale
5. PAQLQ Tool
6. B-IPQ Scale
7. Good2go Scale

APPENDICES

Table 1: MARS Scale

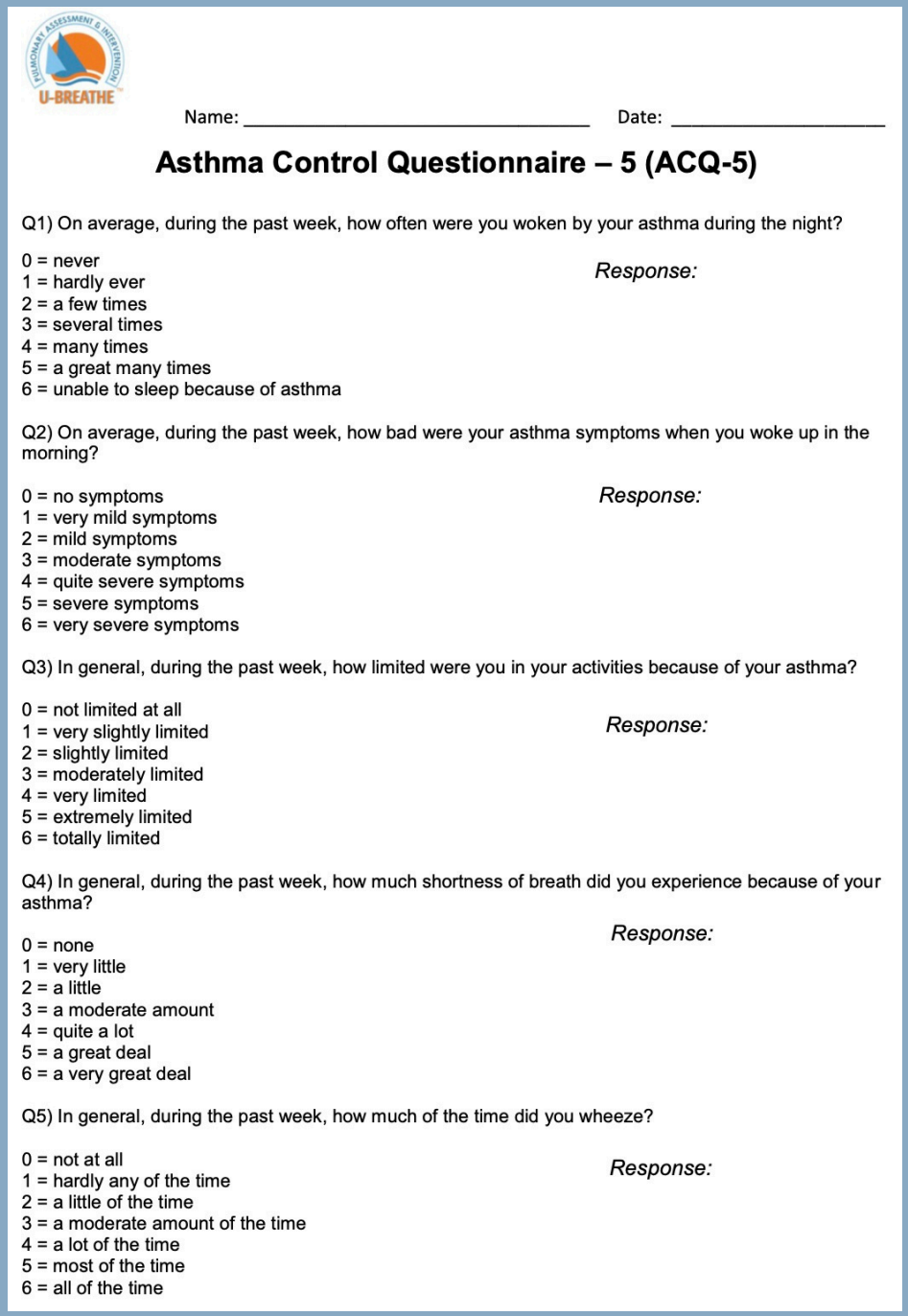
	Always (score = 1)	Often (score = 2)	Sometimes (score = 3)	Rarely (score = 4)	Never (score = 5)
I forget to take my medication.	☐	☐	☐	☐	☐
I change the dosage of my medication.	☐	☐	☐	☐	☐
I stop taking my medication for a while.	☐	☐	☐	☐	☐
I decide to skip a dose.	☐	☐	☐	☐	☐
I take less medication than prescribed.	☐	☐	☐	☐	☐

Table 1: MARS Questionnaire

The **Medication Adherence Report Scale (MARS)** assesses medication adherence by identifying non-adherent behaviours, such as forgetting or intentionally stopping treatment. This tool has demonstrated acceptable reliability and validity across various patient populations.

APPENDICES

Table 2: ACQ Scale



Name: _____ Date: _____

Asthma Control Questionnaire – 5 (ACQ-5)

Q1) On average, during the past week, how often were you woken by your asthma during the night?

0 = never
1 = hardly ever
2 = a few times
3 = several times
4 = many times
5 = a great many times
6 = unable to sleep because of asthma

Response:

Q2) On average, during the past week, how bad were your asthma symptoms when you woke up in the morning?

0 = no symptoms
1 = very mild symptoms
2 = mild symptoms
3 = moderate symptoms
4 = quite severe symptoms
5 = severe symptoms
6 = very severe symptoms

Response:

Q3) In general, during the past week, how limited were you in your activities because of your asthma?

0 = not limited at all
1 = very slightly limited
2 = slightly limited
3 = moderately limited
4 = very limited
5 = extremely limited
6 = totally limited

Response:

Q4) In general, during the past week, how much shortness of breath did you experience because of your asthma?

0 = none
1 = very little
2 = a little
3 = a moderate amount
4 = quite a lot
5 = a great deal
6 = a very great deal

Response:

Q5) In general, during the past week, how much of the time did you wheeze?

0 = not at all
1 = hardly any of the time
2 = a little of the time
3 = a moderate amount of the time
4 = a lot of the time
5 = most of the time
6 = all of the time

Response:

The **Asthma Control Questionnaire (ACQ)** measures the level of asthma control over the previous 4 weeks, helping to relate treatment adherence to clinical outcomes. The ACQ is a reliable, valid and sensitive tool for assessing changes in asthma control.

APPENDICES

Table 3: HEADSSS Tool

TABLE 1 The HEEADSSS psychosocial interview for adolescents

	Potential first-line questions	*Questions if time permits or if situation warrants exploration*
Home	Who lives with you? Where do you live? What are relationships like at home? Can you talk to anyone at home about stress? (Who?) Is there anyone new at home? Has someone left recently? Do you have a smart phone or computer at home? In your room? What do you use it for? (May ask this in the activities section.)	Have you moved recently? Have you ever had to live away from home? (Why?) Have you ever run away? (Why?) Is there any physical violence at home?
Education and employment	Tell me about school. Is your school a safe place? (Why?) Have you been bullied at school? Do you feel connected to your school? Do you feel as if you belong? Are there adults at school you feel you could talk to about something important? (Who?) Do you have any failing grades? Any recent changes? What are your future education/employment plans/goals? Are you working? Where? How much?	How many days have you missed from school this month/quarter/semester? Have you changed schools in the past few years? Tell me about your friends at school. Have you ever had to repeat a class/grade? Have you ever been suspended? Expelled? Have you ever considered dropping out? How well do you get along with the people at school? Work? Have your responsibilities at work increased? What are your favorite subjects at school? Your least favorite subjects?
Eating	Does your weight or body shape cause you any stress? If so, tell me about it. Have there been any recent changes in your weight? Have you dieted in the last year? How? How often?	What do you like and not like about your body? Have you done anything else to try to manage your weight? Tell me about your exercise routine. What do you think would be a healthy diet? How does that compare to your current eating patterns? What would it be like if you gained (lost) 10 lb? Does it ever seem as though your eating is out of control? Have you ever taken diet pills?
Activities	What do you do for fun? How do you spend time with friends? Family? (With whom, where, when?) Some teenagers tell me that they spend much of their free time online. What types of things do you use the Internet for? How many hours do you spend on any given day in front of a screen, such as a computer, TV, or phone? Do you wish you spent less time on these things?	Do you participate in any sports? Do you regularly attend religious or spiritual activities? Have you messaged photos or texts that you have later regretted? Can you think of a friend who was harmed by spending time online? How often do you view pornography (or nude images or videos) online? What types of books do you read for fun? How do you feel after playing video games? What music do you like to listen to?
Drugs	Do any of your friends or family members use tobacco? Alcohol? Other drugs? Do you use tobacco or electronic cigarettes? Alcohol? Other drugs, energy drinks, steroids, or medications not prescribed to you?	Is there any history of alcohol or drug problems in your family? Does anyone at home use tobacco? Do you ever drink or use drugs when you're alone? (Assess frequency, intensity, patterns of use or abuse, and how patient obtains or pays for drugs, alcohol, or tobacco.) (Ask the CRAFFT questions in Table 5, page 25.)
Sexuality	Have you ever been in a romantic relationship? Tell me about the people that you've dated. Have any of your relationships ever been sexual relationships (such as involving kissing or touching)? Are you attracted to anyone now? OR: Tell me about your sexual life. Are you interested in boys? Girls? Both? Not yet sure?	Are your sexual activities enjoyable? Have any of your relationships been violent? What does the term "safer sex" mean to you? Have you ever sent unclothed pictures of yourself on e-mail or the Internet? Have you ever been forced or pressured into doing something sexual that you didn't want to do? Have you ever been touched sexually in a way that you didn't want? Have you ever been raped, on a date or any other time? How many sexual partners have you had altogether? (Girls) Have you ever been pregnant or worried that you may be pregnant? (Boys) Have you ever gotten someone pregnant or worried that might have happened? What are you using for birth control? Are you satisfied with your method? Do you use condoms every time you have intercourse? What gets in the way? Have you ever had a sexually transmitted infection or worried that you had an infection?
Suicide/depression	Do you feel "stressed" or anxious more than usual (or more than you prefer to feel)? Do you feel sad or down more than usual? Are you "bored" much of the time? Are you having trouble getting to sleep? Have you thought a lot about hurting yourself or someone else? Tell me about a time when someone picked on you or made you feel uncomfortable online. (Consider the PHQ-2 screening tool [Table 6, page 26] to supplement.)	Tell me about a time when you felt sad while using social media sites like Facebook. Does it seem that you've lost interest in things that you used to really enjoy? Do you find yourself spending less time with friends? Would you rather just be by yourself most of the time? Have you ever tried to kill yourself? Have you ever had to hurt yourself (by cutting yourself, for example) to calm down or feel better? Have you started using alcohol or drugs to help you relax, calm down, or feel better?
Safety	Have you ever been seriously injured? (How?) How about anyone else you know? Do you always wear a seatbelt in the car? Have you ever met in person (or plan to meet) with anyone whom you first encountered online? When was the last time you sent a text message while driving? Tell me about a time when you have ridden with a driver who was drunk or high. When? How often? Is there a lot of violence at your home or school? In your neighborhood? Among your friends?	Do you use safety equipment for sports and/or other physical activities (for example, helmets for biking or skateboarding)? Have you ever been in a car or motorcycle accident? (What happened?) Have you ever been picked on or bullied? Is that still a problem? Have you gotten into physical fights in school or your neighborhood? Are you still getting into fights? Have you ever felt that you had to carry a knife, gun, or other weapon to protect yourself? Do you still feel that way? Have you ever been incarcerated?

Abbreviations: CRAFFT, Car, Relax, Alone, Forget, Friends, Trouble; HEEADSSS, Home, Education and employment, Eating, Activities, Drugs, Sexuality, Suicide/depression, Safety; PHQ-2, Patient Health Questionnaire 2.
Adapted from Goldenring JM, et al[1]; Goldenring JM, et al.[2]

The **HEADSSS** assessment tool supports the comprehensive assessment of adolescents by exploring key areas of their environment and identifying both risk and protective factors.

APPENDICES

Table 4: eHEALS Scale

		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1.	I know what health resources are available on the Internet	○	○	○	○	○
2.	I know where to find helpful health resources on the Internet	○	○	○	○	○
3.	I know how to find helpful health resources on the Internet	○	○	○	○	○
4.	I know how to use the Internet to answer my questions about health	○	○	○	○	○
5.	I know how to use the health information I find on the Internet to help me	○	○	○	○	○
6.	I have the skills I need to evaluate the health resources I find on the Internet	○	○	○	○	○
7.	I can tell high quality health resources from low quality health resources on the Internet	○	○	○	○	○
8.	I feel confident in using information from the Internet to make health decisions	○	○	○	○	○

Note	Significance
1	Strongly disagree
2	Disagree
3	Undecided
4	Agree
5	Strongly agree

Total score (8–40)	Estimated level	Clinical interpretation
8 à 20	🟥 **Low digital literacy**	Needs close support. Has difficulty finding, understanding or using health information online.
21 à 30	🟨 **Average digital literacy**	Can manage to some extent, but needs guidance, step-by-step instructions and careful supervision.
31 à 40	🟩 **High digital literacy**	Feels confident in searching for, evaluating and using digital health information. Has a good foundation of independence.

The **eHeals** measures self-perceived digital health literacy: searching for, understanding, evaluating and using online information.

APPENDICES

Scale 5: PAQLQ Tool

The use of the **Pediatric Asthma Quality of Life Questionnaire (PAQLQ)** is part of a comprehensive nursing assessment approach.

It allows nurses to:

- Identify the impact of asthma on the adolescent's daily life (emotions, symptoms, activities),
- Detect the areas in which quality of life is most affected,
- Adapt the priorities of nursing support and interventions,
- Measure progress over time during follow-up or therapeutic education.

1. Questionnaire structure

The questionnaire includes 23 items divided into three domains:

- **Symptoms** (10 questions)
- **Activity limitations** (5 questions, including 3 personalised by the patient)
- **Emotional function** (8 questions)

Each item is rated on a 7-point Likert scale, where:

- 1 = severely impaired / extremely bothered
- 7 = not impaired / not bothered at all

The final score is the average of all items (the higher the score, the better the perceived quality of life).

2. Administration procedures

- Target age: 7–17 years
- Average duration: 10 to 15 minutes
- Administration methods:
  - Self-administered version or assisted interview depending on the adolescent's level of understanding
  - Must be completed by the adolescent alone, without parental assistance
  - Can be repeated at regular intervals (before/after an intervention)

APPENDICES

Scale 6: IPQ-B Scale

Item	Item	Scale (0–10)
1	1. To what extent does your illness affect your life ?	___
2	2. How long do you think your illness will last ?	___
3	3. To what extent do you think you can control your illness ? (reverse scored)	___
4	4. To what extent can your treatment help your illness? (reverse scored)	___
5	5. To what extent are your symptoms present ?	___
6	6. How concerned are you about your illness ?	___
7	7. How well do you understand your illness ? (reverse scored)	___
8	8. To what extent does your illness affect your emotional state ?	___
9	9. In your opinion, what are the three main causes of your illness ? a. _____ b. _____ c. _____	

Scoring :

- *Calculate the sum of items 1 to 8 → total score ranging from 0 to 80.*
- *Reverse the scores for items 3, 4 and 7 using the formula: (10 – score)*

Indicative interpretation :

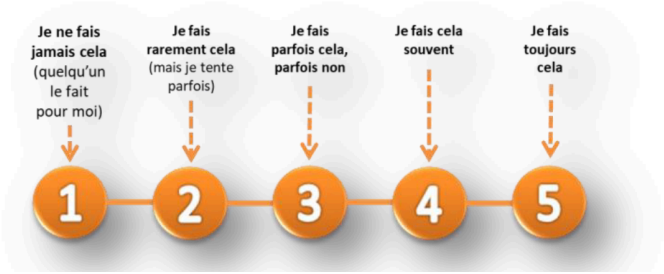
- *< 42 = illness perceived as minimally threatening*
- *42–49 = moderate perceived threat*
- *≥ 50 = illness perceived as highly threatening*

The **Illness Perception Questionnaire - Brief (IPQ-B)** is a brief 8-item tool designed to rapidly assess a patient's cognitive and emotional perceptions of their illness.

APPENDICES

Tableau 7a : Scale Good2go (Teen Version *in French*)

Questions 1 à 20 :



1. Je sais expliquer aux autres ma maladie et les besoins qui y sont associés..... 1 2 3 4 5
2. Je prépare et prends / fais mes médicaments/traitements de moi-même..... 1 2 3 4 5
3. Je participe activement (pose et répond aux questions) pendant les consultations/rendez-vous que j'ai avec les soignants..... 1 2 3 4 5
4. J'organise moi-même les soins qui sont nécessaires à ma santé (ex. : prendre un rendez-vous/convocations, acheter/renouveler les traitements, prendre note/conserver des résultats d'examens)..... 1 2 3 4 5
5. Durant une consultation/rendez-vous, j'exprime mon point de vue et explique ce dont je crois avoir besoin..... 1 2 3 4 5
6. Je peux me rendre seul(e) aux consultations/rendez-vous médicaux..... 1 2 3 4 5
7. À chaque rendez-vous/consultations, je passe un moment seul avec les soignants..... 1 2 3 4 5
8. Avec les soignants, je suis capable de parler de sexualité et de l'impact qu'a ma maladie sur elle (ex. : fonctionnement, contraception, protection contre les infections)..... 1 2 3 4 5
9. Je discute avec les soignants de l'impact qu'a le tabac, l'alcool et les drogues sur ma santé..... 1 2 3 4 5
10. Je suis capable de discuter avec les soignants de comment faire face à mon stress/mes inquiétudes..... 1 2 3 4 5
11. Je discute avec les soignants de l'impact qu'a ma maladie sur ma vie..... 1 2 3 4 5
12. Je connais les noms de mes médicaments et/ou de mes traitements..... 1 2 3 4 5
13. Je sais à quoi servent chacun de mes médicaments et/ou de mes traitements..... 1 2 3 4 5
14. Je sais comment mes médicaments sont payés/remboursés..... 1 2 3 4 5
15. Je connais les conséquences qu'aura ma maladie sur ma santé au cours des prochaines années..... 1 2 3 4 5
16. Je comprends l'impact qu'a/a eu ma maladie sur ma puberté et ses changements..... 1 2 3 4 5
17. Je sais que j'ai le droit d'être informé sur ma maladie..... 1 2 3 4 5
18. Je sais quels soignants j'aurai à rencontrer comme adulte..... 1 2 3 4 5
19. Quand ma maladie pose problème, je sais comment aller chercher de l'aide..... 1 2 3 4 5
20. Je sais comment prendre un rendez-vous avec un soignant..... 1 2 3 4 5

Questions A à E :

A. Je vais régulièrement à l'école ou à un travail..... Oui Peu Non
B. Je participe à des clubs, des groupes, des équipes sportives ou des activités que j'aime..... Oui Peu Non
C. Je suis soutenu(e) par mon entourage (ex : ma famille, mes amis) pour prendre en charge ma maladie..... Oui Peu Non
D. J'ai des amis qui me soutiennent lors de moments difficiles..... Oui Peu Non
E. Je prends soins de ma santé : activité physique, alimentation, hygiène de sommeil..... Oui Peu Non

Scoring (questions 1 à 20 seulement)

POUR LES QUESTIONS BLEUES (questions 1, 3, 5, 8, 9, 10, 11, 16) : domaine « AUTONOMIE EN SANTE »
Somme des réponses aux questions bleues = _____x 2.5 = _____ %

POUR LES QUESTIONS VIOLETTES (questions 12, 13, 14, 15, 17, 18, 19) : domaine « CONNAISSANCES THEORIQUES »
Somme des réponses aux questions violettes = _____x 2.8 = _____ %

POUR LES QUESTIONS ROSES (questions 2, 4, 6, 7, 20) : domaine « COMPETENCES PRATIQUES »
Somme des réponses aux questions roses = _____x 4 = _____ %

APPENDICES

Tableau 7b : Scale Good2go (Family Version *in French*)

Questions 1 à 20 :

1. Il/elle sait expliquer aux autres ma maladie et les besoins qui y sont associés..... 1 2 3 4 5
2. Il/elle prépare et prend / fait mes médicaments/traitements de moi-même..... 1 2 3 4 5
3. Il/elle participe activement (pose et répond aux questions) pendant les consultations/rendez-vous qu' il/elle a avec les soignants..... 1 2 3 4 5
4. Il/elle organise lui/elle-même les soins qui sont nécessaires à sa santé (ex. : prendre un rendez-vous/convocations, acheter/renouveler les traitements, prendre note/conserver des résultats d'examens)..... 1 2 3 4 5
5. Durant une consultation/rendez-vous, il/elle exprime son point de vue et explique ce dont il/elle croit avoir besoin..... 1 2 3 4 5
6. Il/elle peut se rendre seul(e) aux consultations/rendez-vous médicaux..... 1 2 3 4 5
7. À chaque rendez-vous/consultations, il/elle passe un moment seul(e) avec les soignants..... 1 2 3 4 5
8. Avec les soignants, il/elle est capable de parler de sexualité et de l'impact qu'a sa maladie sur elle (ex. : fonctionnement, contraception, protection contre les infections)..... 1 2 3 4 5
9. Il/elle discute avec les soignants de l'impact qu'a le tabac, l'alcool et les drogues sur sa santé..... 1 2 3 4 5
10. Il/elle est capable de discuter avec les soignants de comment faire face à son stress/ses inquiétudes 1 2 3 4 5
11. Il/elle discute avec les soignants de l'impact qu'a sa maladie sur sa vie. 1 2 3 4 5
12. Il/elle connait les noms de ses médicaments et/ou de ses traitements. 1 2 3 4 5
13. Il/elle sait à quoi servent chacun de ses médicaments et/ou de ses traitements. 1 2 3 4 5
14. Il/elle sait comment ses médicaments sont payés/remboursés. 1 2 3 4 5
15. Il/elle connait les conséquences qu'aura sa maladie sur sa santé au cours des prochaines années. 1 2 3 4 5
16. Il/elle comprend l'impact qu'a/a eu sa maladie sur sa puberté et ses changements. 1 2 3 4 5
17. Il/elle sait qu'il/elle a le droit d'être informé sur sa maladie 1 2 3 4 5
18. Il/elle sait quels soignants il/elle aura à rencontrer comme adulte. 1 2 3 4 5
19. Quand sa maladie pose problème, il/elle sait comment aller chercher de l'aide. 1 2 3 4 5
20. Il/elle sait comment prendre un rendez-vous avec un soignant. 1 2 3 4 5

Questions A à E :

A. Il/elle va régulièrement à l'école ou à un travail..... Oui Peu Non
B. Il/elle participe à des clubs, des groupes, des équipes sportives ou des activités qu'il/elle aime..... Oui Peu Non
C. Il/elle est soutenu(e) par son entourage (ex : sa famille, ses amis) pour prendre en charge ma maladie..... Oui Peu Non
D. Il/elle a des amis qui le/la soutiennent lors de moments difficiles..... Oui Peu Non
E. Il/elle prend soins de sa santé : activité physique, alimentation, hygiène de sommeil..... Oui Peu Non

Scoring (questions 1 à 20 seulement)

POUR LES QUESTIONS BLEUES (questions 1, 3, 5, 8, 9, 10, 11, 16) : domaine « AUTONOMIE EN SANTE »
Somme des réponses aux questions bleues = _____x 2.5 = _____ %

POUR LES QUESTIONS VIOLETTES (questions 12, 13, 14, 15, 17, 18, 19) : domaine « CONNAISSANCES THEORIQUES »
Somme des réponses aux questions violettes = _____x 2.8 = _____ %

POUR LES QUESTIONS ROSES (questions 2, 4, 6, 7, 20) : domaine « COMPETENCES PRATIQUES »
Somme des réponses aux questions roses = _____x 4 = _____ %

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