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Title	Perceptions of adolescents and young adults with allergy and/or asthma and their parents on EAACI guideline recommendations about transitional care: A European survey
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Publication date	2021-09-26
Original Citation	Khaleva, E., Knibb, R., DunnGalvin, A., Vazquez-Ortiz, M., Comberiati, P., Alviani, C., Garriga-Baraut, T., Gowland, M. H., Gore, C., Angier, E., Blumchen, K., Duca, B., Hox, V., Jensen, B., Mortz, C. G., Pite, H., Pfaar, O., Santos, A. F., Sanchez-Garcia, S., Timmermans, F. and Roberts, G. (2021) 'Perceptions of adolescents and young adults with allergy and/or asthma and their parents on EAACI guideline recommendations about transitional care: A European survey', Allergy, 77(4), pp.1094-1104. https://doi.org/10.1111/all.15109
Type of publication	Article (peer-reviewed)
Link to publisher's version	10.1111/all.15109
Rights	© 2021, John Wiley & Sons, Inc. This is the peer reviewed version of the following article: Khaleva, E., Knibb, R., DunnGalvin, A., Vazquez-Ortiz, M., Comberiati, P., Alviani, C., Garriga-Baraut, T., Gowland, M. H., Gore, C., Angier, E., Blumchen, K., Duca, B., Hox, V., Jensen, B., Mortz, C. G., Pite, H., Pfaar, O., Santos, A. F., Sanchez-Garcia, S., Timmermans, F. and Roberts, G. (2021) 'Perceptions of adolescents and young adults with allergy and/or asthma and their parents on EAACI guideline recommendations about transitional care: A European survey', Allergy, doi: 10.1111/all.15109, which has been published in final form at https://doi.org/10.1111/all.15109. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Use of Self-Archived Versions.

Download date	2026-11-16 09:28:53
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On-line supplement

Perceptions of adolescents and young adults with allergy and/or asthma and their parents on EAACI guideline recommendations about transitional care: A European survey.

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Online questionnaire

Making allergy, skin disease and asthma care better for young people

The European Academy of Allergy and Clinical Immunology is a medical organisation for doctors and nurses who look after people with allergy, skin disease and asthma. We are currently writing advice for doctors and nurses who look after young people.

Young people are between 11 to 25 years old. During this time they may be cared for by different doctors, nurses and other medical staff. We need to check that the advice and care we are giving to them is helpful for patients and parents.

We want to make allergy, skin disease and asthma medical care better for young people across Europe. To do this, we need to find out what you think about medical care for yourself (or for your child if you are a parent or carer). Thank you for helping by answering the questions below. Your feedback is very important.

We will use your feedback to improve the advice that we give. This should help doctors and nurses to improve their care of young people with allergy, skin disease and asthma. We will publish and present this advice at scientific meetings.

If you are a **young person aged 11 to 25 years or the parent of a young person of this age**, we would invite you to answer our questionnaire.

There are 24 questions, we expect it to take you about 15-20 minutes.

Part one – these questions are about you, your answers will help us to know who has answered this survey

1. Are you a young person or a parent of young person with allergy, skin disease or asthma? *(choose one)*
   - Young person
   - Parent
2. Are you male or female? *(choose one)*
   - Male
   - Female
3. How old are you? *(years)*
4. What type of allergy or asthma or skin disease do you/your child have? *(choose all that apply)*
   - Asthma
   - Food allergy

- Urticaria (itchy rash, sometimes red and with bumps)
- Allergic rhinitis and conjunctivitis (runny or itchy nose or eyes sometimes called hay fever)
- Atopic dermatitis or atopic eczema
- Anaphylaxis in the past (serious or severe allergic reaction with possible breathing or consciousness issues)
- Allergic reaction to a medicine from the doctor, hospital or pharmacy
- Allergy to stings from wasps or bees

5. Which country are you from? *(choose one)*

Part two – these questions are about the draft advice

In this part we are asking you to rate each of the recommendations that we have drafted for doctors and nurses. Please think about how important each recommendation is for you / your child.

Please score each recommendation from 'non important' to 'very important'. You are also welcome to provide some comments about each recommendation.

<u>General recommendations</u>

6. Young people should start to learn how to manage their own asthma, allergies and skin disease when they are about 11-13 years old.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

7. It is important to think about:

- Making sure that clinics have a plan/special document about how to care for young people as they grow up.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

- Telling the young person and their parents or carers about how the plan will work and how it will change as they grow up.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

- Using a checklist to find out when the young person is ready to take more responsibilities for their own asthma, allergy and skin disease as they grow up.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

- Checking that the young person is able to and takes the medicines they have been given.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

- If the young person has to move across from a children's clinic to one for adults, it would be helpful for them to see both children's and adult's doctors in one clinic transiently while they get used to the change.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

- The doctors and nurses caring for young people in children's and adult clinics should have regular meetings to discuss their care.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

8. Doctors and nurses could use web-based and other mobile technologies such as texts or skype to communicate with the young person.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

9. It may be helpful for doctors and nurses to talk to young people about how their asthma, allergies and skin disease may affect their social life (e.g. when being with friends or family), education and career plans.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

10. Doctors, nurses and other medical staff should have special training to help young people with asthma, skin symptoms and allergies.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

11. There should be regular checks of how well the clinic works to make sure it is effective and helpful for young people.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

Treatment of allergy, skin disease and asthma

12. The doctors and nurses should try to make the young people's treatment easy to follow.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

13. Phone reminders, apps and other methods may be useful to help young people to remember their treatment and take more responsibility for looking after their asthma, skin disease and allergies.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

Self-management of allergy, skin disease and asthma

14. A personal action plan covering what to do would help young people manage their asthma, skin disease or allergies.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

15. It would be helpful during the hospital visit to focus on issues and ways to manage asthma, skin disease and allergies where the young person is less confident.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

16. Young people and their family might want guidance from doctors and nurses on how to manage their asthma, skin disease or allergies when the young person is at social events (e.g. sports, celebration, holidays).

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

17. Young people could learn from other contemporaries with asthma, skin disease and allergies about how to manage their life.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

18. Doctors or nurses should have conversations with teenagers designed to strengthen their motivation and commitment to improve their asthma management.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

<u>Psychological issues and help</u>

19. Doctors and nurses should look out for young people who feel anxious or depressed as these may affect their asthma, skin disease and allergies.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

20. Doctors and nurses should find out if young people have experienced stressful events (such as parents' divorce or bullying) which may affect their asthma, skin disease and allergies.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

21. A psychologist may be able to help young people to manage their asthma, skin disease and allergies better.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

Support from family, friends and others

22. Families should be encouraged to support young people as they start to manage their own asthma, skin disease and allergies.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

23. Young people should be encouraged to let their friends know about their asthma, skin disease and allergies and how they can help in an emergency.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

24. Clinics should recommend reliable websites and other useful sources of information about asthma, skin disease and allergies to young people.

Not important	Slightly important	Fairly important	Important	Very important	No opinion

Please provide your comment (optional)

Thank you for helping by answering the questions. Your feedback is very important. We will use it to make allergy, skin disease and asthma medical care better for young people across Europe.

Doctors Kate Khaleva, Graham Roberts and Marta Vazquez-Ortiz on behalf of the European Academy of Allergy and Clinical Immunology Adolescent and Young Adult Task force.

Table S1. Agreement on recommendations by country

Recommendation	Italy N=251	Portugal N=206	Denmark N=54	France N=189	Russia N=186	Spain N=71	UK N=103	P value
Generic advice								
1. Young people should start to learn how to manage their own asthma, allergies and skin disease when they are about 11-13 years old.	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	5 (5,5)	0.212
2. It is important to think about:								
• Making sure that the clinics have a plan/special document about how to care for young people as they grow up.	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	4 (3,5)	5 (4,5)	5 (5,5)	**0.006**
• Telling the young person and their parents or carers about how the plan will work and how it will change as they grow up.	5 (5,5)	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	5 (5,5)	0.388
• Using a checklist to find out when the young person is ready to take more responsibilities for their own asthma, allergy and skin disease as they grow up.	5 (4,5)	4.5 (4,5)	4 (4,5)	5 (4,5)	4 (3,5)	5 (4,5)	5 (4,5)	**0.036**
• Checking that the young person is able to and takes the medicines they have been given.	5 (5,5)	5 (5,5)	5 (5,5)	5 (5,5)	5 (4,5)	5 (5,5)	5 (5,5)	**0.053**
• If the young person has to move across from a children's clinic to one for adults, it would be helpful for them to see children's and adult's doctor in one clinic transiently as they get used to the change.	4 (3,5)	4 (4,5)	4 (3,5)	4 (3,5)	4 (3,4)	4 (3,5)	4 (3,5)	**0.036**
• The doctors and nurses caring for young people in children's and adult clinics should have regular meetings to discuss their care.	5 (4,5)	4 (4,5)	4 (4,5)	5 (4,5)	4 (3,4)	4 (3,5)	4 (4,5)	**0.000**
3. Doctors and nurses could use web-based and other mobile technologies such as texts or skype to communicate with the young person.	4 (4,5)	4 (4,5)	4 (3,5)	4 (3,5)	4 (3,5)	4 (3,5)	4 (3,5)	0.856
4. It may be helpful for doctors and nurses to talk to young people about how their asthma, allergies and skin disease may affect their social life (e.g. when being with friends or family), education and career plans.	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	4 (4,5)	5 (4,5)	5 (4,5)	**0.008**
5. Doctors, nurses and other medical staff should have special training to help young people with asthma, skin symptoms and allergies.	5 (4,5)	5 (4,75;5)	4 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	**0.000**
6. There should be regular checks of how well the clinic works to make sure it is effective and helpful for young people.	5 (4,5)	5 (4,5)	4 (4,5)	4 (4,5)	4 (4,5)	5 (4,5)	4 (4,5)	0.157
Treatment of allergy, skin disease and asthma								
7. The doctors and nurses should try to make the young people's treatment easy to follow.	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	4 (3,5)	5 (4,5)	5 (4,5)	**0.000**
8. Phone reminders, apps and other methods may be useful to help young people to remember their treatment and take more responsibility for looking after their asthma, skin disease and allergies.	4 (4,5)	5 (4,5)	4 (4,5)	4 (4,5)	4 (3,5)	4.5 (4,5)	4 (4,5)	0.917
Self-management of allergy, skin disease and asthma								
9. A personal action plan covering what to do would help young people manage their asthma, skin disease or allergies.	5 (4,5)	5 (4,5)	4 (4,5)	5 (4,5)	4 (4,5)	5 (4,5)	5 (4,5)	0.075

Recommendation	Italy N=251	Portugal N=206	Denmark N=54	France N=189	Russia N=186	Spain N=71	UK N=103	P value
10. It would be helpful during the hospital visit to focus on issues and ways to manage asthma, skin disease and allergies where the young person is less confident.	5 (4,5)	5 (4,5)	4 (4,5)	4.5(4,5)	4 (3,5)	4 (4,5)	5 (4,5)	0.497
11. Young people and their family might want guidance from doctors and nurses on how to manage their asthma, skin disease or allergies when the young person is at social events (e.g. sports, celebration, holidays).	5 (4,5)	5 (4,5)	4.5 (3,5)	4 (3,5)	4 (3,5)	4 (4,5)	5 (4,5)	0.424
12. Young people could learn from other young people with asthma, skin disease and allergies about how to manage their life.	4 (4,5)	4 (4,5)	4 (4,5)	5 (4,5)	4 (3,5)	4 (4,5)	4 (4,5)	**0.046**
13. Doctors or nurses should have conversations with young people designed to strengthen their motivation and commitment to improve their asthma management.	5 (4,5)	5 (4,5)	4 (4,5)	4 (4,5)	4 (4,5)	4 (4,5)	5 (4,5)	0.469
Psychological issues and help								
14. Doctors and nurses should look out for young people who feel anxious or depressed as these may affect their asthma, skin disease and allergies.	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	5 (5,5)	0.683
15. Doctors and nurses should find out if young people have experienced stressful events (such as parents' divorce or bullying) which may affect their asthma, skin disease and allergies.	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	4 (3,5)	4 (4,5)	4 (3,5)	0.083
16. A psychologist may be able to help young people to manage their asthma, skin disease and allergies better.	4 (4,5)	4 (4,5)	4 (3,5)	4 (4,5)	4 (3,5)	4 (3,5)	5 (4,5)	0.579
Support from family, friends and others								
17. Families should be encouraged to support young people as they start to manage their own asthma, skin disease and allergies.	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	4 (4,5)	5 (5,5)	0.320
18. Young people should be encouraged to let their friends know about their asthma, skin disease and allergies and how they can help in an emergency.	5 (4,5)	5 (4,5)	5 (4,5)	5 (4,5)	4 (3,5)	5 (4,5)	5 (5,5)	0.144
19. Clinics should recommend reliable websites and other useful sources of information about asthma, skin disease and allergies to young people.	5 (4,5)	4 (4,5)	4 (3,5)	4 (3,5)	4 (4,5)	5 (4,5)	5 (4,5)	**0.010**

Figures are median (25th centile, 75th centile). Potential responses were 1 "Not important," 2 "Slightly Important," 3 Fairly important", 4 "Important," and 5 "Very Important," plus a "No opinion" option was available. UK, United Kingdom. P-values represent a Kruskal Wallis test was used to compare responses across different countries.

I. Generic section.

Table S2. Feedback on recommendation 1: young people should start to learn how to manage their own asthma, allergies and skin disease when they are about 11-13.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
It promotes confidence, autonomy, independence	++++	++	+++	Perception that responsibility for education lies on both parents and HCPs	++	-	++	Need to start learning about self-management earlier	++++	++	++++
It promotes increased awareness of the risks, symptoms and treatment. It may reduce the risk and need for treatment	+++	++	++	Only under supervision. AYA need reminders and help	+	+	+	Need to start learning about self-management later	+	+	+
This is needed as there is lack of knowledge and support from school or others	+	+	+	Timing depends on the AYA	+	-	+				
This is the best age	+	+	+	Should be a balance between safety and autonomy in this age group	+	+	+				
It may increase adherence to treatment and get them into a habit	+	-	+	Should start learning about self-management from diagnosis	+	+	+				

AYA: adolescents and young adults. HCPs: healthcare professionals. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total number of comments= 178; AYA=55 (30.9%); parent=123 (69.1%). Total number of supportive comments =119; AYA=50 (42%), parents=69 (58%). Total number of conditionally supportive comments =33; AYA =3 (9%), parents =30 (91%). Total number of non-supportive comments =89; AYA =23 (25.8%), parents =66 (74.2%). Overall Total =241; Supportive % of Overall Total = 49.4 %.

Table S3. Feedback on recommendation 3: doctors and nurses could use web-based and other mobile technologies such as texts or skype to communicate with the young people.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
Promotes good communication and supports management	++++	++	+++	Only as complementary to face to face care	+	+	+	Face to face care is preferable	+	+	+
More meaningful for AYA	+++	++	+++	Only as a reminder of medication, expiry dates and appointments	+	+	+	This may be a burden on healthcare resources	+	+	+
Promotes self-efficacy and empowerment	+++	++	++	Only for low risk groups and if shared with parents	+	+	+	Would undermine AYA need to take responsibility for own care	+	+	+

AYA: adolescents and young adults. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total number of comments= 119; AYA= 41(34.5%), parents=78 (65.5%). Total number of supportive comments =139; AYA=51 (37%), parents=88 (63%). Total number of conditionally supportive comments =17; AYA =6 (35%), parents = 11 (65%). Total number of non-supportive comments =14; AYA =7 (50%), parents =7 (50%). Overall Total =170; Supportive % of Overall Total = 82%.

Table S4. Feedback on recommendation 4: it may be helpful for doctors and nurses to talk to young people about how their asthma, allergies and skin disease may affect their social life (e.g. when being with friends or family), education and career plans.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
HCS should be encouraged to introduce sensitive topics into the clinic discussion	++++	++	+++	Engage with community or school and peers to discuss and support living with and managing AYA allergies and asthma	++	+	++	Task for parents	+	+	+
Discussions about how their symptoms may affect day to day life may improve adherence and how to manage future emergencies	++	+	++	HCP mediation between AYA and family, e.g tackling overprotective regimes or AYA adherence	+	+	+	Not necessary	+	-	+
Psychological support may be needed to reduce anxiety or support development	++	-	++	Promote positive self-image with eczema or appearance	++	+	+				
Need for additional help or resources	++	+	+	Future plans, e.g occupational considerations - need to be discussed openly but also positively	+	+	+				
Increased risks with alcohol or smoking	+	+	+								
Food allergy specific, eg unexpected allergens in cosmetics or drinks	+	+	+								
How to manage allergies and asthma around peers	+	+	-								

AYA: adolescents and young adults. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total number of comments = 113: AYA= 32 (28%); parents = 81 (71%). Total number of supportive comments = 121; AYA=35 (28.9%), parents=86(71.1%). Total number of conditionally supportive comments =58; AYA =19 (32.8%), parents =39 (67.2%). Total number of non-supportive comments =4; AYA= 1(25%), parents =3 (75%). Overall Total =183; Supportive % of Overall Total = 66%.

Table S5. Feedback on recommendation 5: doctors, nurses and other medical staff should have special training to help young people with asthma, skin symptoms and allergies.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
Need or importance for awareness of the risk/signs and treatment (HCP & patients)	++	+	++	Need to take into account the specific characteristics due to age or adolescence	+	+	+				
Perceived lack of input, empathy or knowledge from HCP (especially emergency & GP) or caregivers	+++	+	++	The importance of peer-led training	+	-	+				
Develop mandatory, essential and useful recommendation	++	+	++	Need for financial assistance (patients, HCP)	+	+	+				
Need for regular education/ training of HCP, caregivers and patients	++	+	+	Responsibility of transition lies with parents and HCP	+	-	+				
Provide psychological and psychosocial guidance for patients, family and HCP	+	+	+								
Especially important for severe asthma, allergy and emergencies	+	+	+								
Need for an integral and optimum approach and management (HCP, caregivers, school)	+	+	+								

AYA: adolescents and young adults, GP: general practitioner, HCPs: healthcare professionals. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total number of comments = 85: AYA= 23 (27%); parents= 62 (73%). Total number of supportive comments =105; AYA=31(29.5%), parents=74(70.5%). Total number of conditionally supportive comments =11; AYA=2 (18.2%), parents=9(81.8%). Total number of non-supportive comments =0; AYA =0 (0%), parents =0 (0%). Overall Total =116; Supportive % of Overall Total =90.5%.

Table S6. Feedback on recommendation 6: there should be regular checks of how well the clinic works to make sure it is effective and helpful for young people.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
Centres must be evaluated to be sure of their effectiveness and efficiency in supporting AYA to self-manage (also to be evaluated by patients)	++	+	++	Need to use specific guidelines, training and meetings	+	-	+	Lack of confidence and further information is requested	+	+	+
Helps to improve	+	+	+	Responsibility lies with HCP	+	-	+				
Applicable to all carers	+	+	+	Need to improve access to the best specialists	+	+	+				
For patient more responsibility	+	-	+								

AYA: adolescents and young adults, HCP: healthcare professionals. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total number of comments = 43: AYA= 10 (23.3%); parents= 33 (76.7%). Total number of supportive comments =34; AYA=13 (38.2%), parents=21 (61.8%). Total number of conditionally supportive comments =12; AYA =1 (8.3%), parents = 11 (91.7%). Total number of non-supportive comments =10; AYA =1 (10%), parents =9 (90%). Overall Total =56; Supportive % of Overall Total =60.7%.

II. Adherence section.

Table S7. Feedback on recommendation 7: the doctors and nurses should try to make the young people's treatment easy to follow.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
Increase adherence and effectiveness	++	+	++	Only if individualised (depends on age and needs)	+	+	+				
Lower anxiety and increase self-efficacy and empowerment	++	+	+	Only if effective	+	+	+				
Treatment already simple	+	+	+	Only if backed up by HCP or counselling	+	-	+				

AYA: adolescents and young adults; HCP: healthcare professionals. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total number of comments = 61: AYA= 20 (32.8%); parents= 41 (67.2%). Total number of supportive comments =37; AYA=14 (38%), parents=23 (62%). Total number of conditionally supportive comments =23; AYA=7 (30%), parents= 16 (70%). Total number of non-supportive comments =0; AYA =0 (0%), parents =0 (0%). Overall Total =60; Supportive % of Overall Total =61.7%.

Table S8. Feedback on recommendation 8: phone reminders, apps and other methods may be useful to help young people to remember their treatment and take more responsibility for looking after their asthma, skin disease and allergies.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
Promotes good communication and accurate guidance for management	++	++	++	Only as complementary to face to face care and as a reminder of medication, expiry dates and appointments	+	-	+	Would undermine AYA need to take responsibility for own care	++	+	+
More meaningful for teens	++	++	++	Only if practical, educational and interactive	+	+	-	Intrusive	+	+	+
Promotes self-efficacy and empowerment	++	+	+	Only if secure with parent access	+	-	+	In person face to face care is preferable	+	+	+

AYA: adolescents and young adults. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total number of comments =77: AYA =29 (37.7%); parents= 48 (62.3%). Total number of supportive comments =66; AYA=31 (47%), parents=35 (53%). Total number of conditionally supportive comments =11; AYA =3 (37%), parents =8 (73%). Total number of non-supportive comments =18; AYA =6 (33%), parents =12 (67%). Overall Total =95; Supportive % of Overall Total =69.5%.

III. Self-management section.

Table S9. Feedback on recommendation 9: a personal action plan covering what to do would help young people manage their asthma, skin disease or allergies.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
Action plan needs to be shared with peers, schools and others	+	+	+	HCP should develop an action plan with AYA that is individualised and appropriate	++	+	++	Not needed or required	+	+	+
Action plans useful for adherence	+	+	+	Must be clear	+	-	+	Not sure that this is required	+	-	+
Single action plan important for AYA with multiple atopic manifestations	+	-	+	Action plan needs to be supported by information about the condition(s)	+	-	+				
Help rapid treatment	+	+	-	Asthma plans but not other atopic conditions	+	+	-				
				Action plan should be developed before entering adolescence	+	-	+				
				Should be multidisciplinary	+	-	+				

AYA: adolescents and young adults; HCP: healthcare professionals. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total number of comments= 45: AYA = 12 (27%), parents = 33 (73%). Total number of supportive comments =13; AYA=3 (23%), parents=10 (77%). Total number of conditionally supportive comments =39; AYA=7 (17.9%), parents = 32 (82.1%). Total number of non-supportive comments =7; AYA =2 (28.6%), parents =5 (71.4%). Overall Total =59; Supportive % of Overall Total = 22%.

Table S10. Feedback on recommendation 10: it would be helpful during the hospital visit to focus on issues and ways to manage asthma, skin disease and allergies where the young person is less confident.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
This will promote confidence	+	+	+	This support should be personalised	+	+	+	Not clear	+	+	+
Support is needed for related atopic conditions at the clinic	+	+	-	It should assess treatment	+	+	+	All aspects need to be covered	+	-	+
				It should address anxiety and psychological issues	+	+	+				
				This can address particular fears, eg use of AAI	+	-	+				
				HCP and AYA direct dialogue	+	-	+				
				Need for more information	+	-	+				
				It should highlight risks	+	+	-				

AAI: adrenaline autoinjector, AYA: adolescents and young adults, HCP: healthcare professionals. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total number of comments = 46: AYA = 13 (28%); parents = 33 (72%). Total number of supportive comments =11; AYA=4 (36.4%), parents=7 (63.6%). Total number of conditionally supportive comments =33; AYA=9 (27.3%), parents =24 (72.7%). Total number of non-supportive comments =4; AYA =2 (50%), parents =2 (50%). Overall Total =48; Supportive % of Overall Total =22.9%.

Table S11. Feedback on recommendation 11: young people and their family might want some help from doctors and nurses how to manage their asthma, skin disease or allergies when the young person is at social events (eg sports, celebration, holidays).

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
Would welcome such help	+++	++	++	Would value guidance, e.g. school trips, overseas	+	+	+	Recommendation not understood	++	+	++
				The role of support groups and charities	+	-	+	Would be embarrassing	+	+	-
				Asthma and allergy peer group desirable	+	+	+	Not necessary	+	+	+
				Need to involve family and friends	+	+	+				
				Advice needs to be event specific, e.g. sport, university	+	-	+				
				Would prefer to meet older people who live with these conditions	+	+	-				

AYA: adolescents and young adults. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total number of comments = 70; AYA= 24 (34%), parents = 46 (66%). Total number of supportive comments =39; AYA=14 (35.9%), parents=25 (64.1%). Total number of conditionally supportive comments =26; AYA =6 (23.1%), parents =20 (76.9%). Total number of non-supportive comments =18; AYA =5 (27.8%), parents =13 (72.2%). Overall Total =83; Supportive % of Overall Total =47%.

Table S12. Feedback on recommendation 12: young people could learn from other young people with asthma, skin disease and allergies about how to manage their life.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
More meaningful for teens with emotional support and normalisation	+++	+	+++	Only if overseen by HCP	+	+	+	Would undermine AYA need to take responsibility for own care	+	-	+
Promotes self-efficacy, empowerment, and autonomy	++	+	++	Only if individualised	+	+	+	AYA not competent	+	+	+
Practical help, advice and support	++	+	++	With support group	+	-	+	In person face to face care is preferable	+	-	+

AYA: adolescents and young adults, HCP: healthcare professionals. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total number of comments=87: AYA= 21 (24.1%); parents= 66 (75.9%). Total number of supportive comments =89; AYA=24 (27%), parents=64 (72%). Total number of conditionally supportive comments =16; AYA=3 (19%), parents =13 (81%). Total number of non-supportive comments =6; AYA =1 (17%), parents =5 (83%). Overall Total =111; Supportive % of Overall Total =80 %.

Table S13. Feedback on recommendation 13: doctors or nurses should have conversations with teenagers designed to strengthen their motivation and commitment to improve their asthma management.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
Communication is essential for self-confidence and improved care	++	+	+	Do not need to force the AYA, should only be done in agreement	+	+	+				
This will reinforce good adherence, self-management, involvement in social activities	++	+	+	Peer-group to talk about their experiences	+	+	+				
It is dangerous for AYA if they are not prepared to be independent. Needs to be done for risk reduction	+	+	+	Need for psychological support	+	-	+				
It will ensure ongoing adherence even when symptoms-free	+	+	+	Only if needed	+	-	+				
				With the help from family	+	+	-				
				Need for asthma and allergy schools	+	-	+				
				Needs to be done well otherwise can have a deleterious effect	+	+	-				
				Need time for it during the consultations	+	-	+				

AYA: adolescents and young adults. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total number of comments= 42: AYA= 12 (28.6%); parents= 30 (71.4%). Total number of supportive comments =37; AYA= 14 (37.8%), parents=23 (62.2%). Total number of conditionally supportive comments =17; AYA =4 (23.5%), parents =13 (76.5%). Total number of non-supportive comments =0; AYA =0(0%), parents =0 (0%). Overall Total =54; Supportive % of Overall Total =68.5%.

IV. Psychology section.

Table S14. Feedback on recommendation 14: doctors and nurses should look out for young people who feel anxious or depressed as these may affect their asthma, skin disease and allergies.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
Prevention: minimise negative outcomes including isolation, bullying, depression. anxiety, death, low confidence, exacerbations or refusal of treatment	+++	+	+++	Need psychological support for this	++	+	+				
This is important	+++	+	++	With involvement and support of the whole family	+	+	+				
Need to raise awareness of this in AYA	+	+	+	HCP need training in this area	+	+	+				
This area is often ignored or undervalued	+	+	+	Need for additional support, e.g. web chats, workshops	+	-	+				
Particularly important in adolescence	+	-	+	Need to recognise different contributing factors, e.g. autism	+	-	+				
Difficult to open up about fears	+	+	+	Having a consultation without parents	+	+	-				
Needs more time in the consultation for this	+	-	+								

AYA: adolescents and young adults, HCP: healthcare professionals. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++).Total number of comments= 79: AYA=18 (22.8%); parents= 61 (77.2%). Total number of supportive comments =90; AYA=25 (27.8%), parents=65 (72.2%). Total number of conditionally supportive comments =28; AYA =7 (25%), parents =21 (75%). Total number of non-supportive comments = 0; AYA =0 (0%), parents =0 (0%). Overall Total =118; Supportive % of Overall Total =76.3%.

Table S15. Feedback on recommendation 15: doctors and nurses should find out if young people have experienced stressful events (such as parents' divorce or bullying) which may affect their asthma, skin disease and allergies.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
Mention of possible stress factors	++	+	++	Involve psychological support or other	+	+	+	Not part of the allergy consultation	+	+	+
Stress can impact on asthma, allergy or eczema	++	+	+	Information should be acted on	+	-	+	Not understood	+	-	+
The impact of bullying needs to be addressed	+	+	+	Important to talk to the AYA and the parent alone	+	-	+				
School may be a source of anxiety	+	-	+	Important to address feelings post anaphylactic reactions	+	-	+				
Important to ask and look for causes of stress	+	-	+	Ask compassionately	+	-	+				

AYA: adolescents and young adults. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total number of comments = 54: AYA= 13 (24%); parents = 41 (76%). Total number of supportive comments =43; AYA=9 (20.9%), parents=34 (79.1%). Total number of conditionally supportive comments =16; AYA =2 (12.5%), parents =14 (87.5%). Total number of non-supportive comments =7; AYA =4 (57.1%), parents =3 (42.9%). Overall Total =66; Supportive % of Overall Total =65.1 %.

Table S16. Feedback on recommendation 16: a psychologist may be able to help young people to manage their asthma, skin disease and allergies better.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
Important to manage anxiety, stress, depression, improve self-confidence and treatment efficacy	+++	+	+++	Dependent on AYA's mental health or wishes	++	+	++	No need	+	+	+
Helpful when managing allergies whilst with peers, ie how to live with allergy	+	+	+	Need psychologists trained in allergy	+	+	+	Stigma associated with seeing a psychologist	+	+	+
Should be offered to parents too	+	-	+	Should be easy to access and available in all clinics	+	-	+				
Need for allergy and asthma schools or support groups	+	-	+	Needed at certain times in life	+	-	+				
To reduce family conflict	+	-	+	Need to see AYA on their own	+	+	-				
				Only complimentary to medical support	+	-	+				

AYA: adolescents and young adults. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total number of comments=69; AYA=12 (17.4%); parents=57 (82.6%). Total number of supportive comments =50; AYA=9 (18%), parents=41 (82%). Total number of conditionally supportive comments =33; AYA =5 (15.1%), parents =28 (84.9%). Total number of non-supportive comments =7; AYA =4 (57.1%), parents =3 (42.9%). Overall Total =90; Supportive % of Overall Total =55.5%.

V. Support section.

Table S17. Feedback on recommendation 17: families should be encouraged to support young people as they start to manage their own asthma, skin disease and allergies.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
Need for confidence, autonomy or independence	++	+	+	Dependent on the parents' ability; need to support parents and families	++	+	++	Risks associated to autonomy	+	+	+
Responsibility perceived to lie with parents and families	++	+	+	Balance between autonomy and supervision	++	+	+	Responsibility lies on social workers	+	+	-
To increase adherence to treatment	+	+	+	Gradual transition depending on the motivation of the child	+	-	+				

AYA: adolescents and young adults. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total comments = 49: AYA= 11 (22.4%); parents= 38 (77.6%). Total number of supportive comments =28; AYA=9 (32.2%), parents=19 (67.8%). Total number of conditionally supportive comments =34; AYA =5 (14.7%), parents =29 (85.3%). Total number of non-supportive comments =5; AYA =2 (50%), parents =3 (60%). Overall Total =67; Supportive % of Overall Total =41.8%.

Table S18. Feedback on recommendation 18: young people should be encouraged to let their friends know about their asthma, skin disease and allergies and how they can help in an emergency.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
Support from contacts (eg friends, schoolmates, sports mates, teachers) is very important for AYA	+++	++	+++	Need to reduce risk for feeling different, experiencing, embarrassment or bullying	++	+	++	Challenging topic for AYA; AYA do not like talking about it	++	+	++
Need for awareness of the risks, signs, prevention and treatment (eg friends, school, contacts)	+++	++	++	Need help to do this; need for assertiveness training	+	+	+	It may be not useful, eg first aiders scared of using AAI, being sued, insufficient skills	+	-	+
Need to help especially in emergency situations when need AAI or inhalers	++	+	++	Need to be selective, eg just close friends	+	-	+				
				It depends on AYA's opinion	+	-	+				
				It deepens on the age	+	-	+				

AAI: adrenaline autoinjector. AYA: adolescents and young adults. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total comments = 100: AYA= 24 (24%); parents= 76 (76%). Total number of supportive comments =94; AYA=31 (32.9%), parents=63 (67.1%). Total number of conditionally supportive comments =41; AYA =5 (12.2%), parents = 36 (87.8%). Total number of non-supportive comments =22; AYA =1 (4.5%), parents =21 (95.5%). Overall Total =157; Supportive % of Overall Total = 59.8%.

Table S19. Feedback on recommendation 19: clinics should recommend reliable websites and other useful sources of information about asthma, skin disease and allergies to young people.

Supportive themes	Number of comments			Conditionally supportive themes	Number of comments			Non-supportive themes	Number of comments		
	Total	AYA	Parents		Total	AYA	Parents		Total	AYA	Parents
Need for concise, clear, updated and accurate	++	+	++	Need to share information and talk with their peers, friends and family	+	+	+	It is not clear	+	+	+
Need for further and attractive information with new technologies; knowledge is power	++	+	+	Need for talking directly with HCP to understand information	+	-	+	Responsibility of information lies on AYA	+	-	+
Responsibility of providing this type of further information lies with the HCP	+	+	+					Too much internet	+	-	+
Lack of this information from HCP	+	-	+								

AYA: adolescents and young adults, HCP: healthcare professionals. Pluses are based on the number of comments: 0 (-); 1-10 (+); 11-29 (++); 30-49 (+++); ≥50 (++++). Total comments = 39: AYA= 8 (20.5%); parents= 31 (79.5%). Total number of supportive comments =36; AYA=8 (22.2%), parents=28 (77.8%). Total number of conditionally supportive comments =7; AYA =1 (14.3%), parents =6 (85.7%). Total number of non-supportive comments =6; AYA =1 (16.6 %), parents =5 (83.4%). Overall Total =49; Supportive % of Overall Total =73.5%.

Figure S1. Summary of feedback on additional generic recommendations

