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DR. EKATERINA KHALEVA (Orcid ID : 0000-0002-2220-7745)

DR. REBECCA CLAIRE KNIBB (Orcid ID : 0000-0001-5561-0904)

DR. AUDREY DUNNGALVIN (Orcid ID : 0000-0002-1540-3959)

DR. CHERRY ALVIANI (Orcid ID : 0000-0003-1527-0495)

DR. CHARLOTTE G. MORTZ (Orcid ID : 0000-0001-8710-0829)

DR. HELENA PITE (Orcid ID : 0000-0002-7300-928X)

PROF. OLIVER PFAAR (Orcid ID : 0000-0003-4374-9639)

DR. ALEXANDRA SANTOS (Orcid ID : 0000-0002-7805-1436)

PROF. GRAHAM C ROBERTS (Orcid ID : 0000-0003-2252-1248)

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# 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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Ekaterina Khaleva[1], Rebecca Knibb[2], Audrey DunnGalvin[3,4], Marta Vazquez-Ortiz[5], Pasquale Comberiati[6,7], Cherry Alviani[1,8],Teresa Garriga-Baraut[9], M Hazel Gowland[10], Claudia Gore[5,11], Elizabeth Angier[12], Katharina Blumchen[13], Bettina Duca[5,11], Valérie Hox[14], Britt Jensen[15], Charlotte G Mortz[15], Helena Pite[16], Oliver Pfaar[17], Alexandra F. Santos[18-20], Silvia Sanchez-Garcia[21], Frans Timmermans[22], Graham Roberts[1,8,23]

**Affiliations:**

1. Faculty of Medicine, University of Southampton, Southampton, UK
2. School of Psychology, College of Health and Life Sciences, Aston University, Birmingham, UK

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3. Applied Psychology and Paediatrics and Child Health, University College Cork, Cork, Ireland
4. Paediatrics and Child Infectious Diseases, First Moscow State Medical University, Russia.
5. Section of Inflammation, Repair and Development, National Heart and Lung Institute, Imperial College London. United Kingdom
6. Department of Clinical and Experimental Medicine, Section of Paediatrics, University of Pisa, 56126 Pisa, Italy
7. Department of Clinical Immunology and Allergology, I.M. Sechenov First Moscow State Medical University, 119991 Moscow, Russia.
8. The David Hide Asthma and Allergy Research Centre, St Mary's Hospital, Isle of Wight, UK
9. Unitat d'Allergologia Pediàtrica, Hospital Universitari Vall d'Hebron, Barcelona, Spain. Grup d'Investigació "Creixement i Desenvolupament", Institut de Recerca de l'Hospital Universitari Vall d'Hebron (VHIR), Barcelona, Spain.
10. Allergy Action, St Albans, UK
11. Department of Paediatrics, Imperial College Healthcare NHS Trust, London, UK
12. Primary Care and Population Sciences, University of Southampton, Southampton, UK
13. Department of Paediatric and Adolescent Medicine, Paediatric Pneumology, Allergology and Cystic Fibrosis, University Hospital Frankfurt, Frankfurt am Main, Germany
14. Department of Otorhinolaryngology, Head and Neck Surgery, University Hospitals Saint-Luc, Brussels, Belgium.
15. Department of Dermatology and Allergy Centre, Odense Research Centre for Anaphylaxis (ORCA), Odense University Hospital, Kloevervaenget 15, DK-5000 Odense C, Denmark
16. Allergy Center, CUF Descobertas Hospital and CUF Tejo Hospital; CEDOC, Chronic Diseases Research Center, NOVA Medical School/Faculdade de Ciências Médicas, Universidade Nova de Lisboa, Lisbon, Portugal
17. Department of Otorhinolaryngology, Head and Neck Surgery, Section of Rhinology and Allergy, University Hospital Marburg, Philipps-Universität Marburg, Marburg, Germany
18. Department of Women and Children's Health (Paediatric Allergy), School of Life Course Sciences, Faculty of Life Sciences and Medicine, King's College London, London, United Kingdom
19. Peter Gorer Department of Immunobiology, School of Immunology and Microbial Sciences, King's College London, London, United Kingdom
20. Children's Allergy Service, Guy's and St Thomas' Hospital, London, United Kingdom; Asthma UK Centre in Allergic Mechanisms of Asthma, London, United Kingdom
21. Allergy Department, Hospital Infantil Universitario del Niño Jesús, Madrid, Spain
22. Nederlands Anafylaxis Netwerk – European Anaphylaxis Taskforce, Dordrecht, The Netherlands
23. NIHR Southampton Biomedical Research Centre, University Hospital Southampton NHS Foundation Trust, Southampton, UK

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**Address for correspondence:**

Professor Graham Roberts, Paediatric Allergy and Respiratory Medicine, University Child Health (MP803), University Hospital, Southampton NHS Foundation Trust, Tremona Road, Southampton SO16 6YD, UK.

Tel.: +44 (0) 2380796160 E-mail: g.c.roberts@soton.ac.uk

**Short title:** Feedback on recommendations about transitional care in allergy and asthma.

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**ABSTRACT**

**Background**. The European Academy of Allergy and Clinical Immunology has developed a guideline to provide evidence-based recommendations for healthcare professionals to support the transitional care of adolescents and young adults (AYA) with allergy and/or asthma. The goal of this work was to ensure that the draft recommendations are also important for patients.

**Methods.** We surveyed patients aged 11-25 years with allergy and/or asthma and their parents across Europe between 17th February and 16th March 2020. The multilingual survey was distributed through national allergy and asthma patient organisations in Europe as well as through social media.

**Results.** A total of 1210 responses from 24 European countries were collected. There were 415 (34.3%) AYA and 795 (65.7%) parents. The majority of AYA (72.3%) and parents (81.9%) were female. Patients had a history of asthma (61.1%), allergic rhinoconjunctivitis (54.1%), food allergy (53.8%), atopic eczema (42.6%), and anaphylaxis (28.8%). All recommendations achieved the median score of either 'important' or 'very important'. The least supported recommendations were the use of joint clinics with both paediatric and adult physicians attending and the use of web-based or mobile technologies for communication with the AYA. The most supported recommendation was checking that the AYA is knowledgeable and compliant with their prescribed medication. Qualitative analysis revealed conditional approval for some recommendations.

**Conclusions.** There was agreement from patients and parents on the importance of the draft recommendations on transitional care for adolescents and young adults with allergy and/or asthma

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and their parents. The recommendations now need to be implemented into clinical practice across Europe.

**Key words:** adolescents, allergy, asthma, transition, survey, young adults

**Word count:** 2586 words**; Tables:** 2**; Figures:** 3**.**

## INTRODUCTION

Transition has been defined as an 'active and evolving process that addresses the medical, psychosocial, and educational needs of young people as they prepare to move from child- to adult-centered health care' [1]. Several guidelines on general transitional care have been published by the European Academy of Paediatrics[2], Canadian Association of Paediatric health centres[3], American Academy of Pediatrics[4], and National Institute for Health and Care Excellence[5]. Disease specific guidelines are also available to optimise transition for adolescent and young adults (AYA) with different long-term conditions[6-8]. Transition programmes have shown significant improvements in patient care during transition leading to low rates of loss of follow up, high scores for AYA's satisfaction with transition and self-efficacy in managing their disease[9].

Recently, the European Academy of Allergy and Clinical Immunology (EAACI) published the first European guideline on the effective transition of adolescents and young adults (AYA) with allergy and/or asthma[10]. As part of the guideline development process, an online survey was conducted to ensure the draft recommendations developed by the EAACI Task Force (TF) are important for AYA with allergy and asthma and their parents or carers (hereafter referred to as "parents") across Europe. Involving AYA in refining the European recommendations is an essential step because these are the patients who need to be transitioned and adapt to a new type of care. Understanding what is important to them helps to facilitate a smooth transition, ensure treatment adherence and subsequently improve health care outcomes. Parents also play an important role in preparing and supporting adolescents during transition to becoming independent adults. Parents must make a challenging transition themselves from taking full responsibility for their adolescent's healthcare to their child self-managing their disease and becoming a competent patient. It has been shown that assessment of parental perceptions on the transition of AYA with congenital heart defects offered insights into how transition planning could be optimised[11].

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By obtaining the perspective of AYA's and their parents on EAACI draft recommendations for transitional care, we aimed 1) to evaluate the importance of each recommendation independently for each group and 2) to identify additional factors that need to be included in the 'other considerations' section of recommendations.

## METHODS

### Study design

A quantitative, online, cross-sectional survey was conducted. The survey (available in the supplementary materials) was based on recommendations developed by the members of the EAACI Adolescent and Young Adult Task Force (TF) who come from a range of disciplinary and clinical backgrounds, including allergists (specialists and subspecialists), general practitioners, paediatricians, dermatologists, otolaryngologists, adult physicians, nurses, psychologists and patient representatives. Recommendations are based on the results of systematic reviews on the challenges of AYA with allergic conditions[12], interventions for these patients[13] as well as generic transition recommendations from evidence-based guidelines over the last 5 years. In addition, three rounds of a Delphi survey were conducted among TF members in order to achieve a consensus for D level recommendations[10].

### Participants and data collection

We invited AYA, aged 11-25 with allergy and asthma and their parents across Europe who were able to read English, Dutch, Danish, German, Spanish, Portuguese, Italian, French or Russian, to participate in the survey. The survey was distributed through national allergy and asthma patient organisations in Europe (UK, The Netherlands, Italy, Portugal, Spain, Ireland, Germany, Russia, Denmark, France) who then disseminated the link to the survey in SurveyMonkey among their members. In addition, the survey was advertised on social media (e.g. Facebook, Twitter). Before accessing the questionnaire, potential respondents were informed about the survey's purpose, the organisations conducting the survey and the average time required to complete. Responses were collected between 17th February and 16th March 2020.

### The questionnaire

The anonymised survey included 24 questions divided between two parts: 5 questions about demographic information (AYA or parent, age, gender, country, allergic diseases) and 19 questions about the level of importance of each recommendation. Recommendations were divided into five groups, namely 1) generic advice, 2) treatment of allergy and asthma, 3) self-management, 4)

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psychological issues and help, 5) support from family, friends and others. Participants were asked to rank the level of importance for each recommendation using a 5-point scale: 1 “Not important,” 2 “Slightly Important,” 3 Fairly important”, 4 “Important,” and 5 “Very Important,” plus a “No opinion” option was available. An average score of at least 2 was set as the level for acceptance of the recommendation. Options for free-text responses were provided. The wording of the questionnaire was carefully checked to ensure it could be understood by this lay audience, translated into eight languages (English, German, Spanish, Portuguese, Italian, Danish, Dutch, French and Russian) and back translated into English to ensure validity and accuracy. Reading age was tested prior to dissemination of the survey to ensure clarity and understanding. A group of target participants also tested the time required to complete the survey, which ranged from 15 to 20 minutes.

**Qualitative analysis**

Qualitative data analysis was used to summarise free-text comments from AYA and parents. All comments from AYA and parents were analysed separately. Comments in languages other than English were translated by one TF member and checked by a second TF member. Braun and Clarke’s steps for thematic analysis were used for analysis[14]. Each comment was coded and the codes were then combined into themes. In order to ensure that responder views were correctly interpreted, each comment and its code was reviewed in duplicate by patient representatives, clinicians and psychologists from the EAACI TF (EK, GR, CA, RCK, ADG, PC, T. G-B, MHG). Any discrepancies were resolved through discussion and, if necessary, a third reviewer (M.V-O) was consulted. Codes were then split based on the direction of the content: supportive, conditionally supportive or non-supportive (Supplementary materials).

**Statistical analysis**

All data were collected and analysed using SPSS software version 25.0. Descriptive statistics were used to describe respondent characteristics. Medians with lower and upper quartiles are presented for continuous variables given the distribution of the data. Frequency tables with percentages are provided for categorical variables.

A minimum of 50 responders per country was required for the comparison of data between countries. The comparisons were performed by using the Kruskal Wallis test. Summary tables were used to represent the results. Data were considered significant if statistical tests produce a p-value of $<0.05$.

## RESULTS

**Respondent demographics and characteristics**

Among 1425 received responses, 215 (16%) were excluded as they were either incomplete or came from outside Europe. A total of 1210 responses from 24 European countries were analysed. The most

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common countries of residence were Italy (20.7%), Portugal (17.0%), France (15.6%) and Russia (15.4%). There were 415 (34.3%) AYA and 795 (65.7%) parents. The majority of AYA (72.3%) and parents (81.9%) were female. Patients had a history of asthma (61.1%), allergic rhinoconjunctivitis (54.1%), food allergy (53.8%), eczema (42.6%), anaphylaxis (28.8%). Most AYA had one (29.7%) or two (26.9%) allergic conditions but 22.0% had more than four allergic comorbidities. Respondents' characteristics are listed in Table 1.

**Importance of the recommendations on transitional care**

All recommendations were (at minimum) scored as "important" (median score of 4 on the 5-point scale) (Table 2). The most supported recommendation was that of checking that the AYA is knowledgeable and compliant with their prescribed medication, with 68% of AYA and 77.7% of parents reporting this as "very important". The least supported recommendations related to the use of joint clinics with both paediatric and adult physicians attending (only 27.7% AYA and 38.1% parents reported this as "very important') and the use of web-based mobile technologies for communication with the AYA (only 27.0% AYA and 35.6% of parents reported this as 'very important'). In addition to overall data, a sensitivity analysis showed that the results were similar in individual countries with more than 50 responses (Table S1).

Of the 1356 free-text comments received, 978 (72.1%) were made by parents. Summary of the feedback with all themes from AYA and parents may be found in the supplementary materials (Tables S2-S19). Figure 1 (and Figure S1) show the key 'supportive, conditionally supportive and not supportive comments for generic recommendations, Figure 2 presents comments on treatment and self-management of allergy, skin disease and asthma and comments on psychological issues and help, and support from family, friends and others are found in Figure 3. In general, AYA's and parents' feedback was similar (Tables S2-S19).There were some notable exceptions such as parents were more likely to comment that transition should start earlier in adolescence (Table S2).

Almost all comments were supportive with a few conditional ones which were used to improve the recommendations. For example, respondents suggested that a personal action plan should be developed not only when AYA is about to be transferred to the adults' department, but should instead be utilised at an early stage before adolescence. In addition, it was suggested that the action plan should be regularly reviewed by all HCP involved in the individual's care. With regards to motivational interviewing, participants proposed that active involvement of the AYA in discussion would improve self-management of asthma and quality of life. Adolescents suggested that conversation about possible stressful life events that may impact disease control, should be explored in a very sensitive way, and that psychological interventions using cognitive behavioural therapy to improve adherence, self-management and symptom control are likely to be most effective for specific patients, for example, those struggling to self-manage their condition. Professionals who support those with difficulties, such

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as psychologists, should have expertise in allergy and asthma. The family should be enrolled early in the transition process, however the shift from parent to self-management should be done gradually to support AYA empowerment. Telling friends may be difficult for some and AYA suggested that they should be supported and encouraged to start by talking to a few close friends. Parents added that there should be a balance between autonomy and safety and recognised that it may be challenging for them to have to reduce control oftheir child's life.

Key negative comments related to the suggestion that adolescents should learn about self-management before 11 years of age; that the use of aids to improve adherence might undermine AYA taking responsibility for their care; and some felt that AYA might not be happy to share the details of their allergic diagnoses with their friends.

## DISCUSSION

The findings from this pan-European survey supports the value of draft guideline recommendations on the transitional care developed by the EAACI Adolescent and Young Adult Task Force for both AYA with allergic conditions and their parents. Conducting this survey in different European countries and health systems demonstrated that the recommendations are understood by AYA/parents and remain relevant. The rich qualitative data set of almost 1400 comments, and the thematic analysis of the responses to the open-ended questions provided additional insights on their opinions about each recommendation. From this survey we were able to further refine the recommendations based on the range of supportive, conditionally supportive, and minimal number of non-supportive free-text responses.

This survey contributes to the growing literature on the benefits of patient-centred care and understanding of patient perceptions and views for healthcare decision-making[15]. For example, patient-reported experience measures have been used to guide quality improvement across different settings[16]. Moreover, a set of considerations to engage AYA in research have been proposed[17] and several guidelines on transitional care involved this age group and their parents in the development of guideline recommendations[6,18].

Survey participants recognised the value of actively monitoring adherence to treatment throughout transition, but did not consider an overlap in care between paediatric and adult HCP to be particularly important. This finding may be because some countries do not have separate paediatric and adult specialists (allergists, dermatologists, respiratory physicians) and care is mostly led by general practitioners or specialists who treat patients of all ages. In contrast, AYA with inflammatory bowel disease rated joint consultation with both HCP as one of the most valuable features of the transition care program[19]. Other methods of communication between HCP and AYA such as web-based, mobile technologies were also considered less important. Research indicates that AYA generally

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prefer using web-based methods of communications[20] and are less interested in using social media sites for communication with HCP due to privacy concerns[21]. These two less popular recommendations align with other guidelines, which emphasise the importance of suitable use of technology for interaction between patients and HCP[1,5,8] and joint consultations[8,22].

Limitations inherent in the survey method impacted our ability to investigate possible reasons for our findings. Further qualitative interviews might identify why AYA do not fully support joint care by adult and paediatric HCP or the use of technologies for communication with HCP. Some respondents reported that self-management training should start before 11 years of age. We would agree that is appropriate for some AYA in line with developmentally appropriate healthcare.[23] Some AYA find technological solutions, such as an alarm on a mobile phone, to be very helpful to improve their treatment adherence.[24] Some AYA reported concerns about what their friends might think if they shared the details of their allergic diagnoses with them, although others reported this as a positive experience with AYA receiving considerable support from their close friends.[25]

**Strengths and limitations of the survey**

Although the survey covered most European countries, it may not represent the opinions of AYA and their parents in countries not surveyed. Technical limitations meant that comments were not included for the second recommendation; however ranking did allow us to assess importance in both groups. The representativeness of the survey is likely to be high given the large number of responses from patients with a range of allergic conditions, and their parents. Furthermore, 29.7% had one and 22% more than 4 allergic comorbidities. To the best of our knowledge, this survey is the first of its kind to evaluate draft recommendations by patients and their parents through a pan-European survey design and, the high number of free-text comments analysed in this survey allowed for more in-depth understanding of the patient perspective on recommendations concerning transition and transfer of AYA with allergy and/or asthma from paediatric to adult services.

**Implications**

There are several important implications arising from the findings of this survey. Firstly recommendations on transitional care are important for AYA with allergy and/or asthma and therefore, should be implemented within clinical practice across Europe. Secondly, qualitative analysis of comments can help to refine recommendations by allowing for the provision of additional information from the patient perspective.

All generic as well as allergy specific recommendations on adherence, self-management, support and psychological help received positive feedback from both AYA with allergies and/or asthma and their parents in Europe. Recommendations are intended to be useful, practical, facilitate local teams

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to work together and promote transition and transfer where necessary. We would like to emphasise that the application of these recommendations and the effectiveness of the healthcare for adolescents and young adults with allergies and asthma should be revaluated through regular audits[10]. Assessment should involve AYA and families, as well as policy makers, researchers and government agencies[26]. It is hoped that harmonisation of the transition process and practice will improve psychological and physical outcomes as well as the quality of life of these patients.

## CONCLUSIONS

This pan-European survey showed that adolescents and young adults with allergy and/or asthma and their parents find draft EAACI recommendations on transitional care for these conditions important or very important. Qualitative analysis of responses to open-ended questions confirmed the value of these recommendations and provided additional information from a patient perspective. Next steps should include implementation of recommendations into clinical practice taking into account differences between European countries in how transition may be organised.

## CONFLICTS OF INTEREST

GR and RK report research funding from Asthma UK and National Institutes of Health Research into the challenge associated with asthma during adolescents. FT reports being a parent of a young adult with food allergy. None of the other authors have anything to disclose.

## CONTRIBUTIONS

Survey concept and design: GR, EK, M.V.-O. Statistical analysis and interpretation of data: EK, GR. Qualitative analysis: EK, GR, CA, RCK, AG, PC, T.G-B, MHG. Drafting of the original manuscript: EK,GR. Reviewed and edited the manuscript: GR, M.V-O., EA, KB, RCK, PC, CA, BD, CGM, AD, CG, VH, BJ, HP, AFS, T.G-B, SSG, MHG, FT, OF. All authors provided critical review of the manuscript and approved the final version. Obtained funding, GR, M.V-O.

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**Table 1.** Demographics of survey responders.

| **All responders (n=1210)** | **Number (%) of responders** |
|---|---|
| Adolescents | 415 (34.3) |
| Male | 115 (27.7) |
| Female | 300 (72.3) |
| Parents | 795 (65.7) |
| Male | 144 (18.1) |
| Female | 651 (81.9) |

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| Type of allergic disease | |
|---|---|
| Asthma | 739 (61.1) |
| Allergic rhinoconjunctivitis | 655 (54.1) |
| Food allergy | 651 (53.8) |
| Eczema | 515 (42.6) |
| Anaphylaxis | 348 (28.8) |
| Urticaria | 248 (20.5) |
| Drug allergy | 132 (10.9) |
| Venom allergy | 68 (5.6) |
| Number of allergic diseases* | |
| 1 | 359 (29.7) |
| 2 | 326 (26.9) |
| 3 | 257 (21.2) |
| ≥4 | 266 (22.0) |
| Countries | |
| Italy | 251 (20.7) |
| Portugal | 206 (17.0) |
| France | 189 (15.6) |
| Russia | 186 (15.4) |
| United Kingdom | 103 (8.5) |
| Spain | 71 (5.9) |
| Denmark | 54 (4.5) |
| Netherlands | 46 (3.8) |
| Germany | 26 (2.1) |
| Ireland | 25 (2.1) |
| Others** | 53 (4.4) |

* Anaphylaxis is not included as a separate condition. **: Bulgaria n=1 (0.1 %), Greece n=1 (0.1%), Luxembourg n=1 (0.1 %), Poland n=1 (0.1 %), Romania n=1 (0.1 %), Georgia n=1 (0.1 %), Azerbaijan n=1 (0.1 %), Turkey n=1 (0.1 %), Switzerland n=6 (0.5%), Kazakhstan n=3 (0.2%), Belarus n=6 (0.5%), Ukraine n=15 (1.2%), Belgium n=15 (1.2%).

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**Table 2.** The level of importance for each recommendation as regarded by participants .

| **Recommendation** | **AYA n=415** Median (IQR) | **Parents n=795** Median (IQR) |
|---|---|---|
| **Generic advice** | | |
| 1. Young people should start to learn how to manage their asthma, allergies and skin disease when they are about 11-13 years old. | 5 (4,5) | 5 (4,5) |
| 2. 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. | 5 (4,5) | 5 (4,5) |
| 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 (4,5) | 5 (4,5) |
| Using a checklist to find out when the young person is ready to take more responsibilities for their asthma, allergy and skin disease as they grow up. | 4 (4,5) | 5 (4,5) |
| Checking that the young person is able to and takes the medicines they have been given. | 5 (4,5) | 5 (5,5) |
| 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. | 4 (3,4) | 4 (3,5) |
| The doctors and nurses caring for young people in children's and adult clinics should have regular meetings to discuss their care. | 4 (3,4) | 4 (4,5) |
| 3. Doctors and nurses could use web-based and other mobile technologies such as texts or skype to communicate with the young person. | 4 (3,4) | 4 (3,5) |
| 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. Doctors, nurses and other medical staff should have special training to help young people with asthma, skin symptoms and allergies. | 5 (4,5) | 5 (4,5) |
| 6. There should be regular checks of how well the clinic works to make sure it is | 4 (4,5) | 5 (4,5) |

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| | | |
|---|---|---|
| effective and helpful for young people. | | |
| **Treatment of allergy, skin disease and asthma** | | |
| 7. The doctors and nurses should try to make the young people's treatment easy to follow. | 4 (4,5) | 5 (4,5) |
| 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) | 4 (4,5) |
| **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. | 4 (4,5) | 5 (4,5) |
| 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. | 4 (4,5) | 5 (4,5) |
| 11. Young people and their families 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). | 4 (3,5) | 5 (4,5) |
| 12. Young people could learn from other young people with asthma, skin disease and allergies about how to manage their life. | 4 (3,5) | 4 (4,5) |
| 13. Doctors or nurses should have conversations with young people designed to strengthen their motivation and commitment to improving their asthma management. | 4 (4,5) | 5 (4,5) |
| **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) |
| 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. | 4 (4,5) | 4 (4,5) |
| 16. A psychologist may be able to help young people to manage their asthma, skin disease and allergies better. | 4 (3,4) | 4 (4,5) |
| **Support from family, friends and others** | | |
| 17. Families should be encouraged to support young people as they start to manage their asthma, skin disease and allergies. | 5 (4,5) | 5 (4,5) |
| 18. Young people should be encouraged to let their friends know about their asthma, | 5 (4,5) | 5 (4,5) |

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| | | |
|---|---|---|
| skin disease and allergies and how they can help in an emergency. | | |
| 19. Clinics should recommend reliable websites and other useful sources of information about asthma, skin disease and allergies to young people. | 4 (4,5) | 4 (4,5) |

IQR, interquartile range. 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. AYA, adolescents and young adults.

**Figure legends.**

**Figure 1.** Summary of feedback on generic recommendations

AAI, adrenaline autoinjectors; AYA, adolescents and young adults; GP, general practitioner; P, parents; HCP, healthcare professionals. The thematic map includes themes where the total number of comments for each theme ≥11. Information in brackets specifies which group (AYA and/or P) has more than 11 comments in each theme. If none of the groups reported ≥11 comments in the theme but it has ≥11 total number of comments this theme is also included.

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**Figure 2.** Summary of feedback on adherence and self-management recommendations

AAI, adrenaline autoinjectors; AYA, adolescents and young adults; GP, general practitioner; P, parents; HCP, healthcare professionals. The thematic map includes themes where the total number of comments for each theme ≥11. Information in brackets specifies which group (AYA and/or P) has more than 11 comments in each theme. If none of the groups reported ≥11 comments in the theme but it has ≥11 total number of comments this theme is also included.

**Figure 3.** Summary of feedback on psychology and support recommendations

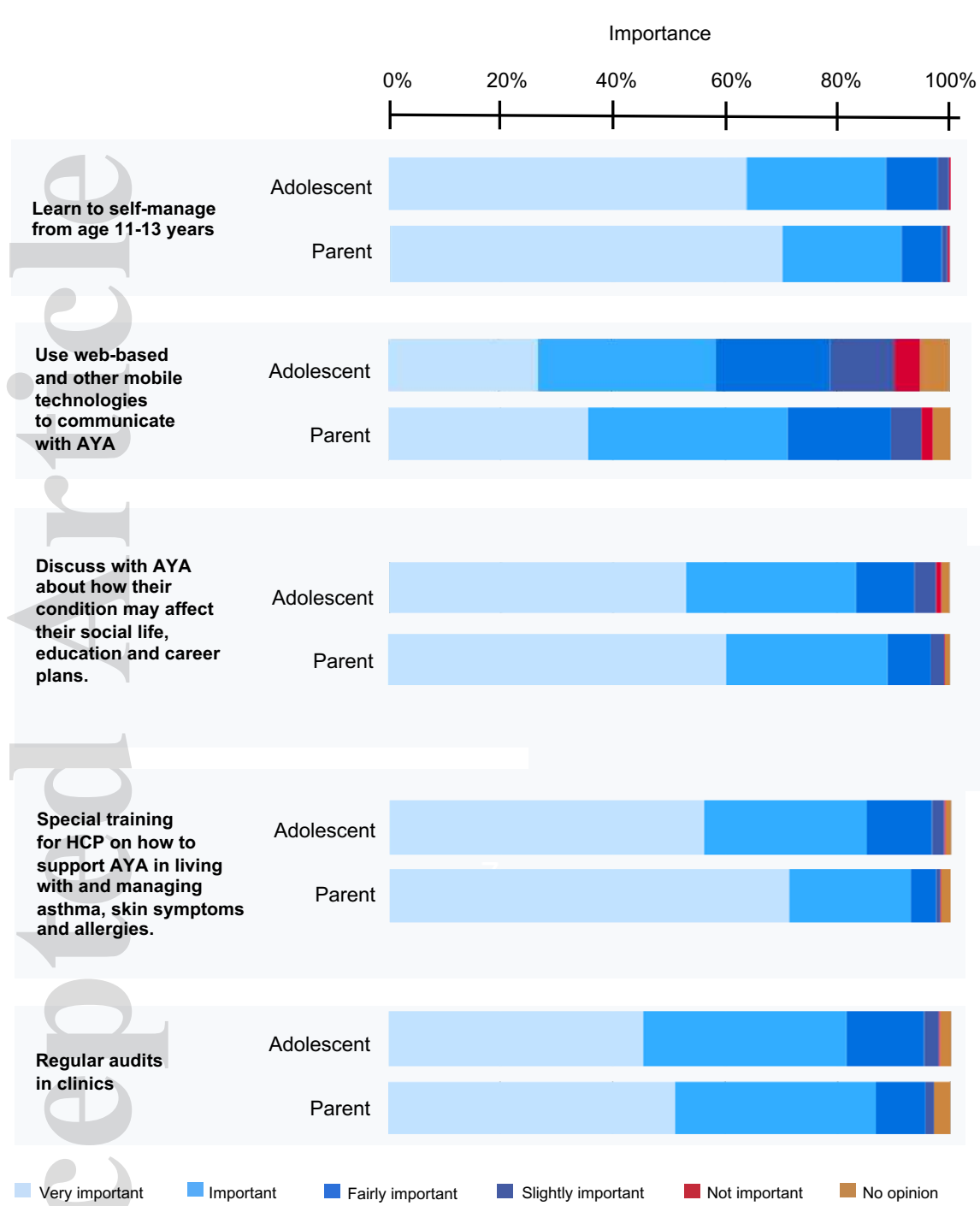
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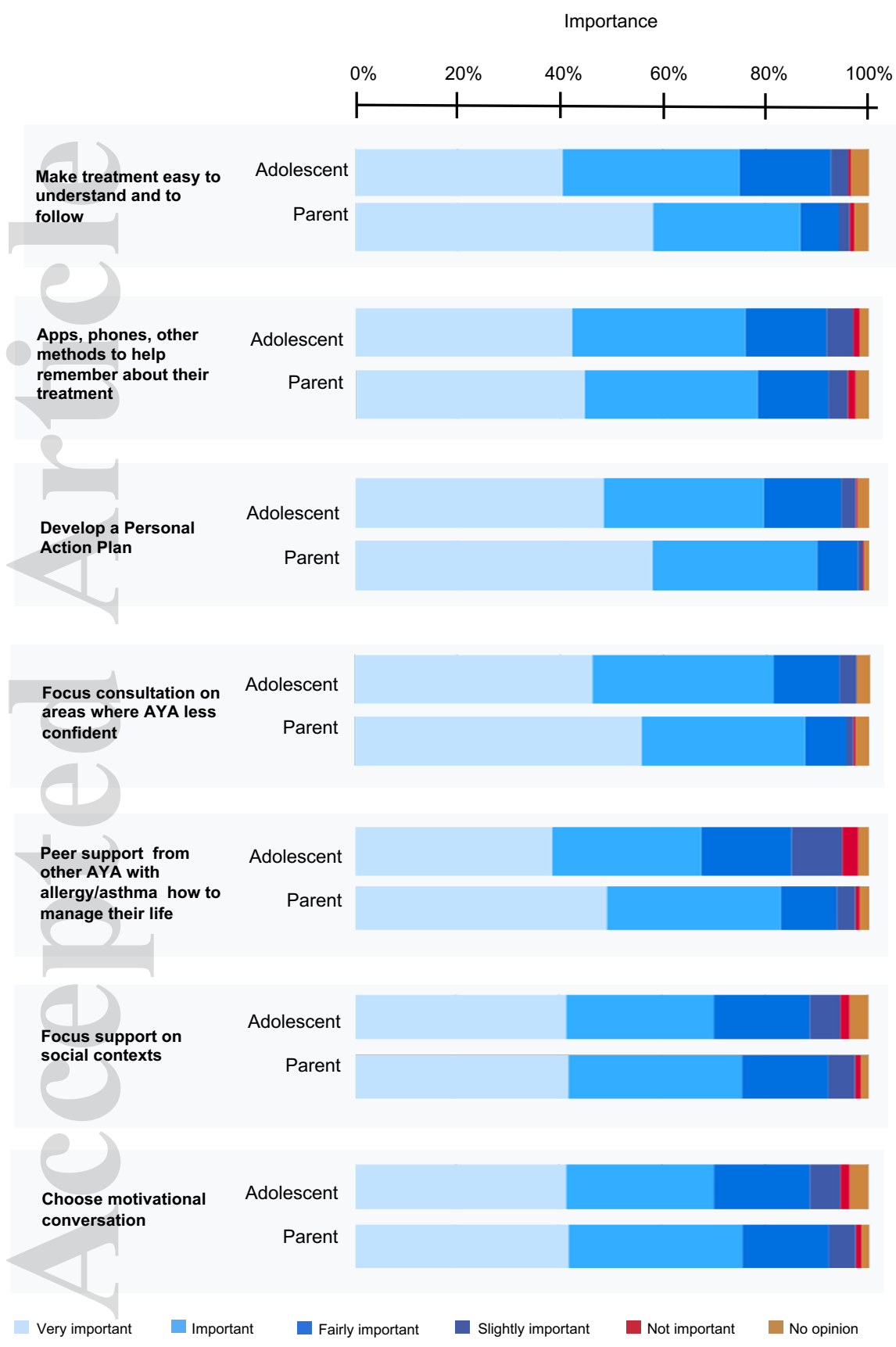





| | Supportive | Conditionally supportive | Not supportive |
|---|---|---|---|
| **Learn to self-manage from age 11-13 years** | • It promotes confidence, autonomy, independence (AYA,P)<br>• It promotes increased awareness of the risks, symptoms and treatment; reduce the risk and need for treatment (AYA,P) | • Perception that responsibility for education lies on both parents and HCPs (P) | • Need to start learning about self-management earlier (AYA, P) |
| **Use web-based and other mobile technologies to communicate with AYA** | • It promotes good communication and supports management (AYA, P)<br>• More meaningful for AYA (AYA,P)<br>• It promotes self-efficacy and empowerment (AYA, P) | | |
| **Discuss with AYA about how their condition may affect their social life, education and career plans.** | • HCPs should be encouraged to introduce sensitive topics into the clinic discussion (AYA, P)<br>• Discussions about how their symptoms may affect day to day life may improve adherence and how to manage future emergencies (P)<br>• Psychological support may be needed to reduce anxiety or support development (P)<br>• Need for additional help or resources | • Engage with community/school and peers to discuss and support living with and managing AYA's allergies and asthma (P)<br>• Promote positive self-image with eczema or appearance<br>• HCP mediation between AYA and family, e.g. tackling overprotective regimes or AYA adherence | |
| **Special training for HCP on how to support AYA in living with and managing asthma, skin symptoms and allergies.** | • Need or importance for awareness of the risk/signs and treatment (HCP & patients) (P)<br>• Perceived lack of input, empathy or knowledge from HCP (especially emergency & GP) or caregivers (P)<br>• Develop mandatory, essential and useful recommendation (P)<br>• Need for regular education/training of HCP, caregivers and patients | | |
| **Regular audits in clinics** | • Centres must be evaluated to be sure of their effectiveness and efficiency in supporting AYA to self-manage (also to be evaluated by patients) (P) | | |

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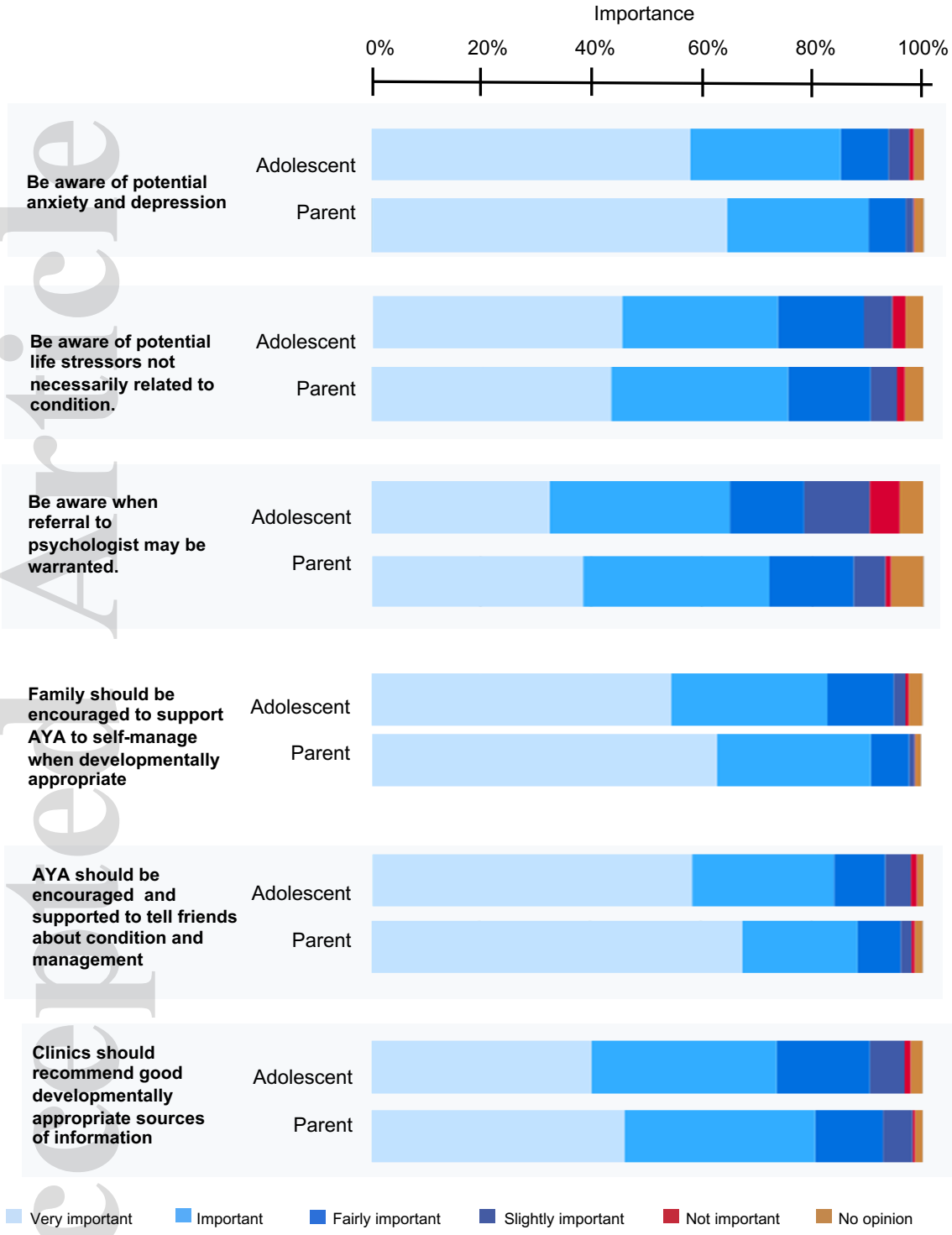
**Figure 1.** Summary of feedback on generic recommendations




| | Supportive | Conditionally supportive | Not supportive |
|---|---|---|---|
| **Make treatment easy to understand and to follow** | • Increase adherence and effectiveness (P)<br>• Lower anxiety and increase self-efficacy and empowerment | | |
| **Apps, phones, other methods to help remember about their treatment** | • Promotes good communication and accurate guidance for management (AYA, P)<br>• More meaningful for teens (AYA, P)<br>• Promotes self-efficacy and empowerment | | • Would undermine AYA's need to take responsibility for own care |
| **Develop a Personal Action Plan** | | • HCP should develop an action plan with the AYA that is individualised and appropriate. | |
| **Peer support from other AYA with allergy/asthma how to manage their life** | • Would welcome such help (AYA, P) | | • Recommendation is not understood |
| **Focus support on social contexts** | • More meaningful for teens with emotional support and normalisation (P)<br>• Promotes self-efficacy, empowerment, and autonomy (P)<br>• Practical help, advice and support (P) | | |
| **Choose motivational conversation** | • Communication is essential for self-confidence and improved care<br>• This will reinforce good adherence, self-management, involvement in social activities | | |

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**Figure 2.** Summary of feedback on adherence and self-management recommendations

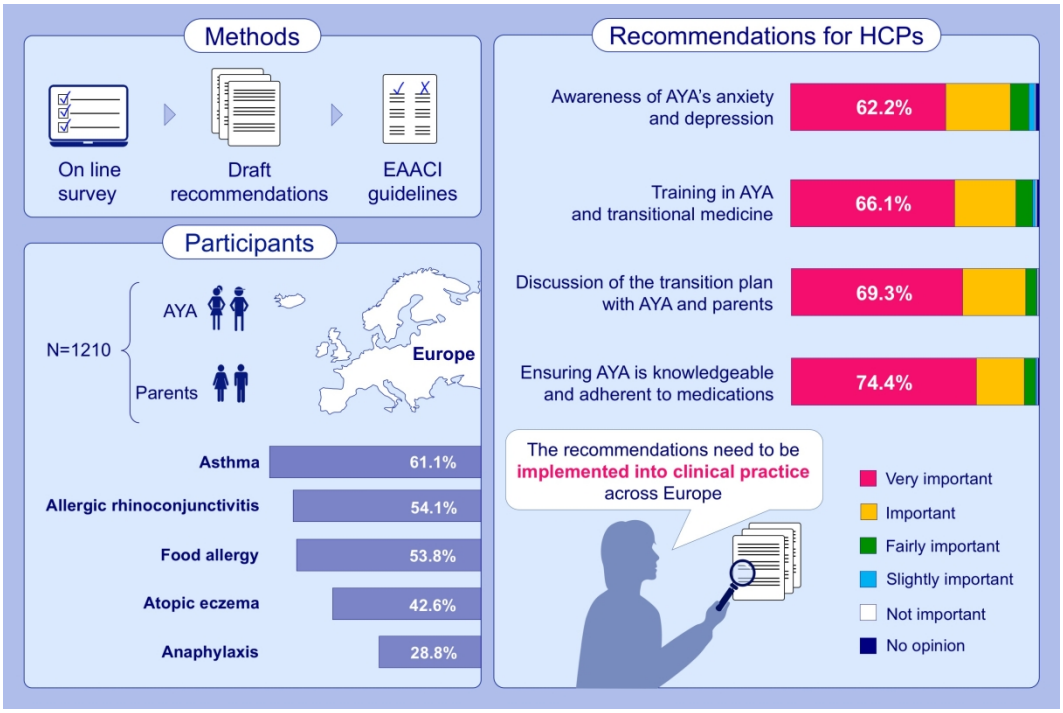



| | Supportive | Conditionally supportive | Not supportive |
|---|---|---|---|
| **Be aware of potential anxiety and depression** | • Prevention: minimise negative outcomes including isolation, bullying, depression. anxiety, death, low confidence, exacerbations or refusal of treatment (P)<br>• This is important (P) | • Psychological support needed | |
| **Be aware of potential life stressors not necessarily related to condition.** | • Mention of possible stress factors (P)<br>• Stress can impact on asthma, allergy or eczema | | |
| **Be aware when referral to psychologist may be warranted.** | • Important to manage anxiety, stress, depression, improve self-confidence and treatment efficacy (P) | • Dependent on AYA's mental health or wishes (P) | |
| **Family should be encouraged to support AYA to self-manage when developmentally appropriate** | • Need for confidence, autonomy or independence<br>• Responsibility perceived to lie with parents and families | • Dependent on the parents' ability; need to support parents and families (P)<br>• Responsibility perceived to lie with parents and families | |
| **AYA should be encouraged and supported to tell friends about condition and management** | • Support from contacts (e.g friends, schoolmates, sportmates) is very important for AYA (AYA,P)<br>• Need for awareness of the risks, signs, prevention and treatment (e.g friends, school, contacts) (AYA,P)<br>• Need to help especially in emergency situations when need AAI or inhalers (P) | • Need to reduce risk for feeling different, experiencing embarrassment or bullying (P) | • Challenging topic for AYA; AYA do not like talking about it (P) |
| **Clinics should recommend good developmentally appropriate sources of information** | • Need for concise, clear, updated and accurate sourses of information (P)<br>• Need for further and attractive information with new technologies; knowledge is power | | |

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**Figure 3.** Summary of feedback on psychology and support recommendations

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