EAACI Guideline on the effective transition of adolescents and young adults with allergy and asthma

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Abstract

Adolescent and young adult (AYA) patients need additional support while they experience the challenges associated with their age. They need specific training to learn the knowledge and skills required to confidently self-manage their allergies and/or asthma. Transitional care is a complex process which should address the psychological, medical, educational and vocational needs of AYA in the developmentally appropriate way. The European Academy of Allergy and Clinical Immunology has developed a clinical practice guideline to provide evidence-based recommendations for healthcare professionals to support the transitional care of AYA with allergy and/or asthma. This guideline was developed by a multi-disciplinary working panel of experts and patient representatives based on two recent systematic reviews. It sets out a series of general recommendations on operating a clinical service for AYA, which include: (i) starting transition early (11-13 years), (ii) using a structured, multidisciplinary approach, (iii) ensuring AYA fully understand their condition and have resources they can access, (iv) active

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monitoring of adherence and (v) discussing any implications for further education and work. Specific allergy and asthma transition recommendations include (i) simplifying medication regimes and using reminders; (ii) focusing on areas where AYA are not confident and involving peers in training AYA patients; (iii) identifying and managing psychological and socioeconomic issues impacting disease control and quality of life; (iv) enrolling the family in assisting AYA to undertake self-management and (v) encouraging AYA to let their friends know about their allergies and asthma. These recommendations may need to be adapted to fit into national healthcare systems.

Abbreviations

AGREE II - Appraisal of Guidelines for Research & Evaluation

AYA- Adolescent(s) and young adult(s)

CBT- Cognitive behavioural therapy

EAACI – European Academy of Allergy and Clinical Immunology

HCP- Healthcare professional(s)

HEADSS -Home, Education/ Employment, peer group, Activities, Drugs, Sexuality, Suicide/ depression) assessment

HRQL – health related quality of life

MI- Motivational interviewing

QOL- Quality of life

TF - Task Force

INtroduction

Adolescents and young adults (AYA) represent a large group of patients with allergy and/or asthma. Their medical care is complicated by the biological and psychosocial changes that occur during adolescence. As AYA gain increasing autonomy, they also have to become more socially and financially independent, whilst their primary relationships switch from family to peer-based interactions. It is now acknowledged that these changes encompass a much longer period than previously thought¹, continuing until around 25 years of age. For these reasons, this guideline focuses on the 11-25 year age group.

The challenges faced by adolescence and early adulthood impact both on the symptoms they experience and how these are managed; they also impact on how the symptoms and management are perceived and accepted. AYA may not fully understand the consequences of diseases. They may fail to take responsibility for self-management, leading to suboptimal adherence to treatment and other negative effects. This period of life is particularly challenging because it occurs when AYA undergo numerous life events linked with changes in education, work, travel and the establishment of more mature relationships. In addition, many AYA are transferred from paediatric to adult medical services, at the same time as they may experience a sense of loss and fear of the unknown which may lead to failure to follow up and more frequent hospitalizations.

Developmentally appropriate healthcare (DAH) recognizes the biopsychosocial developmental changes of AYA and the need to empower young people by embedding health education and health promotion in consultations. It is critical for AYA to acquire the knowledge, skills and confidence required to become independent, competent and expert adult patients. This process is known as transition (Box 1) and entails much more than the simple transfer of a patient from paediatric to adult care. The process of transition is also important when an allergy clinic caters for all age groups. If effectively learnt and utilized, constructive self-management skills will serve to support patients throughout their adult lives enabling them to achieve better health outcomes. We know from a recent European survey that healthcare professionals (HCP) find AYA to be a challenging group to manage.² To understand how to approach this age group, it is necessary to understand what is happening during adolescence.

What is happening during adolescence?

Changes in the brain underpin many changes during adolescence as both complex abstract thought and maturity in decision-making develop. Research in developmental psychology and neuroscience reveals that during adolescence there is an imbalance between systems supporting reactivity and regulation. Prefrontal areas are still developing until late adolescence (>18–21 years), while hypersensitive reward systems have already evolved, creating a disparity between emotions and control. Behavioural economics has shown that risk-taking is not a simple process, and is not only affected by attitudes toward known risks but also by attitudes toward unknown or ambiguous situations, in which the likelihood of positive and negative outcomes are not known.⁶ It is not that adolescents choose to engage in risks, but, rather, they are willing to gamble when they lack complete knowledge. When adolescents meaningfully understand a risky situation, they are even more risk-averse than adults.⁶ In addition, adolescent decision-making typically occurs in busy environments that often involve complex motivations. Prominent motivations at this age, which can compete and conflict with one another, include maintaining status with peers, achieving goals in academic, athletic, or other areas, finding independence and maintaining harmony within the family.

The guideline on the effective transition of adolescents and young adults

This guideline has been prepared by the European Academy of Allergy and Clinical Immunology's Task Force (TF) on Adolescents and Young Adults. It aims to assist HCP in transitioning 11-25 year age patients with asthma and other allergic conditions. In addition, the TF aims to identify gaps in knowledge and implementation, unmet needs and potential future perspectives. The primary audience for this guideline is clinical allergists (specialists and subspecialists), paediatricians, primary care workers, physicians from other related disciplines, nurses, dieticians, social workers and psychologists working across a range of primary, secondary, and tertiary care settings. Healthcare managers, research funding bodies and health policy makers may also find this guideline useful. The development of the guideline has been informed by two formal systematic reviews^{7,8} with systematic review principles being used to identify additional evidence, where necessary. The guideline does not intend to provide advice about the management of individual allergic conditions in AYA. A separate manuscript will provide practical advice on how to implement these transition recommendations into everyday clinical practice and give examples about how to organize a transition clinic and optimise service delivery.

METHODOLOGY

This guideline was generated using the principles of the Guidelines International Network using the Appraisal of Guidelines for Research & Evaluation (AGREE II) approach ^{9,10} (see online supplement – appendix 1). The process started in January 2018 with a web-based discussion about the process and the key clinical areas to address, followed by face-to-face meetings and regular web conferences in which HCP and lay representatives participated.

Ensuring appropriate stakeholder involvement

Members of the EAACI TF on Adolescents and Young Adults from 10 European countries represented a range of disciplinary and clinical backgrounds, including allergists (specialists and subspecialists), paediatricians, psychologists, primary care, dermatologists, otolaryngologists, nurses and patient organization representatives. Additionally, a survey of stakeholders was undertaken in June 2019 to understand how adolescents and young adults are currently managed and the challenges faced by their HCP.²

Systematic reviews of the evidence

Three key questions were addressed: (i) What are the challenges and specific needs of adolescents and young adults with allergic conditions, including asthma, food allergy and anaphylaxis, allergic rhino-conjunctivitis, atopic dermatitis, chronic urticaria, allergic gastrointestinal disease, as well as those with complex multisystem allergic disease? (ii) What specific strategies have proven useful to improve self-management and wellbeing in this population? (iii) What generic approaches are helpful when managing adolescents and young adults? The first two were pursued through two formal systematic reviews (SRs) of the evidence

with a cut-off date of February 10, 2019.^{7,8} The final question was assessed by a SR of the evidence-based adolescent and young adult guidelines from the last 5 years with a cut-off date of June 21, 2019. Individual studies from these guidelines were accessed to determine level of evidence and grade of recommendation. The TF members continued to track evidence published after our systematic review cut-off date and, where relevant, studies were considered by the TF chairs.

Formulating recommendations

The TF members graded the strength and consistency of the key findings from the SRs.^{7,8} These were used to formulate evidence-based recommendations for clinical care based on the relative balance between potential benefits, side effects and risks.¹¹ (Box 2). This involved formulating clear recommendations with the strength of evidence underpinning each recommendation while phrasing was according to the grade of recommendation (Box 2). For many recommendations in the generic section, there was only level V evidence available (Grade D), therefore, 'may be considered' is used. To ensure that these recommendations were robust, a modified Delphi approach was used to achieve consensus within the TF (see online supplement).

The TF aimed to minimize bias at every step. TF members identified the resource implications of implementing the recommendations, barriers, facilitators, potential approaches to the implementation of each recommendation and suggested audit criteria to help with assessing organizational compliance.

Peer review and public comment

The draft guideline was externally peer-reviewed by invited experts from a range of professional backgrounds. The draft was also made available on public domain on the EAACI web site for a 3-week period in February to March 2020 to allow a broader array of stakeholders to comment. All feedback was considered by the TF members and, where appropriate, revisions were made. Further feedback should be addressed to the corresponding author. Additionally, AYA and their parents/carers were invited to consider the importance that they attached to each draft recommendation during the development of the guideline (for further details see online supplement). All recommendations achieved a median of important or very important in both groups.

Identification of evidence gaps

The process of developing this guideline has identified a number of evidence gaps which were prioritized (Table 8).

Editorial independence and managing conflict of interests

This guideline was funded and supported by EAACI. The funder did not have any influence on the guideline production process, on its contents or on the decision to publish. TF members' conflicts of interest were declared and taken into account by the TF chairs as recommendations were formulated.

Updating the Guideline

EAACI plans to update this guideline in 2025 unless there are important advances before then.

General transition (Table 1)

Eight guidelines focusing on the transition of AYA with juvenile-onset rheumatic arthritis^{12,13}, coeliac disease¹⁴, gastroenterological conditions^{15,16}, liver diseases¹⁷, young people using health or social care services¹⁸ and AYA with special health care needs¹⁹ were identified from the last five years. Most of the evidence stemmed from expert opinion derived from clinical experience or qualitative studies reviewed systematically; very few randomized controlled trials were referenced.

Starting transition

Preparation for transition may be considered from early adolescence (11-13 years) in accordance with the patient's developmental stage (Grade D). ¹³⁻¹⁹ This will allow AYA to gradually acquire new knowledge about their disease and develop self-management skills, allowing them to take increasing responsibility for their

medical care. It is generally agreed that the optimal timing for initiation of the transition process cannot be based on chronological age. An individualised, flexible approach is required. The following factors might be considered by HCPs to determine the ideal age to start the transition process: mental and physical development, disease activity, health literacy, adherence to treatment, autonomy in disease management, family's socioeconomic circumstances and school format (due to increased patient responsibility as move up the schooling system).

Transition readiness questionnaires are tools which consist of a list of desirable skills and educational targets that AYA should ideally meet before transfer to adult care. ^{13,15,17,19} There is a lack of validated readiness assessment tools for AYA with allergy and/or asthma but several generic tools are available such as Transition Readiness Assessment Questionnaire²⁰, "Ready, Steady, Go"²¹ and TR(x)ANSITION Scale²². HCP may consider using one throughout the transition process to track progress and identify areas where AYA need more help to build knowledge and understanding, autonomy and self-management skills (Grade D).

Involving the AYA, family and other HCP

Collaboration and engagement of all stakeholders are essential for a successful and smooth transition process. Transition can be complex and more difficult in patients with multiple allergic diseases. It is important that the family are involved in supporting AYA self-management, thereby encouraging independence. During the transition process, HCPs may consider helping AYA (with their parents/caregivers) to understand their allergy and asthma, possible complications, treatment rationale (including medication name, dosing, possible side effects), effective management strategies and how to recognize higher risk symptoms (Grade D). 12,15,16,18,19 Important skills for AYA to learn are how to make appointments, identify when and whom to contact in case of relapse, how to negotiate and understand the transition process and how to access the support available. AYA should ideally be offered portable, accessible information in the form of leaflets, web-pages, or audio for AYA to foster inclusivity and address diverse needs. It may be also helpful for AYA to have their own personal transition plan, developed together with a HCP and written in a form of a 'roadmap' towards agreed short and long term goals and desired outcomes for transition. As adolescents are generally characterized by low levels of adherence, HCP may consider monitoring this more closely during the transition process (Grade D). 12,14-17 It has been shown that AYA are more likely to follow treatment plans and attend adult service medical appointments when they have a good knowledge of their disease and the reasons for treatment^{23,24} and good family support.²⁵

Wider aspects to consider

Another important aspect that HCP may consider covering during the transition process is developing skills related to self-management of allergy and/or asthma, within current and potential future education or work (Grade D).^{12,15,18,19} Other areas for discussion may be life skills, future health concerns, educational and employment goals, independent living and housing options, financial needs, psychosocial aspects, mental health, drugs and alcohol, healthy sexuality and reproduction. HEADSS (Home, Education/ Employment, peer group, Activities, Drugs, Sexuality, Suicide/ depression) assessment is a helpful framework for such discussions.²⁶ Apart from medical appointments, other options for communication between HCP and AYA such as phone calls, web-based or mobile technologies, can be recommended to improve the effectiveness of the transition process (Grade B).^{15,17,18}

Integrated regional approach involving paediatric and adult services

For optimal outcomes, a structured, multidisciplinary transition programme with a shared regional or network protocol developed by HCP, AYA, and parents/carers may be considered (Grade D). ^{12,13,15,17-19} This could include age-appropriate written information. Several guidelines have suggested that regular meetings may be considered between paediatric and adult HCP improve the effectiveness of the transition programme (Grade D). ^{16,17} If transfer to another clinical service is required, it would be helpful for the AYA to have had a recent comprehensive review of allergic conditions to optimize their management plan and generate an up to date transition report. This would cover the AYA's medical history, treatments, emergency care plan, follow-up, comorbidities and any other relevant information. Furthermore, an integrated transition programme

would be helpful with input from paediatric and adult providers and primary care, ideally as part of the well-coordinated multidisciplinary team. This may be considered to include a period of overlap between these services to help build relationships and establish effective adult care and management (Grade D). 12-19 Feedback from the adult to the paediatric clinic and primary care about AYA's attendance, circumstances and any changes in management is essential for continuity of the medical care and flow of information between all HCPs involved in the individual's care.

Training and audit

To achieve a good transition pathway, HCPs may need training to help them understand the developmental aspects of AYAs, the transition process, and how to engage AYA in behavioural change (Grade C). ^{12,13,19} It may be useful to have a lead HCP to coordinate the transition process and training as well as being the contact person for AYA and parents/carers. Lastly, regular audit of a transition service may be recommended to assess key performance indicators and improve service provision (Grade C). ^{15,18,19} Audits should involve AYAs and families, policy and decision makers, administrators, researchers, HCPs and government agencies.

Table 1. Generic recommendations for adolescents and young a dults with allergy and/or asthma $\,$

Generic recommendations		
(Grade, Evidence level)	Other considerations	References*
Preparation for transition may be considered from early adolescence (11-13 years) in accordance with the patient's developmental stage (D, IV-V)	HCP may want to consider the following when deciding when to start the transition process: mental and physical development, disease activity, health literacy, adherence to treatment, autonomy in disease management, family's socioeconomic circumstances and school format.	Foster ¹³ ; Elli ¹⁶ ; CAPHC ¹⁹ ; Vajro ¹⁷ ; NICE ¹⁸ ; Brooks ¹⁵ ; Ludvigsson 2016 ¹⁴
For a transition model to be effective, the following may be considered for inclusion: - the use of a structured, multidisciplinary transition programme within the clinic/healthcare unit (D, I-V)	For a transition model to be effective, the following may be considered for inclusion: Shared regional protocol agreed with HCP, AYA, parents/careers, HCP and regularly updated at least every 5 years. This could include age-appropriate written information and structured transition communication/reports between all paediatric and adult HCP. It may be helpful to have a lead person to coordinate the transition process and be a contact person for HCP, AYA and parents/carers.	Calvo, 2015 ¹² ; Foster, 2016 ¹³ ; Brooks ¹⁵ ; CAPHC ¹⁹ ; NICE ¹⁸ , Vajro ¹⁷

Generic recommendations (Grade, Evidence level)	Other considerations	References*
- informing AYA and parents/caregivers about allergy and/or asthma as well as the transition processes and the support available in a form that is appropriate for their developmental stage (D, I-V)	HCP may want to consider including the following information: purpose of transfer to an adult setting and what to expect when they come there; location of available adult centres, disease characteristics, treatments (including side effects), how to recognize alarm symptom, how to assist AYAs to take on their own care and support available. Ideas for formats: leaflets, web-page, audio for AYA with disabilities. It may be helpful for AYA to have their own personal transition plan ^{17,19} .	Brooks ¹⁵ ; Calvo ¹² ; Elli ¹⁶ ; CAPHC ¹⁹ ; NICE ¹⁸
- a checklist of skills and knowledge to assess AYA readiness for transition (D, I-V)	Tools can be used several times throughout the transition process in order to identify which areas of AYA self-management and well-being need to be addressed and improved. There are no specific allergy and asthma tools but generic ones are available: Transition Readiness Assessment Questionnaire ²⁰ , "Ready, Steady, Go" ²¹ and TR(x)ANSITION Scale ²² .	CAPHC ¹⁹ ; Vajro ¹⁷ ; Brooks ¹⁵ ; Foster ¹³
- active monitoring of adherence to treatment through the transition process (D, I-V)	Adherence may benefit from targeted specific educational and organisational interventions, e.g. more frequent appointments ¹⁵ , repeated education. A good open dialogue and communication is important. AYA with "new onset" of a disease will have minimal prior experience and so need more input.	Calvo ¹² ; Brooks ¹⁵ ; Vajro ¹⁷ ; Ludvigsson ¹⁴ ; Elli ¹⁶

Generic recommendations (Grade, Evidence level)	Other considerations	References*
-a period of overlap between paediatric and adult care providers before AYA is transferred, then feedback from the adult to the paediatric clinic about their attendance and any changes in management (D, I-V)	Where AYA care needs to be moved to another service clinic, AYA medical information (ideally in the form of a transition report) should be transferred to the adult medical service. Where possible, AYA should be seen in a joint paediatric-adult clinic, AYA should ideally see the same HCP in adults' services for at least the first 2 attended appointments after transfer ¹⁸ .	Calvo ¹² ; Foster, 2016 ¹³ ; Elli ¹⁶ ; CAPHC ¹⁹ ; NICE ¹⁸ ; Ludvigsson ¹⁴ ; Brooks ¹⁵ ; Vajro ¹⁷
- regular meetings between paediatric and adult care providers (D, I-V)	Particular focus should be placed on more complex patients. Meetings could be virtual. Process could be informed by areas of the assessment tools e.g. adherence, disease activity outcomes, HEADSS ²⁶ .	$\mathrm{Elli^{16};Vajro^{17}}$
Other options for effective communication between HCP and AYA can be recommended (eg web-based, mobile technologies) (B, I-V)	Options may include web-based communication boards and digital communication tools such as text.	Vajro ¹⁷ ;Brooks ¹⁵ ; NICE ¹⁸
Discussion of self-management of AYA allergy and/or asthma within current and potential future college, university, work or social environments may be considered (D, I-V)	Areas that HCP may want to consider discussing lifestyle, future health concerns, educational and employment goals, independent living and housing options, financial needs, psychosocial, mental health, sexuality and reproduction. Particular attention is required while taking exams, especially in AYA with allergic rhinitis. Additional help may be needed from other professionals, eg psychologist, social and youth worker.	Calvo ¹² ; CAPHC ¹⁹ ; NICE ¹⁸ ; Brooks ¹⁵
Specific training in transitional and AYA care may be recommended for all HCP involved in transition process (C, II-V)	Training in generic transition process, disease-specific and developmentally-appropriate care (e.g. clinical experience, e-learning, workshops) as part of the continuing professional development. Developmentally-appropriate healthcare should be practiced.	Calvo ¹² ; Foster ¹³ ; CAPHC ¹⁹

Generic recommendations (Grade, Evidence level)	Other considerations	References*
Regular audit of a transition service may be recommended to assess key performance indicators and improve service provision (C, I-V)	Audit should involve AYA and families, policy and decision makers, administrators, researchers, HCP and government agencies.	Brooks ¹⁵ ; CAPHC ¹⁹ ; NICE ¹⁸

*Recommendations: Foster 2017^{13} , juvenile-onset rheumatic diseases; Ludvigsson 2016^{14} , coeliac disease, Brooks 2017^{15} , chronic digestive diseases; Vajro 2018^{17} , liver; NICE 2015^{18} , young people using health or social care services; Calvo 2015^{12} ; rheumatic patients with childhood onset; Elli 2015^{16} , gastroenterological patients; CAPHC 2016^{19} , AYA with special health care needs.

AYA, adolescents and young adults; HCP, healthcare professionals; NICE, National Institute for Health and Care Excellence; CAPHC, Canadian Association of Paediatric Health Centres, HEADSS (Home, Education/Employment, peer group, Activities, Drugs, Sexuality, Suicide/depression) assessment.

transition SPECIFIC TO ALLERGIC CONDITIONS AND/OR ASTHMA

Recommendations specific to allergic conditions and/or asthma were developed by the TF based on the two underpinning systematic reviews. 7,8

Improving adherence (Tables 2, 4 and 5)

There are numerous data documenting poor adherence to treatment during adolescence. This is therefore an important issue to consider. HCP should make time to explore barriers which may be related to the patient, particularly their understanding and preconceptions, competing activities, their support or medication regime. Simplifying medication regimes, such as the use of a single inhaler combining inhaled corticosteroid and long-acting β2 agonists, may be recommended to improve adherence (Grade C)(Table 2).²⁷ Several studies indicate that low self-efficacy (confidence in performing a specific activity) is related to poor medication adherence, both in AYA with asthma and/or food allergy. 28,29,30-33 One controlled study showed that text reminders to take medication could improve treatment adherence in AYA with asthma ³⁴; however, the number of participants was small and this finding needs to be confirmed by larger studies. Other types of reminders, such as prompts to take medication, mobile applications and web-based applications, monitors or routines can be recommended to improve adherence, symptom control and quality of life (Grade B)(Table 2).³⁵⁻³⁸ One study with a large sample showed a positive effect of cognitive behavioural therapy (CBT) using a multi-systemic approach on asthma treatment adherence, as well as on asthma knowledge, self-management and symptom control in adolescents. Cognitive behavioural therapy can be recommended to improve adherence (Grade B)(Table 4).³⁹⁻⁴² Also, data suggest that amending family routines to give AYA time to fit in management behaviours may be recommended to improve adherence with medication in AYA (Grade C)(Table 5). 43,44 Finally, avoidance strategies such as dietary restrictions and label reading are also very important but there is little literature to guide the best approach to improving patient adherence to these strategies.

Table 2. Adherence recommendations for adolescents and young adults with allergy and/or asthma

Simplifying medication regimes may be recommended to improve adherence (Grade C, Evidence level IV)

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Simplifying medication regimes may be recommended to improve adherence (Grade C, Evidence level IV)

Strength of recommendation: Weak recommendation with evidence coming from a single study involving participants with asthma from 22 years of $age.^{27}$

Other considerations: Evidence comes from the use of combined corticosteroid and long-acting bronchodilator inhalers for asthma but is likely to be generalizable. If possible use the same inhaler system for all inhaled medications for the same patient and if possible restrict to once daily. Medication reminders,

References: $Axelsson^{27}$.

Medication reminders, mobile applications and web-based applications, monitors or routines can be recommended to improve adherence, symptom control and quality of life (Grade B, Evidence level I-IV)

Strength of recommendation: Weak recommendation for smartphone- based health applications, medication reminders or monitors as only suggested by qualitative studies. 35,36,38 Recommendation for the use of a specific web-application (MyMediHealthApp) is moderate since efficacy proven by a controlled trial. 34

mobile applications and web-based applications, monitors or routines can be recommended to improve adherence, symptom control and quality of life (Grade B, Evidence level I-IV) Other considerations: A

smartphone-based personalized health app, medication reminders or monitors were suggested in qualitative studies. All studies focused on asthma but likely to be also applicable to allergy.

Medication reminders, mobile applications and web-based applications, monitors or routines can be recommended to improve adherence, symptom control and quality of life (Grade B, Evidence level I-IV)

References: Naimi³⁵, Blaakman³⁶, Koster³⁸, Johnson³⁴.

AYA, adolescents and young adults.

Optimising self-management (Table 3)

Empowering AYA with self-management skills can help them become autonomous, expert patients, minimising their dependency on parents and HCP. It is therefore essential that AYA have the knowledge and skills to ensure they can self-manage their allergies and/or asthma effectively and confidently. Focusing consultations on areas where AYA say they are not confident may be recommended to improve self-management including adherence (Grade C). ²⁸⁻³³ Barriers to successful self-management such as poor symptom perception and failure to take responsibility need to be addressed.⁷ Facilitators to self-management which could be employed are the use of routines, simple treatment regimes, better understanding, a positive attitude and support from family, friends and school/college.⁷

To facilitate self-management, a personal action plan may be recommended to assist AYA in self-managing their allergy and/or asthma (Grade C). ^{29,31,45,46} Plans should be developed with the AYA and parents/carers which could be smartphone-based.⁴⁶

Peer-led interventions are recommended to improve asthma-related quality of life, asthma knowledge, and to reduce asthma-related doctor visits and school absence (Grade A). 47-51 Adolescents are likely to mirror the behaviour of their peers. To date, these peer-led interventions have been demonstrated in randomised controlled trials for AYA with asthma; they may also be useful for other allergic conditions.

AYA with allergy and/or asthma are frequently excluded from activities, which may have an impact on their developing social skills. Consideration may be given to supporting the AYA, family and the wider community to allow AYA to be included in social events (Grade D).⁵²⁻⁵⁵ This may involve encouraging them to focus on sports that are less likely to exacerbate asthma (e.g. swimming) or undertake sport at times when symptoms are less likely to be triggered (e.g. avoiding cold mornings or pollen peaks). Ensuring that the menu for school trips or parties does not contain relevant food allergens will be helpful for some AYA; it is therefore important that AYA develop the necessary self-advocacy communication skills to inform organisers about their allergy. Additionally, educating teachers, club staff, and other parents about allergy/or and asthma is important as mistaken beliefs can present a barrier to effective communication and integration in social contexts.^{52,55}

Motivational interviewing (MI) can be recommended to improve understanding and perception of the disease and adherence, thereby reducing asthma symptoms and improving quality of life (Grade B).⁵⁶ MI has been widely used in medicine and other settings in this age group. The approach seeks to increase motivation to change behaviours and then encourages the AYA to set goals for themselves. Training is required for HCP to effectively utilise MI.

Table 3. Self-management recommendations for adolescents and young adults with allergy and/or asthma

Focusing consultation on areas where AYA say they are not confident may be recommended to improve sel

Strength of recommendation: Weak recommendation based on low risk of bias in cross-sectional ^{28,30} and qualitative studies Formulation of a personal action plan with the AYA and their family to enable them to self-manage their a Strength of recommendation: Weak to moderate recommendation based on high risk of bias in one randomized controlled to Peer-led interventions are recommended to improve asthma related quality of life, asthma knowledge, and to Strength of recommendation: Strong recommendation based on low ^{47,51} and moderate risk of bias ⁴⁸⁻⁵⁰ interventional studies Supporting the AYA, family and the wider community to allow the AYA inclusion in social events (e.g. spot Strength of recommendation: Weak recommendation based on low risk of bias in a cross-sectional study ⁵⁵ and qualitative st Motivational interviewing can be recommended to improve asthma symptoms and quality of life (Grade B, Strength of recommendation: Moderate recommendation based on one randomised controlled asthma trial ⁵⁶. Motivational in

AYA, adolescents and young adults. HCP, Healthcare professional.

Addressing psychological issues (Table 4)

Many AYA with allergy and/or asthma have co-existing psychological issues, including anxiety, depression, suicidal ideation, and relational difficulties.^{33,57-74} These problems may magnify the complexities of self-management, care coordination and treatment planning in AYA with allergy and/or asthma. Therefore, the identification and management of psychological issues impacting disease control and health-related quality of life can be recommended (Grade B).

It is known that the social context of a person's life determines the risk of exposure, as well as their susceptibility, the course and outcome of illness.^{75,76} Socioeconomic factors and stressful life events can impact disease control^{34,77-81} and HRQL in allergic diseases^{64,70,82,83}. Therefore, the identification and management of socioeconomic issues and stressful life events impacting disease control and HRQL may be recommended (Grade C).

Where AYA are struggling to successfully self-manage their asthma, psychological interventions using a CBT based or multi-systemic therapy approach can be recommended to improve asthma knowledge, improve adherence, self-management and symptom control (Grade B).³⁹⁻⁴² This is based on a small number of randomised controlled asthma trials. Similar approaches are likely to be helpful where allergy is the key problem.

Table 4. Psychosocial recommendations for adolescents and young adults with allergy and/or asthma

Identification and management of psychological issues impacting disease control and health related quality

Strength of recommendation: Moderate recommendation based on low risk of bias in quantitative cross-sectional ^{57,62,63,65-73} Identification and management of socioeconomic issues and stressful life events impacting disease control at Strength of recommendation: Moderate recommendation based on low risk of bias in quantitative cross-sectional ^{69,81,82}, que Psychological interventions using a cognitive behavioural therapy based or multi-systemic therapy approach Strength of recommendation: Moderate recommendation due to specific population ^{39,41,42} based on low to intermediate risk

AYA, adolescents and young adults; HEADSS (Home, Education/ Employment, peer group, Activities, Drugs, Sexuality, Suicide/ depression) assessment.

Obtaining support (Table 5)

Supportive relationships have been shown to have a positive impact on the management and control of asthma and/or allergic disease and in the overall well-being of AYA. Effective communication and fostering positive views about treatment can improve self-management, adherence, asthma control and quality of life. ^{33,35,38,43,44,53,58,86-89} An unsupportive family environment has been associated with poor outcomes. ⁸⁶Adolescents tend not to report asthma symptoms to their parents and care-givers. Enrolling the family in assisting the AYA to undertake self-management of their asthma and allergy may be recommended (Grade C). ^{33,35,38,43,44,53,58,86-89} This can be gradually achieved over time, as appropriate to the age of the AYA. Simple modifications to the family's routines to create time to take treatment may assist with adherence to therapy. ^{43,44}

From early adolescence onwards, along with growing independence, relationships de-centralise from the core family to peers, friends and other social networks. Social comparison and being part of the group become increasingly important. As a result, the AYA may feel embarrassed about their allergy and/or asthma due to fear of being perceived as different from their peers. To prevent this, it may be recommended to encourage AYA to let their friends know about their allergy and/or asthma and how they can help in an emergency (Grade C). ^{29,31,32,45,59} Friends may be invited to clinic appointments or practical workshops where they can be provided with hands-on training in symptom recognition, the use of adrenaline auto-injectors and other aspects of emergency management of allergy and asthma. ^{29,31,32,45,59}

Promoting allergy and/or asthma awareness (e.g. triggers and treatment) among peers/ co-workers and teachers/ managers to support the AYA patient with self-management may be recommended (Grade C).^{33,45,61,62,90} Information about the nature of the allergic conditions, possible triggers and correct treatment may change their self-perception, and the perceptions of others, and enable improvement in self-management. Increased awareness may also help reduce allergy- and/or asthma-related bullying in schools and online. ^{45,62,90}

Teenagers like to use applications on their mobile phones and look for information on the internet; moreover patients have reported finding online support networks helpful. ^{29,31,33,38,44,45,58-63,87,88} Signposting AYA to high quality reliable online resources about allergy and/or asthma (eg websites, moderated forums) where they can obtain age-appropriate information and advice may be recommended (Grade C).

Table 5. Support recommendations for adolescents and young adults with allergy and/or asthma

Enrolling the family in assisting the AYA to take on the self-management of their allergy and asthma may be recommended (Grade C, Evidence level IV)

Enrolling the family in assisting the AYA to take on the self-management of their allergy and asthma may be recommended (Grade C, Evidence level IV) Enrolling the family in assisting the AYA to take on the self-management of their allergy and asthma may be recommended (Grade C, Evidence level IV)

Strength of recommendation: Moderate recommendation based on low to moderate risk of bias in qualitative ^{33,35,44,53,88} and observational studies ^{38,43,58,86,87,89}. These included AYA with both asthma ^{33,35,38,43,44,53,86,87,89} and food allergy ^{58,88}.

Other considerations: Support the family to slowly empower the AYA to take on more self-management as appropriate to the individual balancing autonomy and safety. Reducing control may be a challenge for some parents. Ask the AYA how they would like their parents/carers to be involved throughout their transition and help them develop confidence in working with the adult's services 18. Give AYA the chance to raise any concerns and queries separately from their parents/ carers respecting their confidentiality and autonomy. This may take more clinic time. Adherence may be improved if the family's routines are modified to assist AYA self-management activities 43,44 .

References: Bruzzese⁸⁹, Bruzzese⁴³, Holley³³, Koster³⁸, Mammen⁵³, Naimi³⁵, Rhee⁸⁶, Rhee⁸⁷, Steensgaard⁵⁸, Stewart⁸⁸, Wamboldt⁴⁴.

Encouraging AYA to let their friends know about their allergy and asthma and how to manage emergencies may be recommended (Grade C, Evidence level IV)

Strength of recommendation: Moderate recommendation based on low to moderate risk of bias in qualitative^{32,59} and observational studies^{29,31,45}. These included AYA with asthma³², anaphylaxis⁵⁹ and food allergy^{29,31,45}.

Encouraging AYA to let their friends know about their allergy and asthma and how to manage emergencies may be recommended (Grade C, Evidence level IV)

Other considerations: Some AYA may find this difficult, they may require support and be encouraged to initially just talk to a few close friends. Provide practical training in symptom's recognition, the use of adrenaline autoinjectors and other aspects of emergency management for friends. Some AYA may want to bring a friend to the clinic for support.

Encouraging AYA to let their friends know about their allergy and asthma and how to manage emergencies may be recommended (Grade C, Evidence level IV)

References: Gallagher⁵⁹, Jones²⁹, Jones³¹, MacAdam³², Warren⁴⁵.

Enrolling the family in assisting the AYA to take on the self-management of their allergy and asthma may be recommended (Grade C, Evidence level IV)

Enrolling the family in assisting the AYA to take on the self-management of their allergy and asthma may be recommended (Grade C, Evidence level IV) Enrolling the family in assisting the AYA to take on the self-management of their allergy and asthma may be recommended (Grade C, Evidence level IV)

Promoting allergy and asthma awareness (e.g. triggers and treatment) among peers/ co-workers and teachers/ managers to support the AYA patient with self-management may be recommended (Grade C, Evidence level IV)

Strength of recommendation:
Moderate recommendation as based on low risk of bias in qualitative^{33,61} and one observational study⁴⁵. These included AYAs with both asthma³³ and food allergy^{45,61}. Signposting AYA to high quality online resources about allergy and asthma (websites, moderated forums) where they can obtain age-appropriate information and advice may be recommended (Grade C,

on low to moderate risk of bias qualitative $^{33,44,59-61}$ and observational studies 29,31,38,45,58,62,63,87,88,91 . These included AYA with asthma 33,38,44,60,62,87,88 , anaphylaxis 59 , allergy 91 and food allergy 29,31,45,58,61,63 .

Moderate recommendation based

Evidence level IV)

Strength of recommendation:

Promoting allergy and asthma awareness (e.g. triggers and treatment) among peers/ co-workers and teachers/ managers to support the AYA patient with self-management may be recommended (Grade C, Evidence level IV)

Other considerations: Efforts should be made to reduce asthma and allergy related bullying especially in schools^{45,62,90} and online⁶².

Signposting AYA to high quality online resources about allergy and asthma (websites, moderated forums) where they can obtain age-appropriate information and advice may be recommended (Grade C, Evidence level IV)

Other considerations: Patients consider online supportive networks to be helpful. Peer support groups may be helpful, for example, voluntary- and community-sector organisations, such as condition specific support groups or charities^{13,18}. Social networks via virtual platforms or electronic communication may be helpful^{13,18}. Moderation of the group is desirable to ensure that interactions within the group are positive.

Promoting allergy and asthma awareness (e.g. triggers and treatment) among peers/ co-workers and teachers/ managers to support the AYA patient with self-management may be recommended (Grade C, Evidence level IV)

References: Fong⁹⁰, Gibson-Young⁶², Holley³³, Monks⁶¹, Warren⁴⁵.

Signposting AYA to high quality online resources about allergy and asthma (websites, moderated forums) where they can obtain age-appropriate information and advice may be recommended (Grade C, Evidence level IV)

References: Bruzzese⁴³, Gallagher⁵⁹, Gibson-Young⁶², Hullmann⁶³, Holley³³, Jones²⁹, Jones³¹, Jonsson⁶⁰, Koster³⁸, Monks⁶¹, Rhee⁸⁷, Stewart⁸⁸, Steensgaard⁵⁸, Suorsa⁹¹, Warren⁴⁵ Wombald⁴⁴.

AYA, adolescents and young adults.

Discussion, gaps in the evidence and future perspectives

Discussion

The EAACI Task Force on Adolescents and Young Adults has developed an evidence-based, clinical practice guideline to help HCP to manage AYA with allergy and/or asthma. Adolescence can be a critical time for AYA as they need to become independent, expert adult patients, successfully self-managing their chronic conditions. This can be seen as a challenge but also as an opportunity for HCP. This is because neurodevelopmentally, adolescents are naturally eager to become more autonomous and are able to learn new skills quickly and easily.

The guideline sets out a series of general recommendations focused on how to run a clinical service for AYA. Key recommendations are to consider starting transition early (11-13 years), using a structured, multidisciplinary approach (involving both paediatric and adult clinics where applicable); ensuring AYA fully understand their condition(s) and have resources that they can access; discussing any implications for self-management in real-world contexts such as further education/work and actively monitoring adherence. Specific allergy and/or asthma transition recommendations are categorised according to improving adherence, optimising self-management, addressing psychological issues and obtaining support. Highlights include simplifying medication regimes and the use of reminders; focusing on areas where AYA are less confident; involving peers in training AYA patients; identifying and managing psychological and socioeconomic issues impacting disease control and quality of life; enrolling the family in assisting AYA to take on self-management and encouraging AYA to let their friends know about their allergy and asthma.

Limitations

Based on the recent survey, we know that there is a lack of adult allergy services, as well as availability of HCP with a specific expertise (psychologists and dieticians) in many European countries². There is a need for an individualized and coordinated transition process between the AYA, family and medical services to ensure the best outcomes. This needs to be multidisciplinary including medical, nursing, dietetic, psychology and other staff. It is important to note that most of the evidence about transition, challenges and interventions in AYA with allergy and/or asthma comes from cross-sectional and qualitative studies. While many of these studies are high quality with low risk of bias, they do not represent a robust form of evidence.

How to implement transition (Box 3)

Transition needs to be implemented as a joint approach from paediatric and adult services. The process is simpler where the allergy service caters for all age groups but a separate AYA transition clinic is still helpful to facilitate a smooth transition care process which addresses the age and developmental specific needs for AYA, that has been shown to be successful in different diseases⁹²⁻⁹⁵. As most HCP have received only minimal specific training on how to manage this age group, this is likely to require additional staff training in delivering developmentally appropriate healthcare (Table 6). Information technology may be helpful in implementing additional support for this AYA group⁹⁶. Some of the likely barriers and strategies facilitated to delivering a transition service for AYA are detailed in Table 7. The task force is now working on practical tools for assisting healthcare professionals to implement transition for allergy and asthma.

Recommendations for policy and training

This guideline has important implications for policy makers, managers and commissioners of both paediatricand adult-centred care in allergy and/or asthma patients. The recommendations could be implemented at a patient, family and society level, through education, training, resources and service delivery design.⁹⁷ Based on the recent survey, HCP find managing AYA to be a challenge². Therefore, it would be helpful to implement training in the generic transition process in undergraduate and postgraduate training programmes (Table 7). Commissioners need to focus on and understand the important components of integrated AYA care that can be shown to improve outcomes.⁹⁸Self-management is a core component of transition. It is associated with cost savings, a more sustainable health system with less utilisation of health services and subsequent easing of workforce pressures⁹⁹. Promoting self-management is in line with international health policy aims which support a 'life course approach and people empowerment'.¹⁰⁰

Gaps in the evidence

Our systematic review summarizes the sizable amount of evidence for the challenges experienced by AYA with allergy/or and asthma⁷. Specific gaps are notable in food allergy, particularly around adherence to dietary restrictions, label reading and cooking skills in AYA. The evidence gaps are predominately in relation to intervention strategies for allergy as the systematic review only found interventional asthma studies⁸. Evidence is urgently needed to help determine the best format for an AYA transition clinic and for the most effective and cost-effective interventional strategies for allergy and asthma (Table 8).

Conclusions

The EAACI Task Force on Adolescents and Young Adults presents recommendations to support the development of a transition clinic for adolescents and young adults with allergy and/or asthma. This should support HCP to help AYA develop into competent and confident adult patients who can successfully self-manage their allergy and/or asthma. Special emphasis is placed on the difference between transition and transfer. Transitional care is required even when AYA are managed in an allergy clinic dealing with all age groups. While it is possible to make evidence-based recommendations, the evidence for some is minimal. Larger, well designed, randomised controlled trials are required in this area. If optimal care is delivered for AYA, they should become expert adult patients with the knowledge and skills to manage their allergy and/or asthma throughout their lives.

Table 6. Training requirements for HCP working with AYA with allergy and asthma

Knowledge An understanding of AYA development including physical, psychological, cognitive and emotional aspects An

AYA: adolescents and young adults. HCP, Healthcare professional.

Table 7. Implementation: barriers, facilitators, audit criteria and resource implications

Recommendation areas

Implementation of a structured, multidisciplinary transition programme involving paediatric and adult HCP for 11-25 year and Medication reminders, mobile applications and web-based applications, monitors or routines to improve adherence, symptom Focusing consultation on areas where AYA say they are not confident to improve self-management including adherence Formulation of a personal action plan with the AYA and their family to enable them to self-manage their allergy and asthmated interventions to improve asthmated quality of life, asthmated and to reduce asthmated doctor vision Supporting the AYA, family and the wider community to allow the AYA inclusion in social events Motivational interviewing to improved asthmated asymptoms and quality of life

Identification and management of psychological and socioeconomic issues impacting disease control and health related quali Psychological interventions using a cognitive behavioural therapy based or multi-systemic therapy approach to improve adh Enrolling the family in assisting the AYA to take on the self-management of their allergy and asthma

Encouraging AYA to let their friends know about their asthma and allergy and how to manage emergencies

Signposting AYA to high quality online resources about allergy and asthma where they can obtain age-appropriate informations of the control o

AYA: adolescent and young adult. HCP: healthcare professionals.

Table 8. Research gaps in the transition management of adolescent and young adults with allergy and asthma

Research gap

Effectiveness and cost-effectiveness of different transition formats for allergy and asthma – should include patient and paren Effectiveness and cost-effectiveness of educational interventions for AYA with allergy and asthma Effectiveness of motivational interviewing for allergy and asthma

Research gap

Effectiveness and cost-effectiveness of psychological interventions (eg CBT) for allergy and asthma

Smart phone applications or other information technology interventions to improve self-management in AYAs with allergy ϵ . The best time for the transfer of responsibilities of care for each facet to management

Development and validation of disease-related knowledge/ transition readiness tools for AYA with allergy and asthma Most effective way of training HCP in AYA management

Value of personal actions plans for AYA to improve outcomes in allergy

Value of patient activation measures in allergy and asthma

Role of the identification and management of psychological and socioeconomic issues in AYA to improve health related qual Strategies to successfully enrol AYA friends to support self-management

AYA: adolescents and young adults. CBT: cognitive behavioural therapy. HCP: healthcare professionals.

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AUTHOR CONTRIBUTIONS

Guideline concept and design: G.R., M.V-O., KK. Acquisition of data including search, all authors. Analysis

and interpretation of data, all authors. Critical revision of the manuscript for important intellectual content, all authors. Obtained funding, G.R., M.V-O.

CONFLICT 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.

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