

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

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

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

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

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

Article type : Editorial

The need for improved transition and services for adolescent and young adult patients with allergy and asthma in all settings

Graham Roberts¹⁻³, Marta Vazquez-Ortiz⁴, Ekaterina Khaleva¹, Audrey DunnGalvin^{5,6}, Claudia Gore^{4,7}, Mary Jane Marchisotto⁸, Charlotte G Mortz⁹, Oliver Pfaar¹⁰, Angel Sánchez¹¹

Affiliations:

1. Faculty of Medicine, University of Southampton, Southampton, UK
2. The David Hide Asthma and Allergy Research Centre, St Mary's Hospital, Isle of Wight, UK
3. NIHR Southampton Biomedical Research Centre, University Hospital Southampton NHS Foundation Trust, Southampton, UK
4. Section of Inflammation, Repair and Development, National Heart and Lung Institute, Imperial College London. United Kingdom
5. Applied Psychology and Paediatrics and Child Health, University College Cork, Cork, Ireland
6. Paediatrics and Child Infectious Diseases, First Moscow State Medical University, Russia.
7. Department of Paediatrics, Imperial College Healthcare NHS Trust, London, UK
8. European Academy of Allergy and Clinical Immunology Patient Organisations Committee, USA

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/ALL.14427](https://doi.org/10.1111/ALL.14427)

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9. Department of Dermatology and Allergy Centre, Odense Research Centre for Anaphylaxis (ORCA), Odense University Hospital, University of Southern Denmark, Odense, Denmark
10. Department of Otorhinolaryngology, Head and Neck Surgery, Section of Rhinology and Allergy, University Hospital Marburg, Philipps-Universität Marburg, Germany
11. Asociación Española de Personas con Alergia a Alimentos y Látex, Madrid, Spain

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

Key words: adolescent, asthma, food allergy, rhinoconjunctivitis, transition, young adult, allergy.

Word count: 990

Conflict of interests:

GR reports research funding from Asthma UK and National Institutes of Health Research into the challenge associated with asthma during adolescents. None of the other authors have anything to disclose.

Contributions:

G.R. M.V-O. and K.K. discussed the initial plan for the editorial. GR generated the initial draft which was critically reviewed and revised by all the authors.

Adolescence is a challenging time for both patients and healthcare providers. Adolescent patients need to learn all the knowledge and skills required to competently and confidently self-manage their allergy and asthma. They have to negotiate the challenging transition from being children, whose medical care is supervised by their parents, to independent expert adult patients. Although adolescent and young adult patients appear to be very robust, the reality is that they have often had a poor experience of medical care and are at surprisingly high risk of morbidity and mortality. An example is the predominance of fatal anaphylaxis in adolescents and young adults [1].

The 2019 survey by the European Academy of Allergy and Clinical Immunology (EAACI) adolescents and young adult task force showed that healthcare professionals find managing this age group to be a challenge [submitted, 2]. Unmet needs were also identified, for example most services do not have an established approach and related resources to effectively support this age group. Furthermore, the majority of healthcare professionals do not feel confident in managing the age-related issues that may complicate self-management of allergic diseases in this age group. Examples include changing personal relationships, education and employment problems, depression and anxiety [3]. There are effective interventions for this age group [4] but their availability in clinical practice is limited.

During adolescence there are huge changes in body stature and form. There are also psychosociological shifts with adolescents' primary interpersonal relationships moving from family-based to peer-based. This means that adolescents and young adults typically pay more attention to peer group values and norms than to their parents or healthcare professionals. Substantial changes in the brain drive many of the behaviours notable in adolescence. It has only been relatively recently recognised that these neurodevelopmental changes continue until about 25 years of age [5]. Development is not a linear process with different parts of the brain developing at different speeds, leading to an imbalance between systems supporting reactivity and regulation [6]. The imbalance is compounded by adolescents, and their valued peer group, relative lack of experience and knowledge. As a consequence, adolescents are more likely to make risky decisions, which may have long-term negative effects on their health and well-being.

That the developmental changes of adolescence are still occurring in the early 20s explains why we should focus on this wider 11-25 year adolescents and young adult age group [7]. With paediatric patients being transferred into adult services around 16-18 years of age [2], plans for

supporting effective self- management in the adult healthcare service need to take into account these ongoing major lifestyle changes and their potential impact. This is particularly so with the patient moving to college, university or work.

The term transition has been coined to describe the approach that healthcare professionals should take to support the development of adolescents and young adults into expert adult patients. It is very much a gradual process with training being focused on the adolescent patient to enable them to slowly take over responsibility from their parents. This would include managing their disease, communicating with the health care professionals on their own, organising their own prescriptions and scheduling medical appointments. This might start at around 11 years of age but will differ for different patients, in order to achieve developmentally appropriate healthcare [8]. Although most patients will have grasped how to manage their allergies by 16 to 18 years of age, adherence to treatment and loss of access to consistent healthcare are more common in this age group, contributing to their increased risk. They therefore require additional support and resources.

Parents can find the process of their adolescent taking on responsibility for their healthcare a stressful experience. They will have built up considerable knowledge and experience at keeping their offspring safe and will be only too aware of their lack of experience. So healthcare professionals also need to support parents, as well as enlisting them as allies, to help them give their adolescents the space to take on these new responsibilities while still being available to support and assist when appropriate.

Many healthcare professionals deal with allergic diseases, including general practitioners, allergists, paediatricians, dietitians, nurses or organ-based subspecialists. They rarely have training in dealing with the specific needs of adolescence and young adults [2]. This is an important unmet need. A shared approach is needed involving all healthcare professionals to provide continuous, comprehensive and effective care. For paediatricians this requires close collaboration with adult colleagues to whom patients are usually transferred at around 16-18 years. For allergists and organ-based subspecialists who see patients of all ages in a single centre, there is still a need to provide a specialised clinic or service focused on this adolescent and young adult age group to ensure that their specific and individual transition needs are addressed to ensure optimal outcomes for both the patient and the service.

To support healthcare professionals in managing adolescent and young adult patients with allergies and asthma, the European Academy of Allergy and Clinical Immunology (EAACI) Task Force is publishing a guideline [*about to be submitted*, 9]. This will provide the framework and practical advice on how to successfully transition this age group and develop a successful transition service. The core characteristics of an integrated allergy healthcare system to meet the needs of this age group include (i) a multidisciplinary approach, (ii) education, (iii) active monitoring of adherence, (iv) focusing on areas where the adolescents and young adults are less confident, and (v) involving peers in supporting the adolescent patient. To illustrate the impact of life with allergic conditions for the adolescent and the parent, we have included links to two brief digital stories (Figures 1, 2; <https://www.patientvoices.org.uk/ttallergies.htm>, last accessed 5th April 2020). If we, as healthcare professionals, are successful in supporting our adolescent patients into becoming competent and confident adult patients, the excess morbidity and mortality seen in this group will be minimised and the patients will be provided with lifelong skills required to best manage their allergic diseases.

Figure 1. Kyle's story – adolescent with allergies



This is the 2.5 minutes digital story of an adolescent with allergies. Access by visualising the quick response (QR) code with your mobile phone and following the link.

Figure 2. Steve's story – parent of an adolescent with allergies



This is the 2.5 minutes digital story of a parent of an adolescent with allergies. Access by visualising the quick response (QR) code with your mobile phone and following the link.

Acknowledgements

We would like to acknowledge the input and commitment of the entire EAACI Task Force on Allergic Diseases in Adolescents and Young Adults, in particular Cherry Alviani, Elizabeth Angier, Katharina Blumchen, Pasquale Comberiati, Bettina Duca, Teresa Garriga-Baraut, M Hazel Gowland, Valérie Hox, Britt Jensen, Rebecca Knibb, Helena Pite, Alexandra F. Santos, Silvia Sanchez-Garcia and Frans Timmermans; all the healthcare professionals who contributed to the task force survey and comments on the draft guideline; all the patients and parents who completed the recommendations survey; and to EAACI for funding the Task Force.

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