**TITLE:**

**A practical toolbox for the effective transition of adolescents and young adults with asthma and allergies – an EAACI Position paper**

**SHort title:**

**An EAACI practical toolbox for effective adolescent transition**

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**ABBREVIATIONS**

AYA: Adolescents and young adults; CBT: cognitive-behavioural therapy; HCP: Healthcare professionals; MI: Motivational Interviewing.

**Abstract**

Adolescence is a critical stage of rapid biological, emotional and social change and development. Adolescents and young adults (AYA) with asthma and allergies need to develop the knowledge and skills to self-manage their health independently. Healthcare professionals (HCP), parents and their wider network play an essential role in supporting AYA in this process. Previous work showed significant limitations in transition care across Europe. In 2020, the first evidence-based guideline on effective transition for AYA with asthma and allergies was published by EAACI. We herein summarize practical resources to support this guideline’s implementation in clinical practice. For this purpose, multi-stakeholder Task Force members searched for resources in peer review journals and grey literature. These resources were included if relevant and of good quality, and were pragmatically rated for their evidence-basis and user friendliness. Resources identified covered a range of topics and targeted healthcare professionals, AYA, parents/carers, schools, workplace, and wider community. Most resources were in English, web-based and had limited evidence-basis. This position paper provides a valuable selection of practical resources for all stakeholders to support effective transitional care for AYA with asthma and allergies. Future research should focus on developing validated, patient-centred tools to further assist evidence-based transition care.

**main text**

**Background**

Adolescence is a challenging time for patients, their parents and their healthcare professionals (HCP).1 The inclusion of adolescent health in the United Nations secretary general’s Global Strategy for Women’s and Children’s Health in 2015 reflects a growing awareness of the importance and specificity of this stage of development. Adolescence is a critical stage of life characterised by rapid biological, emotional, and social development, during which skills for a productive, healthy and satisfying life are developed. As part of this period of growth and development, the status of primary relationships and level of autonomy also shifts. The need to take on responsibility for behaviours and learn to cope with everyday events and challenges falls increasingly on the adolescent.2 Together with these usual developmental tasks, adolescents with an allergic disease face additional challenges that may render them more vulnerable to adverse outcomes, which may include psychological issues (including poor quality of life) and difficulties around adherence and self-management.1 Support is therefore vital for this age group.

However, a recent European survey found that most HCP have not received training in how to support adolescents and young adults (AYA) with allergic conditions and do not have an established paediatric to adult health care transition process.3 Ensuring that every adolescent has the knowledge and skills to self-manage their allergy with confidence is essential for achieving good mental and physical health and development goals and lower risk of adverse outcomes. This is equally necessary when patients stay within the same service as adults, as well as when they are transferred into an adult service, in which case the responsibility for an effective transition is shared by the paediatric and adult teams.

The European Academy of Allergy and Clinical Immunology (EAACI) transition guideline was developed by a multi-stakeholder Task Force from across Europe using evidence-based principles and published to support HCP in effectively managing AYA.2 Its recommendations have been favourably reviewed by AYA and parents from across Europe.4 This paper aims to provide HCP (both paediatric and adult, as well as those seeing all ages), AYA and families with practical and targeted resources to support successful self-management of asthma and allergic conditions.

**Methods**

The EAACI Adolescent and Young Adult task force (a European multidisciplinary team of professionals and patient representatives) reviewed the resources available to support successful self-management and selected those that are likely to be most helpful to HCP, AYA, their families and the wider community. Peer review journals and grey literature were searched, including material from websites, publications from patients, scientific and government organisations. Any resources found that met our aim were reviewed by the Task Force and included if relevant and of sufficient quality. Weblinks were tested and functioning at the time of publication. Resources were pragmatically rated in terms of whether the information provided was based on evidence as ‘moderate’ (some evidence provided, cited or referred to), ‘good’ and ‘very good’. Sources were also subjectively rated with regards to user friendliness as ‘moderate’, ‘good’ or ‘very good’.

**RESULTS – THE Toolbox**

A selection of the key resources is presented in Tables 1 and 2. Additional resources available for HCP are presented in Table S1 in the online supplement. Figure 1 provides an overview of our approach to support an AYA with asthma and allergies. It emphasises the need for awareness and action and explains how to support transition in an effective manner. A glossary of terms is available in table S2 in the online supplement.

**1. Healthcare professionals**

**1.A. Transition Programmes**

HCP touch the lives of AYA during a period of substantial physiological, psychological and social change. Change and desire for autonomy can also mean opportunity, and HCPs can support AYA to develop the knowledge, skills and confidence to self-manage their own health and well-being, which will confer lifelong benefits. There is agreement on the importance of education and support of AYA and their families within a multidisciplinary approach. Getting started with AYA-focussed care is often a challenge for HCPs, who worry about lack of experience, time, resources and competing responsibilities.3

Resources from healthcare settings (primarily generic but some allergy specific) have been developed to assist HCPs of all disciplines in managing healthcare and transition for the AYA, from starting to further developing a transition service. In Table 1 and S1 section A, we present our review of guidelines and transition programmes. These resources explain how to facilitate the type of planning, preparation and transfer tools required to ensure optimum transition from paediatric to adult healthcare services for youth with long-term health needs. They also focus on timing, transfer requirements, and the contributions (roles, tasks) needed by different HCP during the transition process. They include education to upskill HCP and practical sites aimed at AYA and parents with videoclips providing insight into the experience of transition, information to demystify and simplify health-passports and booklets with useful links. However, the evidence-base is weak on the effectiveness of these programmes in supporting positive self-management outcomes. Formal validation is scarce, as are outcome measures specifically for transition.

**1.B. Tools to assess transition readiness**

Transition involves a process of education and empowerment for AYA to become confident to independently self-manage their chronic condition(s), ideally in good time before they reach the legal adult age and/or their care may be transferred to adult services. For this purpose, a number of psycho-educational programs, including disease-specific education and self-management techniques have been developed for a range of chronic conditions.5,6

AYA differ in their degree of independence, maturity and self-care skills. Therefore, the transition process needs to be developmentally appropriate and tailored to the individual. The key to an effective transition and successful transfer is the AYA’s readiness to transition. Transition readiness refers to the “process of building the capacity of adolescents and those who are involved in his/her medical care to prepare for, enter, continue and complete transition”.6 Readiness can be assessed by evaluating the AYA’s willingness and ability (including the necessary skills) to achieve independence and autonomy in managing their condition.7 A number of transition readiness measures are available for use in clinical practice, including ‘Ready Steady Go’, ‘OnTRAC’ or ‘TRAQ’ (see Table 1 and S1 section B for selection of resources).8,9 These tools are generally used repeatedly or gradually over the transition process and they allow: a) to track AYA’s progress and help tailor the transition process to the individual’s needs and goals; b) to identify and promote opportunities for increasing self-management; and c) to help identify AYA at risk of poor transfer in whom further support will be required. Nonetheless, a systematic review conducted in 2014 on the methodological quality of available transition readiness and satisfaction measures highlighted that none had well-established evidence of reliability and validity.10 AYA’s satisfaction with transition programmes has also been assessed as a surrogate of transition effectiveness.

**1.C. Approach to assessing an adolescent patient including psychosocial assessment**

The developmental changes of AYA and the challenges faced by this group require the HCP to adopt a specific approach when communicating and engaging with them. Both the short- and long-term health and wellbeing needs of AYA cannot be viewed in isolation. To deliver developmentally appropriate healthcare, a person-centred approach to AYA should include the medical, psychological, cultural and social aspects. This includes topics such as sexual health, education or vocational planning, psychological issues and lifestyle (including leisure activities, alcohol and drug use). Consideration should also be given to the different challenges that early and late adolescence may bring (such as moving away from the parent’s home), as well as to the development of a stronger sense of self and the need for more independence from parents or caregivers.

AYA with long-term health needs are at increased risk for mental health issues and have unique psychosocial requirements11-13. The HCP is well-placed to assess and highlight any ongoing concerns and ensure that AYA is provided with the necessary support to prevent the morbidity and mortality associated with mental health problems and risky behaviour. In clinic, the regular use of screening tools for psychosocial assessments, such as HEEADSSS14 and Youthchat15 can facilitate this holistic assessment over the transition period.

HCPs should also consider a more condition-specific approach when interacting with AYA with allergy and asthma to ensure that essential topics are covered, such as asking about ingredients, avoiding food cross-contamination in shared accommodation, the impact of smoking or environmental allergens in new housing on asthma control. Concise and developmentally appropriate information should be given throughout the transition process to ensure AYA feel equipped to deal with these changes. See Table 1 and S1, section C for selected resources in this area.

**1. D. Transition report for individual patient/ transfer package**

During the transition process, if it is required to transfer AYA’s care to adult services, HCP should ensure that they have completed a transfer package (see box 1 and Tables 1 and S1, section D). This will facilitate information sharing and strengthen continuity of care across services.

The transfer package includes a transition report, relevant action/emergency plans, a transition readiness assessment and other documents such as information sheets about key areas for the AYA. A transfer of care letter to the adult clinician detailing the contents of the transfer package, confirming transfer of care and upcoming appointments can be useful. When preparing the package, HCPs should consider incorporating particular concerns and priorities from AYA’s and parents’ perspectives.

The transition report is a comprehensive document that outlines the AYA medical history and ensures a holistic approach to the transfer of care. The medical history may include disease course, previous and current treatment, an up-to-date management plan as well as any co-morbidities. Information about adherence, self-management, school/work, hobbies and AYA’s future plans/goals should also be included. The format and content should be acceptable to both the paediatric and adult teams. Providing an updated action/emergency plan will help keep the AYA safe during the transfer of care. Including the most recent transition readiness assessment will allow the adult team to identify the areas where AYA need more support. The transfer package should be distributed to all HCP involved in the patient’s care, including the adult team and primary care. It should be written in a manner that AYA and families can understand.

**1.E. Audit and key performance indicators**

Regular audit of a transition service to assess key performance indicators is recommended to facilitate improvements in service provision.2 The EAACI guideline on AYA transition provided a list of potential audit criteria (see table S3 in the online supplement). Structure, process, and outcome can be audited. This ensures the best quality care is followed and clinical practice is evidence-based. A quality improvement approach of ‘*plan, do, study, act*’ could be followed.16,17 The audit cycle allows to compare against agreed standards and implement change where necessary to achieve improvements. Regular audit with reflection and review within the multidisciplinary team is advised for continuous improvement. Staff should have protected time for this.

Each country may have a different approach and understanding of audit. Also, different units can devise their own key performance indicators and service specifications. Benchmarking services across a region or country may help drive improvements within a wider approach.18,19

**1.F. Resources to help HCP address the psychological impact of asthma and allergy in AYA**

Identifying and addressing common psychological issues AYA encounter when living with asthma and allergies, such as anxiety, depression or low self-esteem, is key to preventing morbidity and mortality. A number of resources have been identified to assist in this area (see tabled 1 and S1, section F).

**Cognitive Behavioural Therapy** (CBT) is one of the most commonly used psychotherapeutic approaches for treating mental health problems. The core concept is the idea that thoughts, emotions and actions are connected, i.e. the way that an individual thinks and feels about something will affect what they do. Another key principle of CBT is that these thoughts and behaviour patterns can be changed. Psychological issues are partly based on unhelpful ways of thinking and learned behaviour patterns. Therefore, improvement occurs with better coping mechanisms and management. A range of online training courses is available on CBT for HCP. The accreditation and level of training provided should be considered carefully.

**Motivational Interviewing** (MI) is a person-centred strategy. It is used to elicit patient motivation to change a specific negative behaviour. Much of the online material for MI relates to training in a particular technique. Some organisations offer online MI training, some for free (See Tables 1 and S1, section F).

**2. patients and families**

**2.A. General transition information and advice**

Throughout the transition process, AYA need to acquire the knowledge and skills to confidently self-manage their allergies and/or asthma. At the same time, their care may be transferred from a paediatric to an adult service. Parents and caregivers, assisted by HCP, need information and confidence to support their young person through this process and to hand over responsibility for self-care to the AYA. This requires access to lay information to prepare for the process. Some useful resources are summarised in Table 2, section A. They include information on the principles, aims, stakeholders, timelines of transition, as well as key areas for self-management, common challenges and questions. The information provided will need to be aligned with the resources and services provided locally. Access to transition readiness assessment tools to monitor progress can be very helpful.

**2. B. Specific advice for AYA and families**

Self-managing asthma and allergies effectively requires AYA to understand their condition, identify and avoid potential triggers and risky situations, manage symptoms - particularly acute emergencies such as asthma attacks or anaphylaxis- and cope with the psychosocial impact of living with these issues in their changing reality. AYA and their support network may feel overwhelmed by the many aspects where AYA need to develop their knowledge and skills to effectively self-manage their conditions and keep safe. In table 2, sections B-E, we have selected a range of web-based resources offering comprehensive information, advice and useful documents on a range of areas relevant to AYA with asthma and allergies, including:

**Written action plans** are patient- or carer-held instructions that help support self-management. They have the potential to address barriers to effective treatment, such as a lack of understanding about the condition and medications prescribed. They are recommended by national and international guidelines20, and their use can improve management21 and asthma outcomes22,23.

We advocate the use of a patient-held, written self-management plan which provides clear individualised treatment guidance. Many action plans available are designed for parents/carers of young children. However, medical communication should gradually be addressed to the AYA themselves in a clear age-appropriate language and format.24 We have not been able to identify adolescent-focused self-management plans for different atopic conditions, including much-needed electronic versions of these, which remains a major gap. Links to action plans for asthma, anaphylaxis and atopic eczema designed to suit all ages, rather than children-focused, are included in table 2, section B.

**Food avoidance and safe food choices** (see table 2, section B)

For patients with food allergy, avoiding the culprit food(s) is the cornerstone of management to prevent potentially life-threatening accidental reactions. Avoidance and making safe food choices involve planning/knowing the full list of ingredients in every single food consumed and ensuring/checking the careful storing, handling, and serving of the food to avoid cross-contamination. This is often challenging for AYA, their families, and their broader network, particularly as many common allergens (cow’s milk, egg, nuts) are widely present in our diets. Also, despite the FIC European Regulation 1169/2011 (and now the UK) on Food Information to Consumers and its implementation through national guidelines, information on allergens in both prepacked and non-prepacked foods is not always easy to find or understand, thus complicating decision-making for allergic consumers to stay safe.25 The overuse of precautionary allergen labelling, as well as incorrect or inaccurate labelling, contribute to this problem. AYA will also need to develop cooking skills as they head towards living independently.

**Leisure, sports and further education** (see table 2, section B)

AYA tend to spend more time away from home and their parents, as the weight of their relationships moves towards friends and peers. As such, parents need to ‘let go’, and AYA need to take increasing responsibility for managing their allergies and asthma. This can be very challenging as many of the lifestyle changes AYA go through involve new situations that may pose risks. For instance, moving from high school to college/university/workplace, sharing accommodation, new friendships, dating, partying, new sports, school trips or international travel. AYA need to learn how to navigate these new situations independently whilst keeping safe. This can be overwhelming for AYA and their parents, who often worry about the risk of life-threatening allergic reactions or poor disease control as they ‘let go’.

For AYA, sharing or disclosing information about their allergies and asthma with new friends, peers, work colleagues, or a partner can be challenging due to feelings of embarrassment, shame or denial. Hence, it is vital to provide AYA and their network with practical resources to promote a supportive environment and help AYA develop the skills and confidence required to share their needs, reduce risks and manage their conditions effectively in the range of new scenarios they will encounter.

**Travelling and patient passport** (see table 2, section C)

AYA with asthma and allergies and their parents/caregivers often feel anxious when travelling, particularly internationally, probably due to uncertainty around exposures, risks and access to foods, medications or emergency care if required in new environments. Before booking a holiday or making travel arrangements, AYA with food allergies in particular, should spend time planning and gathering information to ensure a safe and enjoyable trip.

HCP should provide AYA with asthma and allergies with resources to assist when travelling, including:

-Allergy passport, which is a one-page letter/card summarizing information on their allergic conditions, allergens involved, severity/nature of diseases and medications to carry. An example of an allergy passport with a checklist suggestion is provided in Figure 2.

-Personal management plans including an Emergency Action Plan for anaphylaxis, asthma exacerbations or severe atopic eczema flares, as required.

- Supporting ‘authorization for travel’ forms to carry specific medications or food items within the hand luggage, if required. AYA with asthma and/or at risk of anaphylaxis, asthma inhalers and/or two adrenaline autoinjectors should be always available and not put into the checked luggage.

Whilst traditionally documentation was carried in paper form, documents should also be available electronically on the patients’ mobile devices or in their web-based ‘cloud’ in the required language(s).

**Future career choices and work advice** (see table 2, section D)

AYA with asthma and allergies should aim at optimal control of their health issues to help them reach their full potential. However, some work-related exposures may involve a risk. Available studies show that only a few young people with symptoms of asthma, allergic rhinitis or atopic dermatitis received appropriate career guidance by their physicians and took their atopic disease into account when choosing their occupation.26 There is also evidence that appropriate risk-related career advice leads to higher use of preventive measures at work in AYA with atopic dermatitis.26 Therefore, individualized career counselling by HCP on job-related risks and preventive measures would be an important step in preventing both symptoms/reactions in AYA wishing to begin an occupation and early cessation of the job. For instance, AYA who are allergic to a substance found at the workplace that cannot reliably be avoided, and who develop specific allergic symptoms on contact with that substance, should be advised about and understand the risks involved.

**Psychological issues**

Identifying and addressing psychological issues has been identified as an important aspect in transition care by AYA and their parents.4 Access to local mental health resources may vary across countries/regions. A number of websites offer resources for youth going through mental health issues, as well as for their parents, partners and teachers to help support them. These include information and advice on common problems, self-help initiatives, online CBT for patients and signposting for further support. See table 2 section F.

**3. Schools, workplace and wider community**

**3. A. Schools and workplace**

Education around asthma and allergies is primarily focussed on the home setting. However, children and AYA spend at least a fifth of their waking hours in school27, and, later on, in the workplace. The impact of asthma and allergic diseases, including atopic dermatitis, in school-work life is well recognised.28 Asthma is the leading chronic condition contributing to school absenteeism.29 Allergic diseases may lead to AYA feeling different to their peers and stigma and bullying are commonly reported.30-32 Importantly, emergency situations such as asthma attacks or anaphylaxis often occur in schools. Indeed, anaphylaxis due to food allergy (FA) occurs in schools more than in any other community location.28,37,38 In this context, awareness and education on asthma and allergies are required to create a supportive environment at schools and the workplace where AYA feel safe and included. A selection of resources in this area is provided in table 2, section F.

Against a backdrop of schools being under increasing pressure to maximise performance with less resources, it is unsurprising that many schools are slow to embrace effective risk minimisation management policies for allergy35 and asthma, since this is not directly relevant to academic attainment targets. Teachers are often unaware of school management plans, with many not competent to manage asthma attacks or severe allergic reactions.36 So, AYA often need to self-manage their allergies or asthma at school, to communicate their needs, to prevent or minimise the impact of accidental adverse events, to raise awareness, and to cope with any stigma.34, 37 Although there is a paucity of research carried out in work settings, it is likely that similar challenges exist. Standard allergy policies, such as those supplied by Local Authorities, may lack school-specific practical solutions targeted at the real-world challenges faced by AYA.34 An important part of supporting AYA at school and work is to develop age-appropriate and context specific online resources. These resources, if evidence-based, may promote skills for self-awareness, self-management, social awareness, relationships and social decision-making.

Although online resources targeted to AYA are important, a more effective strategy may be to raise awareness across the whole school community.34 A whole-school approach recognises that all aspects of the school community can impact student health and wellbeing33,34,35 in addition to helping reduce the social stigma and bullying associated with allergies or asthma through correcting current misconceptions, improving knowledge, empathy and overall management awareness. Whole-school risk assessment and appropriate daily risk management may prevent incidents occurring, as well as raise awareness, which may in turn positively impact the quality of life of pupils with food and other allergies and asthma34,39,40. Such an approach could also be applied to the work setting with similar benefits.

**3.B. Friends, peers, wider society including youth groups and sport/leisure**

Civil society has legal and moral obligations towards the individuals who make it up. One of these is to help people feel part of the community in carrying out daily life activities. Equality, inclusiveness, solidarity, dignity, empathy and respect between individuals are human rights based on fundamental values.

AYA strongly feel the influence of friends and peers. This can lead AYA not to reveal their condition(s) out of shame or fear of feeling different, being bullied or being made fun of. This hinders building the support network they need and may put them at risk. Friends, peers and colleagues and the broader community should take allergies and asthma in AYA seriously, understand and respect their needs and adhere to their care plans to help them keep safe. For instance, involving AYA in activities that could pose a risk should be avoided, even if these may seem trivial such as smoking, drinking, tasting food or exchanging tools or equipment.

A range of useful resources has been identified for the broader community in their supporting role to AYA (see table 2, sections B-F). Portals gathering resources in languages other than English are summarized in table 2, section G.

**DISCUSSION**

Adolescence is a crucial period of change and vulnerability. Transition care for AYA with asthma and allergies is perceived as important by HCP, AYA and their parents alike3,4. HCP have a pivotal role in advocating for AYA’s needs and supporting them to develop the knowledge and skills required to self-manage their conditions independently beyond adolescence. However, transitional care provision has significant limitations across Europe. The broad scope of AYA healthcare transition, along with competing priorities and limited resources, may lead to HCP feeling overwhelmed when approaching the needs of this age group3,4.

Following on the publication of the EAACI Guideline on effective transition and previous work by the taskforce, this ‘toolbox’ paper provides a careful selection of practical resources to help implement the guideline and assist the multiple stakeholders involved in transition, including paediatric and adult HCP, AYA, their families, school and workplace, and the wider community.

The structured and pragmatic approach, with clear signposting to the resources available, should allow anyone and everyone involved in transition care to identify resources to help meet their needs. This includes from basic elements to get started to more specific resources to further develop services (for instance, by systematically incorporating psychosocial and readiness assessment tools) or to signpost AYA or their families to good quality advice on a particular area (such as travelling or psychological support). The wider use of telemedicine and web-based resources due to the covid-19 pandemic may provide opportunities for more convenient and effective interactions with AYA, and many of the resources selected can be used in this context41, 42. We believe this pragmatic selection of resources is a great opportunity for all stakeholders, particularly HCP, to engage with transition to help meet AYA’s needs and improve their long-term health.

**Limitations**

We are aware of the wide differences regarding service provision and funding across Europe, which may impact on the implementation of the resources presented. Irrespective of the setting, our resources reflect the principles underpinning AYA healthcare transition, i.e. the recognition that AYA have specific needs to achieve effective self-care and they deserve special, developmentally appropriate attention and advice.

The taskforce undertook significant efforts to engage European clinicians and searched in multiple common languages. The materials found to be relevant and of good quality was included, which is mostly in English. This limits its direct applicability and highlights the need for high quality resources in other languages. Also, resources are often web-links, which may cease to function. To mitigate this, we selected key resources with evidence of longevity, i.e. part of large well-funded programmes, where possible. Some resources may be subject to influence by industry via sponsorship.

Many resources presented have been developed by experts with a pragmatic approach, hence lacking methodological rigour, such as formal validation or evidence on effectiveness. Future research should focus on developing validated, patient-centred tools for an effective transition process and successful transfer to adult care.

**Conclusion**

Developed by a multidisciplinary Task Force from across Europe, this is the first ‘toolbox’ providing a careful selection of practical resources to help all stakeholders involved in transitional care to help implement the recent EAACI Guideline on effective transition into clinical practice. Addressed at HCP, AYA, families and the wider community, this aims to support AYA with asthma and allergies develop the knowledge and skills required to effectively self-manage their health independently. There is a need to monitor guideline implementation and audit practice to ensure evidence-based standards are met.

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**Conflicts of interest**

GR and RK report research funding from Asthma UK and National Institutes of Health Research into the challenges 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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**Authors’ contributions**

GR, MV-O and CG produced the manuscript concept and design. All authors involved in the acquisition of data including search, and analysis and interpretation of data, and critical revision of the manuscript for important intellectual content. GR and MV-O obtained funding.

**Tables, Figures and Box**

Table 1. Key transition resources for healthcare professionals (HCP)

Table 2. Transition resources for adolescents and young adults (AYA), parents, carers and wider family, school, work and wider community.

Table S1. Additional transition resources for healthcare professionals (HCP)

Table S2. Glossary of terms for healthcare professionals (HCP) and patients

Table S3. Suggested audit criteria and key performance indicators

Fig 1. The ‘A to F’ of managing transition

Fig 2. EAACI Allergy Passport - Medical Authorisation for Travel

Box 1. Transition package overview

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