

CORRESPONDENCE

Allergy UK, a national patient organisation, response to the BSACI guideline: prescribing an adrenaline auto-injector

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Dear Professor Roberts,

On behalf of the many patients and carers who have contacted Allergy UK, I would like to present a summary of the concerns raised about the recently published BSACI Guideline on 'Prescribing an Adrenaline Auto-injector'. It is important that these issues are shared with the BSACI and that the BSACI and authors have an opportunity to consider and respond.

Allergy UK is the only national patient organization that represents the breadth of the allergic community, with approximately 8000 calls per annum to our Helpline, around 2000 people engaged in our support groups, and a growing social media following of 20,000. Allergy UK has been contacted by a significant number of people who have advised that their interpretation of the guideline has created concern and anxiety for them and their families.

As Chief Executive of Allergy UK, I would like to state that this guideline includes some excellent recommendations about patient care, a majority of which we at Allergy UK, and many of those we support, welcome and endorse. It is good to see recommendations that an adrenaline auto-injector should always be prescribed for those at risk of anaphylaxis, that risk management should be based on an individual patient's circumstances, that there is a requirement for referral to an allergy specialist for accurate diagnosis, treatment and advice on avoidance of triggers, advice for emergency treatment and personalised care plans, and essentially, it is important that ongoing training and education is undertaken in the use of adrenaline auto-injectors (AAIs), including in schools. We strongly support recommendations that ensure that those at risk receive best practice care to safeguard life.

However, there are elements of this guideline which remain unclear, and those which appear to conflict with other existing guidance, and it is fair to say that this has caused a storm of protest from many living with allergic disease across the United Kingdom. This is specifically around the recommendation on the number

of AAIs to be carried, which appears to conflict with both that of the Medicines and Healthcare Products Regulatory Agency (MHRA), which states that people prescribed an AAI should 'carry two adrenaline auto-injectors at all times', and that of the European Medicines Agency's Committee for Medicinal Products for Human Use, which also recommends that patients should be prescribed two AAIs to carry at all times. Unfortunately this issue has served to detract attention away from the other excellent recommendations in the guidelines.

In reviewing and interpreting the comments we have heard from those living with or caring for people with allergic disease, we conclude that they are based on a number of very real fears and concerns that people with allergy and their families are expressing in the context of their understanding of allergic reaction risk. This is a world where GPs have little or no training in allergy, and with approximately one allergy specialist to every 700,000 allergy sufferers in the United Kingdom, there are long waiting periods before seeing a specialist, if indeed they are referred at all.

The recommendation around the prescription of an AAI is in the context of a confusing and worrying environment for allergy sufferers in which 'carry two' has provided a level of reassurance – that a second AAI is available and can be used if necessary during an anaphylactic reaction. We believe that the recommendation around the prescription of AAIs lacks clarity, conflicts with other recommendations and, importantly, has caused alarm in a community where effective diagnosis and treatment may be inconsistent.

While we do understand that the recommendations are intended for specialists, we would urge the BSACI to carefully consider the dissemination of these recommendations to GPs, where allergy risk assessment knowledge and understanding may not be available in some cases due to lack of primary care training in allergy. We are all in agreement that it is imperative that patient care is not affected and this guideline aims to improve management of those at risk of anaphylaxis.

To summarise the main areas of concern raised:

- The BSACI guideline appears to conflict with other existing guidance on the prescription of AAIs, which

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cannot be helpful, particularly in primary care, and is confusing for people living with allergy.

- The circumstances suggested in the guideline for prescribing one or two may not be clear enough for health professionals who have limited knowledge about allergy.
- Those living with allergic disease strongly believe that having only one AAI reduces the chances of surviving an anaphylactic shock if, for example, it is misfired or is faulty.
- The circumstances described in the guidance require more clarity – for example, what constitutes ‘geographical isolation’? How is this defined? How will this be interpreted?
- Greater clarification is needed on what constitutes ‘avoidable risk’.
- What is the difference between ‘consider AAI’ and ‘AAI recommended’? How would a non-specialist make this decision?
- A previous mild reaction does not always indicate future mild reactions and there is evidence available which suggests patient fatalities can occur after an initial mild reaction.
- Existing guidance, such as the MHRA and the BSACI’s Paediatric Allergy Action Plan, is very clear that if

a person is experiencing a severe allergic reaction and still feels unwell 5 to 15 min after the first injection, then they should use their second AAI. Ambulance arrival times can exceed the 5-15 min mark and, at a time when ambulance response times are recorded as being below target, for those living with the fear of an anaphylactic shock, for themselves or a loved one, the risk of not having a second AAI is too great a risk to take.

I would like to reiterate that the guideline is a much welcomed and supportive document which highlights many of the important improvement areas for the management of those at risk of anaphylaxis. I wish to confirm that we are committed to working with the BSACI in a collaborative way, focused on a patient-centred approach.

We thank you for taking time to seriously consider the genuine concerns raised by the allergic community we support and for acknowledging the anxiety and stress that can go hand in hand with living with allergy.

Yours Sincerely,

Carla Jones
Chief Executive, Allergy UK