

PATIENT AND CARER INVOLVEMENT: GETTING THE BASICS OF ALLERGY PRACTICE RIGHT

It is very tempting to plan an issue of the journal around the exciting new developments in managing allergic diseases. Because molecular approaches have been applied to allergic disease, we now have a panoply of novel diagnostic tools and an ever-expanding number of so-called biological therapies to take into account. These must be employed by adopting precise or personalised medical approaches to individual patients; however, the costs are currently prohibitive and, in most cases, unnecessary. In this editorial I have, therefore, decided to return to the basics of medicine and focus on optimising healthcare delivery. This can be achieved only by involving patients and carers in all the steps during the research cycle and the planning of clinical service delivery.

While Andy Bush, in his article, describes the use of new biologicals for genuine uncontrolled asthma, he emphasises the need to get the basics right. Rather than referring patients to a specialist unit for expensive biologicals, first identify why the asthma is uncontrolled. This lack of control may be due to a number of factors: incorrect diagnosis, an incorrect treatment or inhalation device, failed communication between health professional and patient (the lack of accord) leading to poor concordance, psychosocial issues or adverse environmental exposures. A home visit could identify many of the causes and solutions which will improve the health and economic outcomes at minimal cost compared to prescribing omalizumab, for instance!¹

Allergic diseases are long-term multi-organ-system conditions. We favour the descriptor 'Allergic Dance (or perhaps Tango)' rather than the much-misunderstood 'Allergic March', but there is no doubting the large number of patients who have several manifestations of allergic reactions.² So often patients are referred to system specialists – dermatologists for their eczema, respiratory physicians for asthma, among several other specialists. This approach tends to fail to include the common underlying mechanisms and also comes with a high economic burden for both patients and the health services. Theoretically, allergists are in the best position to deal with all the allergic manifestations; however, it is important to be aware that not all itchy rashes are eczema or urticaria, not all of that wheeze is asthma or that sneeze is allergic rhinitis, or that diarrhoea and vomiting are allergic in origin. But the system specialist approach to diagnosis may be needed in collaboration with allergists. For these reasons, the organisation of healthcare delivery needs to be integrated with a road-map (pathway) for both patients and healthcare professionals.

Unfortunately, the many published guidelines for managing allergic diseases have not resulted in the expected improvement in clinical outcomes. Integrated care pathways are likely to be the best way for guidelines to be delivered efficiently.^{3,4} While inpatient care pathways for an asthma exacerbation are successfully employed widely to reduce costs and the



length of hospital stays,⁵ implementing pathways for long-term management is much more difficult to achieve. Indeed, a study of prescribing asthma preventers following discharge from hospital showed no reduction in readmission rates during the subsequent year. This was predominantly associated with the failure to prescribe or to redeem hospital-recommended prescriptions. Those prescribed preventers in primary care resulted in fewer readmissions.⁶ This emphasises the need to integrate hospital and community care. Its implementation requires a scientific approach to quality improvement. Sophie Spitters recently submitted her outstanding PhD thesis on this very topic and provides guidance on the evidence base of the optimal processes for achieving integrated care.

Education and training are fundamental to establishing gold-standard integrated care for patients with allergic diseases.⁷ This education must start during undergraduate training for all future health professionals and continue throughout the careers of all those in primary, secondary and tertiary care settings. However, allergic diseases are common problems and the general public should be able to recognise allergic symptoms and to access appropriate care. This could be facilitated through relatives, friends, pharmacists, schools or workplace colleagues. Education should, therefore, be delivered to all stakeholders. There is evidence that education about asthma delivered to non-asthmatic children will benefit their asthmatic classmates.^{8,9} Jennifer Protudjer from Manitoba is an accomplished researcher in the field of allergic disease. Her recent research has focused on the social, psychological and financial burden of food allergy and how to overcome this through education. She provides us with guidance on how to optimise the management of food allergy in schools.

Many allergic diseases arising in early life persist into adulthood. However, the transition from paediatric to adult care is often unsatisfactory during a period of life where there is the greatest risk of fatality or severe adverse events. Young people with long-term conditions have strong feelings about the way they should be managed, but all too frequently they are not involved in the healthcare planning process. The European and British allergy organisations are currently reviewing this phase of transition and guidelines on it will be forthcoming. In the interim, I have provided my own perspective on the trials and tribulations as young people with allergic diseases navigate the health system. I feel very strongly that the direct involvement of patients with lived experiences of transition should be co-designers of the process as equal partners with health professionals. Marta Vazquez-Ortiz is the co-lead for the EAACI transition task force with Professor Graham Roberts. I am delighted that she agreed to co-author the article on transition, which provides a list of the key criteria to include when establishing a programme that focuses on young persons.

The art of medicine encompasses not only science and the application of evidence but also empathy combined with a caring approach. Indeed, for many centuries, caring was all that was available to clinicians. It was assumed that warmth, sympathy and understanding would enhance placebo responses. While this may well be the case, recent research has identified other factors that influence outcomes when using ostensibly inert interventions. These findings should have an impact on the design and interpretation of outcomes from placebo-controlled clinical trials. There is also a down

side to the placebo approach: it has the potential in some circumstances to lead to adverse effects (Nocebo), which I have highlighted in those with severe asthma in a following article.

I have emphasised the importance of involving patients and their carers at all levels of planning clinical services. It is recognised that they should also be active participants in the planning and conduct of medical research.^{10–13} The James Lind Alliance (JLA) has developed a methodology for Priority Setting Partnerships (JLA-PSPs): this methodology links healthcare professionals to patients and carers in order to identify research priorities.¹⁴ The outcome is a list of the top 10 priorities for individual conditions, which includes many allergic diseases. I strongly recommend those who are considering undertaking allergy research to access the JLA website to gain a better understanding of the process of identifying priorities and of those studies already published (<https://www.jla.nihr.ac.uk/about-the-james-lind-alliance/about-psps.htm>).

We are all familiar with patient experience and patient outcome measures; but we are probably less so about 'Core Outcome Sets (COS)'. They have become a focus of scientific medical societies which have established task forces in many areas of medicine. The Core Outcome Measures in Effectiveness Trials (COMET) Initiative has defined COS and how they should be developed as a collaboration between physicians, patients and carers. The COMET definition of COS is 'an agreed standardised set of outcomes that should be measured and reported, as a minimum, in all clinical trials in specific areas of health or health care'. The website <https://comet-initiative.org/> is an open repository for published and in-progress COS development for any condition, including those for eczema, asthma and rhinitis. While designed primarily for clinical research, they should also be employed in clinical practice. Daniel Munblit is chairing a current initiative to develop Core Outcome Measures for Food Allergy (COMFA), funded by the European Union Horizon 2020 framework programme. Notably, close to 50% of the participants in the Delphi exercise to define the outcomes are food allergy patients and their carers (<https://comfa.eu/news/comfa-consensus-meeting-results-15-may-2023/>).

In a separate article in this issue, Dikeledi Matuka and colleagues report on the adverse effects of mould exposures in the workplace. Sadly, these effects also occur in home and outdoor environments. In the past, when investigating house dust allergy, colleagues and I identified mould allergens in house dust, although we could not show an association between the levels and evidence of allergy to moulds in the occupants.¹⁵ Their study is therefore a welcome contribution to our knowledge and understanding of the association between mould and allergic responses.

Dr Spur's case presentation of WAS raises ethical issues, a number of which I discuss in this issue. Curative treatment is by haematopoietic stem-cell transplant (HSCT) or targeted gene therapy. Both approaches have potentially adverse consequences. In addition, because the costs are high, the question to be asked is this: Does the healthcare professional offer these to all families or only to those with sufficient financial resources?

I end this Editorial with two apposite quotations. The first is the full definition of evidence-based medicine, which includes the need to account for patient values and expectations. In order to deliver this, we must avoid the use of medical and scientific jargon, as iterated by the doyen of an integrated approach to medicine:

David Lawrence Sackett (1934–2015), a pioneer in evidence-based medicine, defines the integrated approach as

[t]he conscientious, explicit and judicious use of current evidence in making decisions about the care of individual patients. It requires the integration of clinical expertise, external evidence and patient values and expectations (Sackett DL. *BMJ* 1996;312:71).

And Martin Henry Fischer (1879–1962), who is most famous for his teachings on the art and practice of medicine, and for famed quotations known as 'Fischerisms', wrote:

You must learn to talk clearly. The jargon of scientific terminology which rolls off your tongues is mental garbage.

John O Warner

Emeritus Professor of Paediatrics, National Heart and Lung Institute, Imperial College, United Kingdom; Honorary Professor of Paediatrics, University of Cape Town, South Africa

REFERENCES

- Bracken MB, Fleming L, Hall P, et al. The importance of nurse led home visits in the assessment of children with problematic asthma. *Arch Dis Child*. 2009;94:780–784. <https://doi.org/10.1136/adc.2008.152140>.
- Levin ME, Warner JO. The atopic dance. *Curr Allergy Clin Immunol*. 2017;30:146–149.
- Warner JO, Spitters S. Integrating care for children with allergic diseases: UK experience. *Curr Allergy Clin Immunol*. 2017;30:130–135.
- Daniels L, Barker S, Chang Y-S, et al. Harmonizing allergy care-integrated care-pathways and multidisciplinary approaches. *World Allergy Org J*. 2021;14(10):100584. <https://doi.org/10.1016/j.waojou.2021.100584>.
- Sudarmana A, Lawrence J, So N, Chen K. Discharge criteria for inpatient paediatric asthma: A narrative systematic review. *Arch Dis Child*. 2023;108:839–845. <https://doi.org/10.1136/archdischild-2022-325137>.
- Chen KY-H, Aye Tun N, Jones R, et al. Effectiveness of asthma preventer dispensing for preventing childhood asthma readmissions: A multisite cohort linkage study. *Arch Dis Child*. 2023;108:673–677. <https://doi.org/10.1136/archdischild-2022-324549>.
- Barker S, Daniels L, Chang Y-S, et al. Allergy education and training for physicians. *World Allergy Org J*. 2021;14:100589. <https://doi.org/10.1016/j.waojou.2021.100589>.
- McCann DC, McWhirter J, Coleman H, Calvert M, Warner JO. A controlled trial of a school based intervention to improve asthma management. *Eur Resp J*. 2006;27:921–928. <https://doi.org/10.1183/09031936.06.0035604>.
- McWhirter J, McCann D, Coleman H, Calvert M, Warner J. Can schools promote the health of children with asthma? *Health Educ Res*. 2008;23(6):917–930. <https://doi.org/10.1093/her/cym081>.
- Hoos A, Anderson J, Boutin M, et al. Partnering with patients in the development and lifecycle of medicines. *Ther Innov Regul Sci*. 2015;49(6):929–939. <https://doi.org/10.1177/2168479015580384>.
- Elwyn G, Crowe C, Fenton M, et al. Identifying and prioritizing uncertainties: Patient and clinician engagement in the identification of research questions. *J Eval Clin Pract*. 2010;16:627–631. <https://doi.org/10.1111/j.1365-2753.2009.01262.x>.
- Batchelor JM, Ridd MJ, Clarke T, et al. The Eczema Priority Setting Partnership: A collaboration between patients, carers, clinicians and researchers to identify and prioritize important research questions for the treatment of eczema. *Brit J Derm*. 2013;168:577–582. <https://doi.org/10.1111/bjd.12040>.
- Turner PJ, Andoh-Kesson E, Baker S, et al. Identifying key priorities for research to protect the consumer with food hypersensitivity: A UK Food Standards Agency Priority Setting Exercise. *Clin Exp Allergy*. 2021;51:1322–1330. <https://doi.org/10.1111/cea.13983>.
- James Lind Alliance. The James Lind Alliance guidebook (version 9). Oxford: James Lind Alliance, 2020. Available from: <https://www.jla.nihr.ac.uk/jla-guidebook/>. Accessed 30 April 2021.
- Warner JA, Little SA, Pollock I, Longbottom JL, Warner JO. The influence of exposure to house dust mite, cat, pollen and fungal allergens in the home on primary sensitisation in asthma. *Pediatric Allergy Immunol*. 1990;1(2):79–86. <https://doi.org/10.1111/j.1399-3038.1990.tb00015.x>.