Harmonizing allergy care-integrated care pathways and multidisciplinary approaches

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ABSTRACT

There is a wide time gap between the publication of evidence and the application of new knowledge into routine clinical practice. The consequence is sub-optimal outcomes, particularly concerning for long-term relapsing/remitting conditions such as allergic diseases. In response, there has been a proliferation of published guidelines which systematically review evidence for the gold-standard management of most allergic disorders. However, this has not necessarily been followed by improved outcomes, partly due to a lack of coordination across the patient pathway. This has become known as the “second translational gap”. A proposed solution is the development and implementation of integrated care pathways (ICPs) to optimize patient outcomes, with the notion that evidence-based medicine requires evidence-based implementation. ICP implementation is shown to improve short-term outcomes for acute conditions and routine surgery, including reduced length of hospital stay, improved documentation and improved patient safety. However, this improvement is not reflected in patient experience or patient-centered functional outcomes. The implementation of life-long, cost-effective interventions within comprehensive pathways requires a deep appreciation for complexity within allergy care.

We promote an evidence-based methodology for the implementation of ICPs for allergic disorders in which all stakeholders in allergy care are positioned equally and encouraged to contribute, particularly patients and their caregivers. This evidence-based process commences with scoping the unmet needs, followed by stakeholder mapping. All stakeholders are invited to meetings to develop a common vision and mission through the generation of action/effect diagrams which helps build concordance across the agencies. Dividing the interventions into achievable steps and reviewing with plan/do/study/act cycles will gradually modify the pathway to achieve the best outcomes. While the

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management guidelines provide the core knowledge, the key component of implementation involves education, training, and support of all healthcare professionals (HCPs), patients and their caregivers. The pathways should define the level of competence required for each clinical task. It may be useful to leave the setting of care delivery or the specific HCP involved undefined to account for variable patterns of health service delivery as well as local socioeconomic, ethnic, environmental, and political imperatives. In all cases, where competence is exceeded, it is necessary to refer to the next stage in the pathway. The success and sustainability of ICPs would ideally be judged by patient experience, health outcomes, and health economics. We provide examples of successful programs, most notably from Finland, but recommend that further research is required in diverse settings to optimize outcomes worldwide.

Keywords: Allergy, Integrated care pathways, Multidisciplinary team, Healthcare

BACKGROUND

Allergy remains a key target for national and international public health strategies, due to its increasing prevalence, the life-long impacts of an allergy diagnosis on the patient, and the possibility to threaten life. Over the last decade, several publications have highlighted the growing burden of allergic disease, including The World Allergy Organization’s (WAO) ”White Book on Allergy” in 2010, updated in 2013.1 They estimated that allergic disease affects around 20-30% of the world’s population, with more than 150 million individuals reporting allergy in Europe alone. The prevalence of allergy is increasing in both developed and developing countries, with a significant burden carried by developing countries who see sharper increases associated with urbanization2 alongside a paucity of allergy care infrastructure.

The patient’s allergic disease journey can start at any age (Fig. 1). In most cases, allergy is diagnosed in childhood with the responsibility of care placed on the parent or guardian. The patient transitions into self-management as they mature to adulthood. Standards of care vary worldwide from the first point of contact (ie, emergency departments or primary care) through to gaining access to specialist care for accurate diagnosis, treatment, and education.3 Quality patient support must be ongoing through life stages. This is especially key for patients with food allergy, considering the challenges created by the ubiquity of food in relation to cultural and social practices4 and the changes in nutritional requirements with age.5

A diagnosis of allergic disease extends into a psychological, social, and economic burden on patients, their households, teachers, schools, and work-places. Health services face direct medical costs stemming from the diagnosis, management, and prevention of allergy, while families bear indirect costs such as travel to medical appointments, lost days from education or work, and often more expensive avoidance diets.6-8 A recent systematic review estimates the average cost to be $8220 per household with one member with allergic disease, per year.8 Lower income families face the highest economic burden in the case of food allergy, due to the costliness of avoidance diets, increased hospital visits, and need for emergency care.9 The overall burden will be even greater amongst asylum seeker and refugee families who may not have access to information and labelling in their first language. In addition, a lack of culturally sensitive health education can lead to unequal care between children of different racial backgrounds, with Black and Hispanic children found to have shorter follow-up with an allergy specialist than White children with the same food allergy.10 Meanwhile, the psychological consequences of allergy are known to compromise school attendance, family relationships, and the development of social skills.11 Such economic, social, and psychological complexities create barriers to optimizing long-term management and quality of life for allergy patients.

These factors demand a multidisciplinary, patient-centered approach to allergy care, wherein multiple healthcare professionals (HCPs) address
the bio-psycho-social aspects in a patient’s journey, ideally led by an allergy trained health professional taking account of locality specific patterns of healthcare. It is crucial that this team is trained effectively in allergy and engages with opportunities to enhance their knowledge and expertise over time.

Over the last two decades, it has been recognized that several unmet needs exist in the allergy field, including a paucity of allergy specialists, inadequate training, and fragmentation of the patient journey due to poor communication between stakeholders and services. These factors feed into suboptimal allergy care. Fragmentation of allergy care poses particular problems when patients require parallel care from various HCPs. Despite extensive reports on these unmet needs, the real-life application of recommendations and guidelines has been compromised by a lack of prioritization and investment on a national level.

In this paper, we review global heterogeneity in the structure of allergy care and access to specialist treatment. We seek to promote a harmonized, multidisciplinary approach through the development of integrated care pathways (ICPs). Through this, we hope to promote the highest, contextually achievable standards of holistic allergy care. At present there is no single best practice model or well-defined guideline for the implementation of integrated care, and although the concept of integrated care is easy to understand, it is difficult to achieve because of its inherent complexity. Many factors have been found to present important challenges and barriers at the clinical, meso, and macro level. Thus, a systemic perspective is required to understand the barriers and enablers that can facilitate implementation of integrated care.

CLINICAL GUIDELINES ERA

There is a clear need to continuously develop the delivery of high-quality healthcare which optimizes patient experience and safety whilst ensuring the best clinical outcomes, particularly for long-term conditions. Reports such as the “Allergy: the unmet need from the United Kingdom,” published in 2003, have shown that even affluent developed settings face suboptimal patient experience and outcomes despite extensive publications on the efficacy of interventions. The Royal College of Physicians follow-up report 7 years later in 2010, “Allergy: Still not meeting the unmet need”, showed that the issues had still not been adequately addressed, despite multiple intervening parliamentary reports. These training and service issues are not just a problem in the United Kingdom but are identified as a global unmet need by the WAO.

Much of the emerging research around new allergy diagnostics and treatments escapes comprehensive and critical evaluation by...
individual HCPs, who are now overwhelmed with conflicting local, national and international advice.

In response to this so-called “knowledge-practice gap”, various national and international organizations have developed an array of clinical guidelines which assimilate published evidence. International examples are laid out in Fig. 2. The United Kingdom’s National Institute for Health and Care Excellence (NICE) has produced guidance on allergy topics including eczema, anaphylaxis, insect venom immunotherapy, omalizumab therapy, food allergy, and drug allergy. The British Society for Allergy and Clinical Immunology (BSACI) developed guidelines for many other allergic conditions, including allergen immunotherapy for allergic rhinitis, drug allergies, specific food allergies such as to milk, nut peanut or egg, chronic urticaria/angio-oedema, and anaphylaxis. Beyond addressing the clinical aspects of care, a minority of these guidelines include direction on supporting patient self-management and education.

GUIDELINE DEVELOPMENT WITH PATIENT/CAREGIVER INVOLVEMENT

Guideline development has moved away from what became known as GOBSAT (“Good Old Boys Sat Around the Table”) and is now considered firmly evidence-based. However, guidelines based purely on Cochrane reviews and meta-analyses ignore important elements of evidence-based medicine: “integration of clinical expertise, external evidence, patient values and expectations” (emphasis added). Considering that patient expectations and values form a crucial part of everyday allergy care, they should also underpin guideline development, otherwise said guidelines risk failing to meet patients’ needs. The Canadian Society for Allergy and Clinical Immunology (CSACI) have published oral immunotherapy guidelines incorporating patient engagement which may represent an example of movement toward patient-focused guideline development. In a similar vein, BSACI identify representatives of patient support organizations to be key in the development of a recent National Allergy Education Strategy. However, currently, guideline development rarely involves patients and care-givers, which is likely to jeopardize patient outcomes.

SECOND TRANSLATIONAL GAP

It is assumed there is a linear relationship between release of evidence-based guidelines and their subsequent implementation. However, implementation of clinical guidelines for allergic conditions has been inconsistent, especially in primary care where most patients are managed. A study from Belgium surveyed 350 general practitioners (GPs) of whom only 31% acknowledged they were aware of the Allergic Rhinitis and its Impact on Asthma (ARIA) guidelines. Only 48% of the surveyed GPs correctly addressed 4 rhinitis scenarios testing concordance with 4 ARIA guideline standards. Poor management and inadequate patient education can have serious consequences. For example, even when epinephrine auto-injectors have been correctly prescribed, it is common for caregivers to fail to use the injector during an anaphylactic reaction in their children. In a similar vein, the 2014 UK National Review of Asthma Deaths identified that over 60% of investigated asthma deaths were potentially avoidable. Failure to follow established management guidelines, poor recognition of asthma control, and adverse psycho-social
circumstances were key factors related to deaths. A review 3 years later found that asthma control perception in patients and HCPs was still lacking, and asthma management remains fatally flawed. This disconnect between the development and publication of clinical knowledge and its implementation in practice is known as the "second translational gap".

Attempts thus far to close the second translational gap and achieve proper implementation of clinical guidelines have delivered modest improvements. For example, a systematic review of initiatives to improve asthma guideline implementation showed that in two-thirds there was improved physician concordance with guidelines and about 50% showed improvement in patient outcome measures.

The second translational gap not only applies to acute management of the allergic patient but also support of the patient's self-management in the long-term. This is an area often missed in guideline implementation strategies. In the same systematic review, only 6% of the studies focused on care outside of hospital and hence the review primarily addressed the management of acute severe exacerbations rather than long-term control. Once the patient leaves hospital after an acute event they must be empowered to take responsibility for their own care with harmonized multidisciplinary team (MDT) support as needed.

VARIATIONS IN THE ALLERGY CARE INFRASTRUCTURE

Any recommendations towards global standardization and improvement of the patient experience must account for differences in healthcare infrastructure between countries.

Fig. 3 shows a simplified representation of the patient journey across 5 different countries, from the primary manifestation of allergy to specialized MDT care. Although there are clear similarities, including the universal challenge of the second translational gap, it is important to consider the other factors that contribute to the complex variability of international allergy care infrastructure. There are significant differences worldwide regarding the recognition of Allergy as clinical specialty and the prevalence of
practicing specialists, with many countries in Latin America and Europe lacking Allergy as either specialty or subspecialty. This leads to variable waiting times between each “stage” in the journey, which may leave the patient with prolonged periods of no support, as seen in Hong Kong, where the ratio of adult allergists to patients can reach 1:2.8 million. There is also heterogeneity in the nature of third-level care, for instance in the use of allergy immunotherapies between the United States and Europe. Different infrastructures place variable pressure on the primary care physician or GP who potentially stand as the first HCP to be involved, as well as the gatekeeper to higher levels of care. Supporting the patient in the community, as well as referring the patient in a competent and timely manner, remains a significant responsibility for GPs, many of whom lack specific training in allergic disease. Meanwhile, in developing countries, many patients with allergies may be wholly managed in the primary care setting without ever seeing a tertiary specialist. Our figure is unable to represent patients with comorbidities involved in multiple pathways of care, or patients who face social and economic barriers to navigating care, as previously discussed. These factors add further complexity and variability to the patient journey.

An attempt to streamline specialist care is seen in the formation of allergy centers; hubs of allergy specialists who coordinate expert multidisciplinary care. These centers can facilitate strong collaboration between physicians and allied healthcare professionals (AHPs), improve teaching, and boost research. The formation of allergy centers (with the potential benefit of improving recruitment to the allergy specialty) can be viewed as a key step in achieving more expert, cohesive care for patients with allergic disease. However, due to distribution of population or infrastructure design, this step may not be possible in many countries. The successful implementation of strategies depends upon careful consideration of context, and recommendations to improve allergy care must be adapted according to differences in healthcare provision, demographics, and disease patterns.

THE CONCEPT BEHIND INTEGRATED CARE PATHWAYS

ICPs, also known as care paths and clinical pathways, are patient focused tools that define the sequence and timing of actions needed to achieve the best patient outcomes with the greatest efficiency. They have the potential to streamline approaches in order to minimize variation in patient care and outcomes. With an aim to consolidate the definition of ICPs, the European Pathway Association (E-P-A) held a consensus meeting which considered various surveys and a literature review of studies using the term. They produced the definition: "a complex intervention for the mutual decision making and organization of care for a well-defined group of patients during a well-defined period". Characteristics of ICPs described in this paper are depicted at Fig. 4.

The E-P-A definition assumes the pathway process is time bound, which applies more easily to planned surgery or acute illness. Evidence of ICP implementation in these settings has shown significant reduction in hospital complications and length of stay, with improved documentation of care and patient safety. However, studies generally fail to demonstrate improvement in patient satisfaction and patient-focused functional outcomes such as independence in activities of daily living. Based on the E-P-A definition, ICPs were assumed to achieve these outcomes via improved mutual decision making and improved organization of care; however, this was not always the case.

Different approaches are required when dealing with long-term and/or repeatedly relapsing-
remitting diseases, with allergy as a prime example. A systematic review showed that asthma ICPs decreased the length of hospital stay but did not reduce hospital costs or reduce subsequent visits due to asthma exacerbations. This demonstrates that, despite effective management of the acute problem, the underlying issues which led to loss of control were not addressed. It is, therefore, not surprising that patients perceive inadequacies in their experience of ICPs. A French study of patients’ perspectives highlighted unstructured follow-up, lack of patient education, and poor communication as contributory factors. The authors propose “a more coordinated care pathway at each phase of the disease that is consistent with the expectations and goals of the patients”. It follows that patient-centered outcomes are more likely to improve if patients are involved in ICP development.

In recognition that the publication of guidelines did not resolve many of the allergy service delivery issues, the Royal College of Pediatrics and Child Health (RCPCH) (UK) developed 8 national-level ICPs based on evidence reviews, expert consensus, and stakeholder input to support guideline implementation. The pathways defined the sequence of steps for diagnosing and managing the common allergic disorders in the form of algorithms. For each step there is a listing of the competence required, which provides the HCP with the information to judge when their service can no longer deliver the requirements, and referral is needed.

The generation of political will to support allergy care improvements remains a challenge. Despite a succession of reports providing overwhelming evidence of need, the UK government’s Department of Health refused to endorse the RCPCH allergy ICPs. To overcome this barrier, the emphasis must move away from centralized control towards local initiatives which address local health needs. Existing ICPs do not define the location of delivery of care or indeed which specific HCP should be involved, and such flexibility facilitates adoption into any healthcare system, from specialist settings to primary care and into the patient’s home. Whilst recognizing the challenges of international variation in allergy care infrastructure, the RCPCH pathways suggest potential for development of international models in the future.

**DEVELOPMENT AND IMPLEMENTATION OF INTEGRATED CARE PATHWAYS—OPPORTUNITIES AND BARRIERS**

ICPs are a proven effective intervention to improve care coordination and quality of care, however their implementation presents important challenges. The effective implementation of ICPs goes beyond the development of guidelines and may require a profound change across system levels. A multilevel systems approach holds promise in accurately representing real-life situations and, thus, with proper research design and methods, can facilitate effective and efficient resolutions for system-wide challenges. Firstly, a strong defining factor of success is the identification and targeting of a specific patient population, such as patients and families living with food allergy. Next, a strategic vision towards integrated care and governance is needed at the macro level. At the meso level, cohesion of services is vital to ensure care coordination. At the micro level, strong clinical leadership and buy-in promotes multidisciplinary and collaborative work. Other facilitators include strategic alignment, sharing of data between levels of care, monitoring and evaluation, a quality feedback loop, incentives for training in communication and team-work skills, and taking account of and commissioning the whole patient pathway to enhance patient experience and continuity.

Experience has highlighted that the development and implementation of pathways is not a simple process and requires the expertise of patients and their caregivers, quality improvement, and social science, health economists, educationists, and all other HCPs likely to be involved. The process commences with analysis of the local health requirements and unmet needs. All stakeholders must be mapped in relation to commitment and influence. At one extreme are patients and caregivers with the highest commitment and often least pre-existing influence. At the other extreme are politicians with high influence but often the least commitment. Having identified key movers and shakers, meetings should be held in which all participants are equal contributors, with
an aim to agree to the “vision” and the “mission” of the group, with particular emphasis on the patient perspective. This can take the form of collaboratively designing an action/effect diagram, as demonstrated in Fig. 5.

According to established management theory, the implementation process should be broken into small achievable steps. On the left-hand side of the diagram is the overall aim (vision) and moving towards the right are the defined steps of the process to achieve this aim. The steps can then be prioritized, given a time frame, and allocated a working team with resource support. Regular meetings are useful for reviewing progress using the plan/do/study/act cycle. In this way, the pathways can be adapted as experience and evidence develops, ensuring that all stakeholders remain involved and engaged as the process becomes embedded. Successful working requires an identified manager or coordinator, regular joint meetings and the effective sharing of electronic records, together with a clear purpose and institutional support. Tertiary allergy center HCPs may be well-placed to lead the process but theoretically any member of the team could lead, and all should have the opportunity to be local “allergy champions”. Patient and caregiver feedback is critical as poor patient experience will undermine the process and is associated with poor clinical outcomes. The COVID-19 pandemic has highlighted the value of telemedicine which has the potential to enhance effective delivery of integrated care while reducing direct and indirect healthcare costs. It will be crucial to evaluate the impact of widening telemedicine on patient outcomes and experience in the context of integrated allergy care.

A similar process can be applied to other aspects of allergy care, for example in the design of education and training strategies. This has been demonstrated by BSACI who recently formed an Allergy Education Network, comprising of a range of HCPs from different settings, clinical academics, and representatives from patient support organizations to develop a strategy document which “align[s] educational goals with the care needs of patients progressing through an integrated healthcare system”. Their strategy is underpinned by a shared vision, patient-centered goals and a holistic, multidisciplinary approach. Detailed discussion of education which commences during undergraduate and primary training of all healthcare professionals is presented in a separate paper.

MULTIDISCIPLINARY ROLES IN THE ALLERGY INTEGRATED CARE PATHWAY

It is evident that defining the competences expected of various HCPs working in allergy care is
needed to promote a coherent multidisciplinary approach. In this section we aim to produce a flexible framework, explaining how different clinical roles can contribute to the patient journey, depending on local resources and skill-sets.

**Physician roles and responsibilities within allergy care**

A proposed framework for physician roles in the allergy ICP is outlined in Table 1, adapted and updated from de Monchy et al 2013, and demonstrates how tasks might be rationally distributed. We emphasize primary care as a key ground for intervention in allergy, with a "strong influence on disease prevention and control, quality of life, and patient satisfaction." Promoting postgraduate education opportunities to GPs would boost their confidence in diagnosing, managing and referring patients appropriately.

The paper “Allergy Education and Training for Physicians” considers that the traditional approach to the "level of care" and designated physician roles is now outdated and lacks universal applicability. Instead, we propose a “level of competence” approach (Fig. 6), which can be mapped onto a variety of infrastructures, irrespective of allergology specialty recognition. A medical graduate should possess a "core" amount of knowledge and clinical skills necessary for recognition and interpretation of allergic disease. "Additional competences" are required to manage patients with allergies more independently and provide appropriate advice, whilst "specialist competences" equip physicians to deal with complex diagnostics and management strategies. This concept is encompassed in the training of GPs with a Special Interest (GPwSIs) and pediatrics with SPecialist INterest (SPIN) in the United Kingdom.

| Position | Key roles |
|----------|-----------|
| GP       | - Able to manage cases of allergy where the allergen is clear and avoidable, and the allergy symptoms are mild  
- Complex cases may be referred to allergist and/or organ-based specialist |
| Occupation health physicians | - Understanding of work environments and potential allergens  
- Early intervention in occupational allergy through regular monitoring  
- Able to assess exposure of allergen and give advice about avoidance/prevention  
- Maintain close collaboration with allergist to identify trigger |
| Internists, emergency medicine, general pediatricians | - Able to manage acute cases and issue emergency treatment  
- Provide management of the acute problem and rapid referral  
- Link patients with evidence-based resources to help them manage their condition while waiting to see a specialist  
- Not within their role to identify allergen and counsel long-term |
| Organ-based specialists | - Able to use standard allergy diagnostic tests, laboratory tests and function tests relevant to their field  
- Able to provide organ-based therapy  
- Work in partnership with allergist regarding further testing or allergy specific treatment if necessary |
| Allergist/clinical immunologist | - Able to manage multi-organ allergic disease which requires further analysis  
- Prescribe and manage allergen immunotherapy  
- Coordinate care at the interface between the patient’s condition, the preventative strategies and the available treatment options  
- Use of new techniques such as endotyping & biological agents |

Table 1. The roles and responsibilities of physicians in allergy care. Adapted and updated from de Monchy et al, 2013.
It is key to emphasize the physician as an educator: an educator of patients to support their self-management skills, and at the specialist level, as leaders in the field and educators of other HCPs.

Allied health professionals in allergy care

The growing prevalence of allergic diseases has been accompanied by an increasingly prominent role for AHPs. The complexity of allergy as a chronic condition demands an emphasis on patient-centered practice to optimize physical and mental well-being and prevent adverse outcomes. To this end, it is vital to develop core professional competences for AHPs working in allergy care, and to ensure MDT members are aware of their respective roles and responsibilities. Fig. 7 draws upon the recommendations of the European Academy of Allergy and Clinical Immunology (EAACI) and collaboration with WAO committee members to mark out core competences expected of all HCPs working in allergy care, as well as a model for the specific unique responsibilities each role could hold.

Nurses

Nurses are crucial to the success of an allergy service. As found in medical education, formal teaching on allergy as a discreet subject in the nurses’ training is lacking. A personal connection with someone who has allergies may spark an interest to self-educate so that they can understand the situation better, which may lead to them seeking a career in allergy. They may also enter allergy care by chance rather than by active choice. They will often learn initially "on the job", and, in time, gain appropriate competence and clinical understanding thanks to peer teaching and explanation, but perhaps without a detailed immunology lens to underpin their clinical activities. In dedicated allergy clinics, the nurse will learn many skills from other professionals and may have opportunity to expand their role within the department. Common tasks range from conducting tests, such as skin prick tests and...
spirometry, to teaching technique on devices, such as inhalers and adrenaline autoinjectors, and teaching families and patient’s skills such as applying eczema creams and correctly using inhalers, depending on local requirements and legal environments. These nurses also offer some counselling for the patients and their families as an approachable and familiar face of the professional team. They often have more time with the patient than the physician, and hence their advice can be personalized to the patient and their family. This can also help to reinforce medical advice, which may be difficult for the patient to retain after the consultation, particularly if they have received large amounts of information in one session.32,71

The importance of a wider MDT education in allergy is often highlighted. Specialist training for nurses and other AHPs enables them to understand not only the "how" of allergy care, but also the "why" and even the "why not", which becomes more relevant if they progress onto a research path. Nurses with further training can step into roles such as “Nurse Consultant” and act as a professional in allergy in their own right. Appropriately trained nurses can run independent clinics to reduce waiting times in oversubscribed services and may also conduct research within the team or independently.72

Dietitians

Dietitians can offer a very tailored role within the allergy team. They can assist families with early introduction of food allergen sources while maintaining diet diversity,73 ensure individualized

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Fig. 7 A proposed model for the responsibilities of key members of the multidisciplinary team (MDT) in allergy care, including a center of core competences expected of all healthcare professionals working in allergy. The overlap of the circles illustrates the potential for certain responsibilities to be shared differently across members of the MDT according to local contexts.
allergen avoidance, advise on suitable substitute foods, and maintain or improve nutritional intake and status across IgE74 and non-IgE mediated food allergies.75 They can also aid diagnosis by taking an allergy focused diet history based on their vast knowledge of allergen content of foods,76 as well as developing food challenge protocols and preparing challenge foods.77 In cases of cow’s milk allergy, dietitians have the unique skill to choose the most appropriate infant formula or cow’s milk substitute.78 They also have the practical skills to guide families through the process of baked milk and egg introduction ladders.79 The role of the allergy dietitian in inducing and maintaining oral tolerance is also evident from recent research.80 Parents, however, report a much wider role for the allergy dietitian, who offer families emotional support and reassurance.81 Timely contact from a well-trained allergy specialist dietitian in food allergy can make the difference between a poor quality of life with incidences of anaphylaxis and a well-balanced and healthy life.82 Dietitians play an important role in educating and mentoring allergy specialists and allergy nurses in training. It is crucial to give individual dieticians the confidence to develop their own personal allergy network and bring a unique perspective to food allergy research.

Psychologists

Psychologists have a key role in supporting their health professional colleagues in the MDT to deliver appropriate psychological support to their patients. This is important in allergy care due to the quality of life and mental health burden faced by patients with allergic disease; therefore, quality psychological care can provide measurable benefits for patients and their caregiver. The patient’s role in food allergy management involves a constant endeavor to avoid encountering allergens, which has clear impacts on school life (including school trips), social life, and family life. Further anxiety can be linked to medical tasks such as administering an epinephrine auto-injector and having skin prick tests, blood tests, or food challenges.

Psychologists can implement evidence-based strategies and support the work of the MDT. In addition, they play a major role in the promotion of healthy behavior, the implementation of therapeutic and brief medical visit interventions, outpatient follow-up services for patients in need of more intensive services (that cannot be delivered during routine medical visits), and long-term psychological treatment in tandem with medical care. Integrated models allow for continuity of care from diagnosis onward and can also enhance the transition process from pediatric to adult care.83,84 Improved psychological functioning and adaptive coping can result in better physical health and mental well-being for patients and families. Despite this, at present, few pediatric allergy clinics in Europe have funding for dedicated psychological services, and overall access to psychological services is limited. It is crucial that psychologists have an inherent place within the MDT to facilitate this service for all patients with allergy and their families.

Beyond the psychologist’s role, all healthcare staff in allergy care, and particularly physicians, play a part in the delivery of psychosocial care, within their existing role and competence. However, there has been limited guidance on how this can be achieved harmoniously across professions, as most competence frameworks are developed for profession-specific clinical training programs. This creates an opportunity for future work in this area.

Pharmacists

Pharmacists are crucial to the allergy MDT. Their engagement is particularly important when allergy patients present to the community pharmacy and their treatment can be accessed over-the-counter, a common scenario for allergic rhinitis.85,86 The ARIA program has developed specific ICP guidance for pharmacists to work through for patients with rhinitis symptoms.86 This guidance supports pharmacists to make accurate diagnoses, offer appropriate treatments, and refer onwards when necessary, and can be adapted to local needs and resources.

Community pharmacists may be the first HCPs contacted by a patient with possible allergic problems and are also well-placed to deliver targeted interventions and support patients in self-management of their allergic disease. Two systematic reviews have demonstrated that such interventions can improve adherence, quality of life,
Pharmacists are also crucial players in the management of drug allergy. In cases of reported penicillin allergy, pharmacists with relevant training are able to interview patients to confirm or confute their allergic status, and if appropriate, can make recommendations to the medical team regarding whether beta-lactams should be prescribed. In addition, pharmacists can make patients aware of common food allergens used in drugs, such as milk protein. With this in mind, it is important that the role of the pharmacist in the allergy MDT is promoted so that, where local resources and training allow, they can support the healthcare team and the patient by offering expert pharmacological care.

Role of patients, caregivers, and patient support organizations

We have emphasized the importance of involving patients at every step in the implementation of ICPs. Their lived experience of interactions with medical services should be harnessed to guide quality improvement. Patient reported experience measures (PREMS) are a useful tool in audit progress during implementation programs and have recently been developed specifically for pediatric patients with allergic disease. For example, in a pediatric UK cohort, patients were asked about their positive or negative experiences during an acute allergic reaction in various situations in the pathway. The only positive responses related to the patients’ own homes and in allergy specialist services, indicating intervention may required for implementation in emergency and primary care settings. Health professionals must appreciate that patients are experts in their own disease and must have an equal role in planning management.

It is not uncommon for patients of allergy and their caregivers to seek out information online, especially when newly diagnosed. Search tools allow them to ask questions in real time, as they arise in the daily management of their condition. Considering the extent of misinformation accessed on the internet, signposting patients towards credible sources of support is essential.

Patient organizations can help patients to manage their condition and live safely and confidently with their allergic disease, for instance, through offering evidence-based resources and peer mentors. By working from the patient’s viewpoint, they can fill in the gaps on how to live with allergic diseases beyond the medical issues, responding to queries that may not arise during consultations. For example, effective patient resources that supplement physician management of food allergy have been associated with improved quality of life as well as improved parental knowledge and confidence in managing their child’s food allergy. A study of support group engagement amongst young allergy sufferers demonstrated that the groups improved self-esteem and self-management capabilities. Many patients place particular value on the perspective of peer mentors who have “walked in their shoes”. For example, in the case of food allergy, learning how to access accurate ingredient information requires awareness of regulations in that region, as well experience of asking the right questions of food business operators who will vary in their understanding of allergy.

In the allergy space you have various leading groups, for example Allergy & Anaphylaxis Australia and Allergy UK, with Food Allergy Canada and Food Allergy Research & Education (FARE) in the United States providing focused support for food allergy patients. Another prime example is the Anaphylaxis Campaign in the United Kingdom, which has played a role in influencing government policies. Increased awareness has boosted research funding, allergen guidance, labelling, scrutiny of the food industry, and public information on allergy. Alongside providing educational tools and programs, Food Allergy Canada have successfully influenced food labelling regulation and increased access to epinephrine auto-injectors, specifically through the shortages in 2018 and beyond through successful advocacy for more suppliers in the Canadian market. The Anaphylaxis Campaign in the United Kingdom has been the key initiator of a national Anaphylaxis death registry which is now an EAACI program. Other such registries can be used to guide quality improvement (QI) and audits of progress locally and nationally.
These organizations can play a key role in educating other stakeholder groups in the community (such as schools, community centers, workplaces, and food outlets) to build public awareness of allergy and its management. They may also be well-placed to advocate to authorities and government for better access to allergy care, and for tighter regulations in the food industry and access to allergen information. This is especially pertinent in allergy, as the economic burden lies most significantly with the individual and not on the healthcare system; therefore, system cost savings will not be the key driver as might be the case in other health conditions. Advocacy on behalf of those directly impacted by allergic disease is critical to motivating governments to act.

Critical enablers for an effective patient organization include a core principle of evidence-based healthcare and mechanisms that actively seek input from the patient community they represent. Oversight from a qualified medical advisory board and regular engagement with HCPs and the research community is also essential. Recognizing such patient organizations as valuable players in allergy care can help patients access the holistic support they need to live confidently with allergic disease. This relies on active engagement from both HCPs and patients, and broader investment from government authorities.

Multidisciplinary learning and development

It is the professional responsibility of every MDT member to work within their scope of practice and ensure that they are sufficiently qualified to conduct their daily tasks. A robust network of learning allows the MDT to keep abreast of new developments and adjust their practice accordingly, which could take the form of regular literature reviews, peer education, and planning sessions. When individual MDT members broaden, deepen, and consolidate their knowledge, it enables the allergy team to work together more cohesively and consistently, and could also give HCPs scope for advancement into specialist consultant roles through accredited programs.

In the allergy setting, learning can be achieved and maintained by the social constructivist approach, where learners work alongside others to construct the learning for themselves with guidance and scaffolding from seniors and teachers. This is especially important for AHPs as new knowledge builds on to their existing understanding. As allergy is such a dynamic field, a thorough scientific grounding is vital. It is important that they are supported through the learning process with time, sponsorship (financial support), supervision, and academic support both locally and from their educating institutions.

AHPs should have the opportunity to share their work and experiences, to conduct research for analyzing change in practice and to learn about the patient experience with allergy within their department’s services and beyond. There is, therefore, a responsibility to create infrastructure which supports AHPs as academics as well as clinicians, and to provide them with opportunities to conduct their own research.

When expert knowledge is integrated effectively, and focused on solving problems, it can yield significant innovation. However, research has shown that although there is good will regarding joint-working in theory, in practice, teams may not implement ICPs. It can be challenging to communicate the goals of integrated working in a continuous, accessible manner. This requires a high-level of input from administrative and clinical staff, which may be inhibited by local resources. In addition, team development takes significant time, and change occurs at different paces for different teams. When the goals of ICPs and the HCP’s role within these is unclear, there can be perceived tension between the individual’s core responsibilities and team responsibilities, resulting in a cynical attitude towards change. Sustained education regarding integration, realistic goals, and financial input are critical if ICPs are to facilitate and develop joint working in integrated teams.

MEASUREMENT OF ICP EFFICACY

A key goal of ICPs has been to reduce the existing fragmentation and support integration of systems, services, organizations, professionals, and the wider communities depending on local context and needs. Any improvement or change strategy needs to ensure that it is properly benchmarked. A baseline or control assessment of the current situation is vital in order to discover the value (or the
disadvantages) of any new intervention. This requires time and resources to collate required data as well as recognizing what tools are needed to assess what the new ICP is designed to do. Furthermore, the impact of integrated care must be measured from the perspective of patients and service users (in terms of their care experiences as well as their health outcomes) in addition to measuring the impact from the health staff and organizational perspectives.

There are validated statistical techniques for establishing significance of benefit using continuous pre- and post-intervention data harvesting. This can give an indication of real time change which should be reviewed regularly by the ICP implementation team using the plan/do/study/act cycle. Each significant change can be associated with components of the intervention or external factors. Adjustments can then be introduced in a stepwise fashion to achieve the best outcomes.

There are a few examples of successful implementation of ICPs for allergic diseases, most notably from Finland where a national strategy has shown considerable health economic benefits, whilst reducing morbidity and mortality from asthma. Similar programs are now being recommended in Norway and other countries in Europe. A UK local district pediatric implementation program based on the care-pathways defined by the RCPCH has achieved reductions in demands for unscheduled care and healthcare costs. The recommendation is to initiate more research into strategies to improve healthcare delivery for people with allergic and airway diseases. We recommend that WAO formulates proposals for implementation strategies to reduce the second translational gap and to gather quantitative and qualitative outcome data.

CONCLUSION

Over the last 60-70 years there has been a significant worldwide increase in the prevalence of allergic diseases. This has occurred at the same time as a burgeoning of knowledge about the basic mechanisms and evidence of the efficacy of therapeutic interventions. Despite the expanding evidence base, many unmet needs in allergy care have been identified over the last 2 decades. Suboptimal allergy care has been attributed to a paucity of allergy specialists, inadequate training of HCPs, and fragmentation of the patient journey with poor communication between services, which poses a particular problem for allergy patients who require concurrent care from multiple HCPs. The time between acquisition of new knowledge and its application in practice, known as the second translational gap, is very wide. Hitherto the response to address unmet needs and improve standards of care has been the generation of evidence-based management guidelines. Sadly, there is little evidence that publication of guidelines has achieved measurable benefits for patients, predominantly because they are not consistently adopted in practice. Evidence-based medicine requires evidence-based implementation.

The development of ICPs has achieved significant benefit in hospital services for elective surgery and management of acute presentations such as an asthma exacerbation. However, application to the management of long-term, relapsing, and remitting conditions like allergic disease is much more complex. It requires coordination of a wide range of agencies including patients and their caregivers, multidisciplinary teams across all settings, as well as educational, workplace, social services. There is now well established and evidence-based quality improvement methodology which can be used to develop and implement ICPs for patients with allergic disease. These are best applied locally to account for locality specific socioeconomic, ethnic, environmental, and political issues. The fundamental principles of the methodology are scoping the problems, stakeholder recruitment, and mapping (always including patients and their caregivers), agreeing upon the aims and strategy to implement competence-based-pathways, rapidly acquired continuous data feedback, plan/do/study/act meetings to modify actions based on data, and a health economic evaluation to support sustaining of the program. Education of health-professionals, patients, caregivers, and the general public is a
critical component for success and is addressed in a separate paper.

More research is now required to provide the evidence which will inform on the optimal processes to achieve significant reductions morbidity and mortality from allergic disease worldwide.

Abbreviations
World Allergy Organization (WAO), Healthcare Professional (HCP), Integrated Care Pathway (ICP), The United Kingdom’s National Institute for Health and Care Excellence (NICE), The British Society for Allergy and Clinical Immunology (BSACI), Allergic Rhinitis and its Impact on Asthma (ARIA), Multidisciplinary Team (MDT), General Practitioner (GP), Allied Healthcare Professionals (AHPs), European Pathway Association (E-P-A), Royal College of Pediatrics and Child Health (RCPCH).

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JOW, ML, TG, BM, SGD, LD and SB made contributions to the conception and design.
JOW, CV, DM, LD, SB and AK assisted with literature searching.
LD, SB and JOW authored the first draft of the manuscript.
JOW, CV, TG, JG, SGD, ML, LD, SB, BM, HH, RVG, CDQ, RGA, ES provided critical contributions to the manuscript.
CV, ML, JG, JOW, LD and SB contributed to the graphic works.
JOW provided supervision of the manuscript.
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