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Original Research

## Patient perspectives in asthma: Listening to and learning from a new paradigm in translational research

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### 1. Background

When requested to write an editorial on “*patient perspectives in asthma*” for this special issue on Innovations in asthma, rather than go to the literature and performing a systematic review of what has been already written we elected instead to jointly write an article on how patients’ needs might be better understood and addressed based on the experiences of the Patient and Public Involvement team (PPI) of the Asthma UK Centre for Applied Research to outline how and why healthcare professionals can collaborate with people living with asthma. The co-authors are a general practitioner, a researcher and a patient.

### 2. Introduction: healthcare for people living with asthma

Asthma is classified as a chronic disorder but differs from many other chronic disorders in that the aim of treatment is normalization rather than optimization. Furthermore, asthma, in common with diabetes, is a dynamic disease, as recognized by the inclusion of symptom variability accompanied by variable airflow obstruction in its definition. Because each of us is unique, our experience of any disease process is also unique although, as a generalization, will share similar experiences to others suffering from that disease. How this attempt at normalization is interpreted differs significantly between clinicians and patients. Clinicians are driven by the desire to obtain asthma control whereas patients just want to be well enough to live their lives normally [1].

We have seen a major transition of care from a paternalistic model wherein the clinician had the ultimate authority, and the patient did what they were told, to a model which was more collaborative, and now to a new model which is the provision of personalised care. The model aligns very closely with the concept of evidence-based medicine proposed by Sackett [2].

Personalised care suggests a very close co-operative relationship between clinician and patient, a situation which implies a long-term

relationship and continuity of care, often at odds with the patient lived experience of fragmented care of variable quality [3].

Over time a valuable literature has developed around unearthing the patient agenda and shared decision making between the individual patient and their clinician, but as time moves on so does the potential multi-faceted role of the patient in sharing decisions and experiences concerning medication adherence [4] and participating in treatment decisions [5], thus working together to achieve guided self-management becomes a reality rather than an aspiration [6,7].

There has been, and remains, a mismatch between patient and clinician ideas of what asthma control looks like, with patients unaware of what treatment goals are; for example two-thirds of a large sample who believed their asthma was controlled, were in fact uncontrolled [8], believing that “control” meant keeping their symptoms at a manageable level, often by the frequent use of reliever medication [1,9]. Translation interventions are needed to address gaps in care delivery and who better to ask than those who are to receive care, the patients, providing a scientific rationale to justify the concept [10].

### 3. The lived experience

The “real” patient perspective below is an account of one patient’s journey with asthma, mirroring some of the changes in asthma care over the decades (loosely indicated) with a clear message concerning care inconsistencies, clinician attitudes, difficulties in care continuity as well as the adverse impact of asthma on quality of life and the lead up to participation in the research process but also illustrating the impact of many of the domains of importance mentioned above.

#### 3.1. Living with asthma: one person’s journey

##### 3.1.1. Time period: 1960’s and 70’s

My childhood memories are of winters where the same symptoms

Abbreviations: UK, United Kingdom; GP, General Practitioner/s; AUKCAR, Asthma UK Centre for Applied Research; PPI, Public Patient Involvement; HCP, Health Care professional/s; ELF, European Lung Foundation.

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would appear. An itchy nose and sore throat would develop into a streaming head cold and chest infection, with a wheezy cough that seemed to last forever. A visit to the local General Practitioner (GP) resulted in a course of antibiotics together with the “brown mixture” to clear my tubes, and an orange flavoured linctus. A diagnosis of asthma was never mentioned. Fast forward to my mid-twenties. My symptoms changed and I experienced a tight feeling in my chest with a cough and wheeziness, which made me feel really unwell and developed hay fever (allergic rhinitis), which aggravated the symptoms in my chest. (note: this could almost have been written by Charles Blackley [11]).

### 3.1.2. Time period 80's and 90's

The following autumn I had pneumonia and I was making a series of weekly review visits to the GP, who checked my peak flow and listened closely to my breathing. A diagnosis of asthma was made, and I was prescribed two inhalers, the brown one puff twice a day and the blue, when I was wheezy. I got married, had children, a part time job and was managing my asthma, until when I was in my thirties the blue inhaler (Ventolin) stopped being effective; I had times when I struggled to breathe, and having moved to the North Yorkshire Dales the nearest hospital was 25 miles (40 km) away. Managing my asthma became a whole new ball game. Thank goodness for a GP who was pro-active, monitored me closely and provided a nebuliser and nebulises of salbutamol.

At this point with support from my GP and husband, I began to actively manage my asthma. Living with a condition that was not going away required questions to be asked. For example -what were the triggers for my asthma. Now it was the winter cold virus which was the trigger, emerging during the school winter term carried home by our children. Avoiding this situation was not possible. The cold triggered my asthma and I had to learn to recognise the early symptoms and contact the GP for an appointment – which was a straightforward process with an appointment the same day. I did not have a rescue pack at this point, which was not an issue as a GP appointment was so readily available.

### 3.1.3. Time period: early 2000's

A move back to London changed everything. Colds from our children were no longer a problem as they were grown up and lived elsewhere. My asthma exacerbations were more severe, although not more frequent. The GP practice did not know me, and I had not yet established a patient doctor/nurse relationship. The way in which the health service operated had also changed. If I needed a nebuliser, then I had to purchase one and the GP prescribed the nebulises. This together with a rescue pack of prednisolone and antibiotics helped me self-manage my asthma exacerbations. I was also put forward by my GP to be a participant in a research study in London looking at vitamin D levels in people with asthma. I was gaining more insight into asthma and its impact on my lifestyle.

### 3.1.4. Time period: post 2010

A move to an area of Greater London and my hay fever transitioned to perennial allergic rhinitis, present all year round. This was associated with an increase in my asthma exacerbations. A new GP and Asthma Nurse quickly established an excellent doctor/nurse patient relationship with me and communicated closely with one another. Different strategies were implemented over several years. Although not always successful, we developed a clearer picture of my asthma. My diagnosis changed to allergic asthma and I was referred to respiratory medicine at a London hospital. Living with asthma now required some changes in my lifestyle. I became keener to understand my asthma and how best to manage it. I retired early from my full-time occupation at 60 years of age, creating space for me to increase my levels of fitness with daily walks and swimming two to three times a week unless I was experiencing an asthma exacerbation.

An ability to remember dates of when exacerbations commenced, and the symptoms experienced and the actions I took coupled with

results from blood tests, allergy tests and breathing tests have helped health professionals to diagnose and prescribe a course of immunotherapy, as I am most allergic to grass and tree pollens.

## 3.2. Activation

It was during one of the follow up appointments in clinic that I was approached and asked to consider participating in Patient and Public Involvement (PPI) for asthma. This has opened new opportunities to speak with other people living with asthma. What a wealth of knowledge we share between us. Meeting with health professionals and academics to listen and share my/our views about a proposed research topic, the data collected in a project or being a participant in a project, reading material for publication and being a co-author and being a participant in videos. As a PPI member I'm actively involved in my own health and the health for those with asthma in the future through working with other PPI's researchers, HCPs and improving care for people with asthma. Living with asthma is not easy and can be life threatening. Informed HCP, families and support groups are essential to support a person to be able to manage their asthma.

## 3.3. Time period: current

No longer am I a patient who is passive about her condition, but through my decades of experience aggregated with the other participants in the PPI, I can contribute actively and positively in shaping the research reaching out to identify the best holistic solutions for those with asthma.

## 4. PPI: evolution from involvement to partnership in research (Fig. 1)

### 4.1. Patient and public involvement (PPI) in asthma research

At the Asthma UK Centre for Applied Research (AUKCAR) we have adopted a systematic approach to including people living with asthma at all stages of the research process. This has involved elements of training for the patients involved, with particular reference to research methodology. The time invested in this process has been well spent in defining research questions and co-designing research studies and interpretation of results. This naturally progresses to patients becoming co-applicants for research grants, co-authors in journal articles or, in other words, becoming valued colleagues placing PPI at the heart of the Centre [12]. In addition to involvement in research projects, we have four PPI Patient Leads who sit on our Centre Management Committee and contribute to the overall running of the Centre.

### 4.2. Collaboration in research

The IMpLementing IMpROved Asthma self-management as RouTine (IMP[2]ART) programme of work has benefitted from PPI since inception [13]. A PPI Patient Lead was involved in the creation of the pilot study and development of the programme grant, and there is a dedicated PPI team of 10 people impacted by asthma who contribute to the development and refinement of the implementation strategy through face-to-face meetings, teleconferences and email. Following a recent discussion group, facilitated by the PPI Patient Lead, we created videos for our dedicated “Living with Asthma” website, providing tips on managing asthma for people with asthma, by people with asthma. In addition, people with asthma were involved in designing the website in the creation of a number of resources specifically for people living with asthma to ensure they are of interest to and accessible by people living with asthma [14].

Description	Facilitating factors	Challenges
<ul style="list-style-type: none"> <li>No involvement</li> <li>Occasional involvement</li> <li>Consultation with patient groups</li> <li>Co-operation in research</li> <li>Collaboration in research</li> <li>Developing research ideas</li> <li><i>Implementing research</i></li> </ul>	<ul style="list-style-type: none"> <li>none: ad hoc approach</li> <li>formation of patient groups <i>e.g. ELF</i></li> <li>training in research methodology</li> <li>inclusion in research teams and formulation of research questions</li> <li><i>inclusion in guideline development</i></li> </ul>	<ul style="list-style-type: none"> <li>Acceptance of patients</li> <li>Accessibility/availability of (trained) patients</li> <li><i>Funding of patients</i></li> </ul>

Fig. 1. Evolution of patient partnership in translational research (Italicised items indicate emerging challenges).

#### 4.3. Collaboration in real life trials

The lived experience of disease offers a different perspective on disease management to that taken by health care providers and to a lesser extent by health care professionals. It is by consulting patients and finding out what is important to them and what barriers to care they meet or perceive that we can co-create a new reality. This is as true in the creation and use of real-life evidence to better inform care provision, especially now as there is a clear acceptance of the role real life research in informing guideline outputs [15].

#### 4.4. Partnering with patients in healthcare

Recently a tool has been developed to formally evaluate the degree of partnership between patients and health care professionals (HCPs). To achieve this the authors identified seven domains of importance: Confidence/Trust, Autonomy, Participation in decision making, Information sharing, Personal context, Empathy, and Expertise [16]. Of note, three of the authors were patient researchers.

In essence the HCP and patient need to buy into each other in order to develop mutual confidence and trust. This importantly is a bidirectional relationship established to achieve jointly decided objectives. This cultivation of patient autonomy facilitates information sharing and participation in decision making in particular recognising individual circumstances. For this to occur, it is likely that this relationship will develop over a period of time which implies a degree of continuity of care, the importance of which is illustrated in the account above. There is a big need, particularly with the increasing role of e-health/m-health to actively seek patient participation in co-development, co-design of any initiative seeking the optimal means to integrate e/m/health solutions, a stance recognized as being a critical success factor. The position statement of the European Academy of Allergy and Clinical Immunology on mobile health technologies states unequivocally '*Patient centred care should be personalised, pro-active and patient driven: and To ensure patient centeredness and relevance, patients should be involved at every phase of the design, implementation and updating process*' [17] a reality based position differing markedly from systems which espouse e/m-health initiatives in the pursuit of efficiency and resource allocation, a system designed with little or no input from clinicians or patients which will serve to further fragment care and deprive access to care for those who are illiterate [18].

#### 4.5. What we have done and how

We have a PPI member as a co-applicant on the App for Asthma Connected Plus study which explores the implementation of Internet-of-Things solutions to support asthma self-management. They were significantly involved in the study design and contributed to two qualitative studies exploring patient and clinical perspectives of using devices to manage asthma. Their contribution was essential in providing a patient perspective to the qualitative analysis, helping reduce subjectivity of findings. They are involved in dissemination of findings and a co-author on study papers [19].

During the COVID-19 pandemic, some people living with asthma were identified as being at higher risk of severe illness from COVID-19

and additional government public health guidelines were created to support those living with asthma. Together with PPI members, we created a project reviewing the information available in English online for people living with asthma to explore the accessibility of the information, whether it encouraged asthma self-management and if it addressed health actions to minimize the risk of contracting COVID-19. A PPI member was involved in study design and analysis meetings providing valuable public insight into what is "accessible" and what people with asthma wanted to know when living through the COVID-19 pandemic. In addition, the PPI member is also a co-author on the published manuscript due to their contribution to the project [20].

#### 4.6. Challenges

As always, when there is innovation, the problem of funding is thrown up. Granters of research funding only recognise funding from the commencement of a project, while ignoring investment in creation and development of research proposals. Thus mechanisms must be developed and deployed to ensure that patients, with their wealth of lived and practical experience, are not excluded from research, by the error of omission [12].

### 5. The next step/frontier - coproduction throughout the project life-cycle

#### 5.1. The concept

Previously, PPI members were brought into the research project after the study scope had been generated and deemed "worthy" to proceed to apply for funding. At the Centre, we are changing this model, and have started by asking our PPI members what topics are important for us collectively to research – and co-create the research project from there.

#### 5.2. The example

PPI Patient Lead Elisabeth was concerned at the lack of research on older adults, so we co-designed a project to address this gap in the evidence base. Elisabeth was involved at every stage: idea generation, project design; research management; analysis; dissemination. Elisabeth was involved in the recruitment and selection of the team, and we jointly supervised two undergraduate students to undertake the qualitative interviews and analysis. In addition, various PPI members helped review the interview topic guide, participant facing documents, and took part in pilot interviews to test the questions and help train the medical students in interview techniques.

After the students had conducted the interviews, Elisabeth was again involved in the qualitative analysis, providing valuable patient insight into constructing the themes and she reviewed the final report. We presented our findings at the Primary Care Respiratory Society UK Conference, where we won "Most patient-centred poster" and have recently published our findings with Elisabeth as a co-author due to her prominent role within the project. The success of this project is attributed to the full coproduction with a PPI member from idea generation to dissemination. We should all be aiming for coproduction in our research to ensure we are undertaking research that is of benefit to the people it

impacts [21].

### 5.3. Patient participation in guideline production

Given the recent research from a different, but relevant disease area, (allergic rhinitis) which concludes that “patients do not follow guidelines” [22] perhaps as a community we need to alter not only the ways in which asthma research is formulated and planned, executed and but also analysed and translated utilising a tripartite approach of patients, clinicians and researchers, to paraphrase Sackett: ‘using their individual expertise to create and address research questions (and provide answers) in order to create the best available evidence, to create guidelines which meet the needs of clinicians and patients alike.’

### CRedit authorship contribution statement

**Dermot Ryan:** written jointly, edited. **A. Keighley:** reviewed and accepted by all. **T. Jackson:** reviewed and accepted by all.

### Declaration of competing interest

With regard to the current submission none of the authors declare any conflict of interest.

All authors are associated with the AsthmaUK Centre of Applied Research.

Dermot Ryan is a vice president of the Respiratory Effectiveness Group.

He is a director of the International Primary Care Respiratory Group and a member of the EUFOREA asthma board.

### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.rmed.2022.107013>.

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