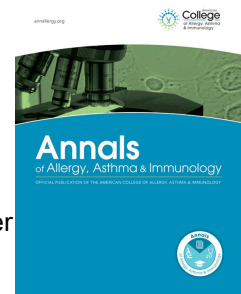


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Elissa Michele Abrams, MD FRCP, Matthew Greenhawt, MD FAAAAI MBA, Jennifer Lisa Penner Protudjer, PhD



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The Need for Patient Voices in Food Allergy Research

Elissa Michele Abrams MD FRCPC^{1,2}, Matthew Greenhawt MD FAAAAI MBA^{3,4}, and
Jennifer Lisa Penner Protudjer PhD^{1,5-9}

¹Department of Pediatrics and Child Health, The University of Manitoba, Canada

²Division of Allergy & Immunology, Department of Pediatrics, Faculty of Medicine, The University of British Columbia, Vancouver, British Columbia, Canada

³Children's Hospital Colorado, Aurora, Colorado, United States

⁴University of Colorado School of Medicine, Aurora, Colorado, United States

⁵George and Fay Yee Centre for Healthcare Innovation, Winnipeg, Canada

⁶The Children's Health Research Institute of Manitoba, Winnipeg, Canada

⁷Institute of Environmental Medicine, Karolinska Institutet, Stockholm, Sweden

⁸Centre for Allergy Research, Karolinska Institutet, Stockholm, Sweden

⁹Food and Human Nutritional Sciences, The University of Manitoba, Canada

*Corresponding author

Dr J Protudjer

501G-715 McDermot Avenue

Winnipeg, MB Canada R3M 3P4

+1 204 480 1384

Jennifer.Protudjer@umanitoba.ca

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JP is a member the steering committee of Canada's National Food Allergy Action Plan.

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3. Mixed Methods
4. Patient Engagement
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Abbreviation:

CIHR	Canadian Institutes of Health Research
OFC	Oral Food Challenge

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Food allergy disproportionately affects children (1), with global estimates of prevalence as high as 10% (1). Much attention has focused on the prevention, management and treatment of food allergy (1), commonly through clinical trials, which are used to inform policy and research priorities. However, these studies do not take into account shared decision-making or patient-centered preferences, or account for the underlying dogma that “evidence doesn’t make decisions – people do” (2). To date, there has been little focus on pragmatic research that allows for variability in therapy, or qualitative- and mixed methods research. As such, there is an unmet need to reconsider the research methods used to addresses the prevention, management and treatment of food allergy, and the types of studies that influence healthcare policy.

For clarification, we define “patient” per the Canadian Institutes of Health Research (CIHR): “overarching and is inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends” (3). Thus, by definition, patients need to be, and remain at the core of, healthcare discussions and research outcomes. Unless patients are actively engaged in all stages of research – from clinical studies to implementation research to the inclusion of patient-centered outcomes - they are consciously excluded and thereby lack a voice in their own care. Of greater concern is that practice and policy changes may not reflect patients’ needs and reduce feasibility and acceptability of any subsequent implementation.

Patients’ voices can be heeded through patient engagement, and qualitative and mixed methods research. (3). Patient engagement must be promoted throughout the research process, beginning with patients as active stakeholders in setting priorities and identifying what questions need to be asked. Early engagement increases the likelihood that research is relevant to patients (3). Likewise, patients should have a voice in providing key input with regards to study design, inclusion of patient centered outcomes, and knowledge dissemination and translation (3). Patient engagement adds value in multiple ways: compliance, setting future patient-oriented research and funding priorities,

identifying previously undescribed areas of concern, providing stakeholder engagement in the process which improves uptake and external validity, and more. This commitment to patients is underscored by major funding agencies. For example, CIHR, the Patient-Centered Outcomes Research Institute, and the United States' National Institutes of Health encourage patient engagement throughout the research process, including patient partners on grant applications, and collaboration with community organizations (3, 4). Although not yet commonly reported in food allergy research, patient engagement has been reported as positively impacting asthma studies, through shared decision making processes (5). We view the paucity of patient engagement studies in the area of food allergy as a call to action, particularly given the threats that food allergy poses to the roles of food in our patients' lives. Of equal import, we must engage with ethnically and economically diverse populations to gain a more representative understanding of patients' needs and preferences, as well as to create greater trust.

Patient priorities can also be understood through qualitative research. This methodology is rooted in a quest to understand how a population constructs meaning, through data from through interviews, focus groups, observation and document examination, amongst others. Anxiety is a common underlying cause of significant morbidity to allergic families (6, 7). Yet, food allergy-related anxiety neither receive attention, nor can be comprehensively understood in randomized, controlled trials. But, as food has physical, social, mental and spiritual roles in every society, it behooves us to listen to patient voices, and ultimately use their experiences to inform family-centered healthcare priorities around that address this anxiety.

Qualitative research can also be collected and/or interpreted in conjunction with quantitative methods within the same study. It is beyond the scope of the present editorial to comprehensively review the ways in which qualitative and quantitative data can be mixed. However, the point of inference is the starting point at which the researcher begins to interpret decide which findings align, which diverge, and for which one method provides detail whereas the other does not. This latter

observation is critical, and the goal of mixed methods research, as “silence” from only one method provides heightened understanding and direction for future work. Subsequently, meta-themes (those that cross both methods) can guide knowledge translation and inform policy (8).

Mixed methods research is gaining popularity in food allergy research (9). Oral food challenges (OFC) are widely considered the gold standard for determining if a child has achieved tolerance to particular food. Yet, OFC remain underutilized, the reasons for which were described in a recent mixed methods study (9). Deterrents differed by type of care providers: pediatricians described long wait times, whereas pediatric allergists described lacks in resources and standardized guidelines. In contrast, parental survey responses and interview transcripts confirmed a greater need for correct information and psychosocial resources (9). All of these findings warrant consideration in developing OFC guidelines and resources. More recently, we provided evidence from a mixed methods study of families with children with multiple food allergies, including milk (10). Based on quantitative data, we identified that, regardless of a child’s other allergies, milk allergy was reported as carrying the most social, time and anxiety, and financial burden. A qualitative analysis of free text responses provided greater insight into each of these burdens, including public confusion with lactose intolerance, and an unwillingness of others to accommodate the allergy (10). This information will provide direction to meaningfully engage with childcare centres and schools to support children with milk allergy.

As humans, we recognize the ubiquity and multiple roles of food as a form of nourishment. But, when each of these roles is threatened by food allergy, there is a fundamental need to understand both the mechanistic and biological processes, and the social impacts of the disease. To this end, the way in which we think about, and conduct food allergy research needs to shift toward a patient-centered approach. We must remember that evidence does not make decisions, but rather that people do (2).

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