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RESEARCH LETTER

WILEY

Patient-reported outcomes in food allergy: Speaking the same language to address some of the GAPS

To the Editor,

The shift to patient-oriented research, which reflects the voices of patients and caregivers who are experts by experience (EBE),[1] has resulted in meaningful research and outcomes. Concurrent shifts towards research that addresses equity, diversity and inclusion have similarly prompted awareness that much research has included patients who represent narrow demographics, specifically affluent White families in high-income countries.[2] These shifts are essential and exciting though not without methodological challenges, ranging from ways to respectfully engage underrepresented groups, to interpreting findings through culturally respectful lenses.

Food allergy (FA) has substantial psychosocial impacts.[3–5] However, less is known about how or if these findings reflect culturally, socioeconomically and geographically diverse populations. Such relevance requires detailed and contextualized understanding, which can be gleaned through qualitative designs. The Global Access to Psychological Services for FA (GAPS; Aston University Research Ethics Committee REC ID number 1621) study aims to explore the need and uptake of psychological services in multiple countries and languages (Figure 1, Panel A). In the present paper, we aimed to provide guidance, informed by our own experiences conducting a multilingual, international qualitative study, for groups wishing to perform similar work (Figure 1, Panel B).

To recruit diverse populations within a country, we recruited via multiple methods, including social media and via patient organizations, and selected participants based on gender, age, ethnicity, number and type of allergen(s) and age at diagnosis. All participants provided written informed consent.

Semi-structured interview guides were developed through literature review and engagement with content and methodological experts and EBE. For practical reasons, the original development occurred in a single language (English). Translation of the instrument occurred per World Health Organization guidelines and included both forward and backward translation.[6] Forward translation involved instrument translation from the original language to the target language(s), a process that required the translator to have language skills at maternal language proficiency, and familiarity with health concepts and terms. Thereafter, interview guides were independently back-translated, during which time the translators did not have access to the document in the original language. Although presented linearly, this process involved several rounds, until the translation was deemed satisfactory and any differences, including unclear/complicated terms, were resolved. Thereafter, the document was considered to be a final translation.[6]

As those managing FA carry a heavy psychological burden,[3–5] more complete insight is gained when participants are able to express themselves in their mother tongue, and wherever possible, with an interviewer who understands age-informed language use, cultural context and vernacular. A lack of such understanding may contribute to erroneous use of a word or misinterpretation of a comment. To this end, interviewers were encouraged to request clarification of a term, despite the interruption.

Some researchers collect multilingual qualitative data and complete the translation prior to analysis as it may contribute to the clearer establishment of linkages of transcripts.[7] Translation prior to analysis, however, increases the potential for bias where an analyst may not speak the language used to collect data or have the cultural frame of reference to comprehensively interpret the data.

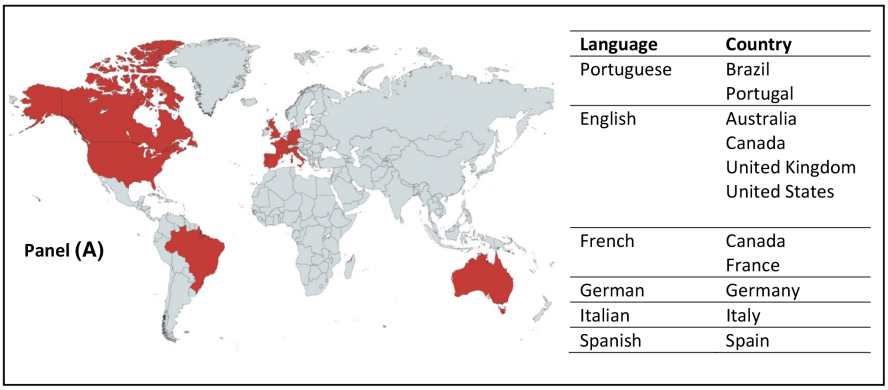
Linguistic misinterpretations or incomplete analyses may occur and parts of the original data set may be lost in translation."[8,p.4] Multiple analysts can provide an opportunity for intercoder reliability—a necessary step in multilingual analysis given the risk of misinterpretation in the absence of a holistic knowledge of the culture and language, including regional variation. This guidance is distinct from triangulation, or the use of multiple data sets, analysts or theories, which is often used to enhance credibility in qualitative analysis.[9] Developing a multilingual team was time-intensive and established through existing networks. To facilitate new collaborations, initial contact was with mutually known colleagues. Time demands were substantial, and ranged from translation to differences in institutional processes.

Financial resource demands ranged from inter-institutional transfers of funds for research assistant salaries to participant honoraria and translation costs. E-gift cards are a common form of honoraria, but non-standard amounts when distributed in different currencies had varying purchasing capacities. The translation was charged by the word, the price of which was negotiable with the translator given the volume of work. Short-text translations (e.g. social media posts) were more efficiently and cost-effectively translated by the study team. As is good practice for all qualitative research, interviewers were trained to remain professional,[9] and empathically neutral,[9] and our research team was governed by the ethical approval of our host institution. Herein, our team additionally sought clarification if cultural context or expressions were unclear, and avoided conversation with, or counselling the participant. This included refraining from the use of colloquialisms, which may not be well-received or understood by other cultures/in other languages. Likewise, as cultural norms related to food preparation and childcare differ between countries, interviewers were trained to respectfully and neutrally explore subjects without raising any of their own cultural norms. Finally, as we sought to recruit diverse populations, it behoved the research team to remain mindful of their privilege, both to collect personal data and as a product of their education and employment.

Key messages

- Patients' voices are critical for comprehensive allergy management, yet non-English-speaking groups are often underrepresented.
- We designed a method to amplify the multilingual voices of those living with food allergies.

Investigations into the psychological burdens of FA must acknowledge participants' rights to fully and freely express themselves in their preferred language. Considerations presented herein are critical for multilingual qualitative studies at every stage of the study, beginning with instrument development and continuing through data collection and analysis.



Language	Country
Portuguese	Brazil Portugal
English	Australia Canada United Kingdom United States
French	Canada France
German	Germany
Italian	Italy
Spanish	Spain

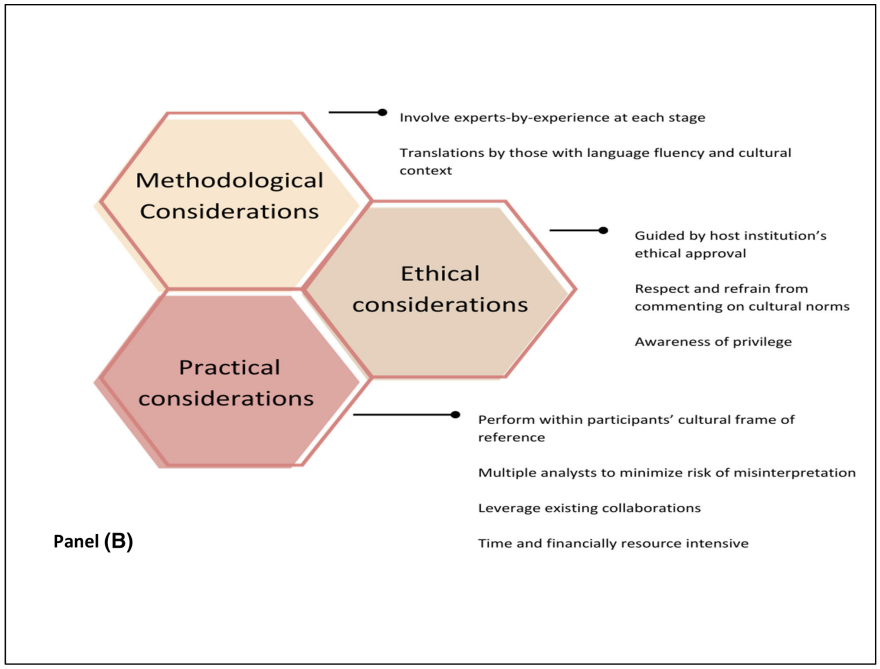


FIGURE 1 Countries involved in GAPS as of May 2023 (Figure created using mapchart.net; Panel A) and; Best practice guidance on methodological, practical and ethical considerations (Panel B).

KEYWORDS

education, food allergy, pediatrics, prevention, qualitative

AUTHOR CONTRIBUTIONS

JLPP wrote the first draft of the manuscript and is a GAPS investigator. HB, CJJ, MJM, LJH and RCK contributed to the intellectual content of the manuscript, approved the final version of the manuscript for submission and are GAPS investigators. CR contributed to the intellectual content of the manuscript and approved the final version of the manuscript for submission.

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CONFLICT OF INTEREST STATEMENT

JLPP is Section Head, Allied, Canadian Society of Allergy and Clinical Immunology and is on the steering committee for Canada's National Food Allergy Action Plan. She reports consulting for Novartis, Nutricia and ALK Abelló. HB reports research grant support from NIH, Aimmune and DBV Technologies and speaker fees from DBV Technologies and Chair for the Paediatric section 2019–2022 European Academy of Allergy and Clinical Immunology. CJJ reports research grant support from NIHR. MJM reports advisory work for Novartis, University of Michigan, and GA2LEN. LJH reports research support from NIAID and Leidos. CR reports none. RCK reports research grants from NIHR, Food Standards Agency, Aimmune, National Peanut Board, Novartis; honorariums from DBV Technologies, Nutricia; is Chair of the Psychology working group of the BSACI and sits on BSACI council.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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