

Challenges and unmet needs in FPIES from the parents and adult patients' perspective: An international survey

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Clinical Implications

Key priorities for the food protein–induced enterocolitis syndrome parent/carer/adult patient community are better awareness about food protein–induced enterocolitis syndrome among health care professionals and having diagnostic/prognostic biomarkers to avoid misdiagnosis and guide safe food introductions. Future research and clinical improvement initiatives should focus on these areas.

Food protein–induced enterocolitis syndrome (FPIES) is a potentially severe and poorly understood type of food allergy. Little is known about its pathophysiology and no diagnostic or prognostic biomarkers exist. Also, “it does not look like an allergy” and awareness among health care professionals is poor, which hinders prompt diagnosis and early access to appropriate care. The International FPIES Association as well as experts highlighted this lack of awareness as one of the key unmet needs nearly a decade ago.^{1,2} Research on FPIES has increased recently, contributing to better understanding of its epidemiology, natural history, and clinical presentation, including increasing reports in adults.^{3–5} The International Consensus on FPIES published in 2017 was an important milestone to help improve and harmonise clinical practice.⁶ In this rapidly evolving field, an in-depth up-to-date assessment of patients' perspectives is required to further develop meaningful patient-centered research and improvements in clinical care. In this study, we aimed to assess the challenges and unmet needs of both parents/carers of children with FPIES and adults with FPIES.

We conducted an observational cross-sectional study using an online survey targeted at parents/carers of children with FPIES and adults with FPIES (self-reported). The survey was developed by the study authors and reviewed by the FPIES Foundation Medical Advisory Board. As a “Patient and Public Involvement” initiative, review by an Ethics committee was not required. All responses were anonymous and kept confidential. The survey was in English and used a parallel mixed-methods approach, including qualitative data (open-ended questions on challenges and needs when living with FPIES) and quantitative data (demographic characteristics, clinical characteristics, as well as Likert-scale ratings of potential unmet needs, satisfaction with health care, and impact on family life and well-being). The full

survey is available from authors on request. The study was advertised through patients' organizations including FPIES Foundation, FPIES UK, Food Allergy Canada, and Allergy & Anaphylaxis Australia, via their membership email lists and/or social media (Twitter/Facebook). The survey was disseminated via link to SurveyMonkey between May 6, 2020, and July 18, 2020. Quantitative data were analyzed and presented as percentages/absolute numbers, mean/SD, or median/interquartile range as appropriate. Comparative analysis between data relating to children and adults was performed using parametric or nonparametric tests as appropriate. A *P* value of less than .05 was considered statistically significant. PASW Statistics 27 (SPSS, Inc, Chicago, Ill) was used. Qualitative data were reviewed by 3 authors (R.K./E.K./S.M.) and analyzed using Braun and Clarke's Reflexive Thematic Analysis method. A combined inductive and semantic approach was followed during coding and theme development.

The survey was completed by 285 respondents, of whom 248 (87%) were parents of a child with FPIES, 5 (1.8%) carers of a child with FPIES, 21 (7.3%) adults with FPIES, and 11 (3.9%) adults with FPIES who also had a child with FPIES based on self-reporting. Mean respondents' age was 36.9 ± 8.2 years, 270 (94.7%) were female, and 257 (90.2%) had attended college. Most respondents were based in the United States (70.5%, 201 of 285), followed by Australia (15.8%, 45 of 285), Canada (7.4%, 21 of 285), the United Kingdom (6.7%, 19 of 285), and other (3.2%, 9 of 285). Patients' mean current age was 4 ± 3.3 years for children and 41.1 ± 12.8 years for adults with FPIES. Age at FPIES onset was 0.4 ± 0.5 year for children and 19.1 ± 16.6 years for adults. Acute FPIES was reported in 45.6% (135 of 296 total FPIES cases, including those 11 parents of children with FPIES who also had FPIES themselves), both acute FPIES and chronic gut symptoms in 49% (145 of 296), and chronic gut symptoms only in 6.1% (18 of 296). FPIES to multiple food triggers was reported in 76% (225 of 296). A mean of 3.5 ± 2 professionals had been involved in patients' FPIES care. Mean score for satisfaction with allergist/gastroenterologists' care was 4.1 ± 1.7 and for nonspecialists' care was 3.5 ± 1.7 , range 1 (“very dissatisfied”) to 6 (“very satisfied”). Mean score for impact on family life was 2 ± 1 and on patient's well-being was 2.4 ± 1.1 , range 1 (“hugely affected”) to 5 (“not at all affected”). Further patients' characteristics, including differences between children and adults, are described in Table E1 in this article's Online Repository at www.jaci-inpractice.org.

The following unmet needs were rated as the “top 5”—in decreasing order of importance (mean score, SD), range 1 (“not essential”) to 9 (“absolutely essential”): increased awareness/knowledge among health care professionals to avoid delay in diagnosis (8.7 ± 0.91); increased awareness/knowledge among medical students to avoid delay in diagnosis (8.51 ± 1.14); prognostic test to predict resolution of FPIES to culprit foods (8.4 ± 1.19); prognostic test to predict safe new foods to be introduced in patient's diet (8.4 ± 1.2); diagnostic test to identify FPIES acutely against common differentials (8.04 ± 1.63). The top 3 unmet needs above received higher rating by parents/carers than by adults, as did the need for peer support, online peer forum, and research into the burden of FPIES. See

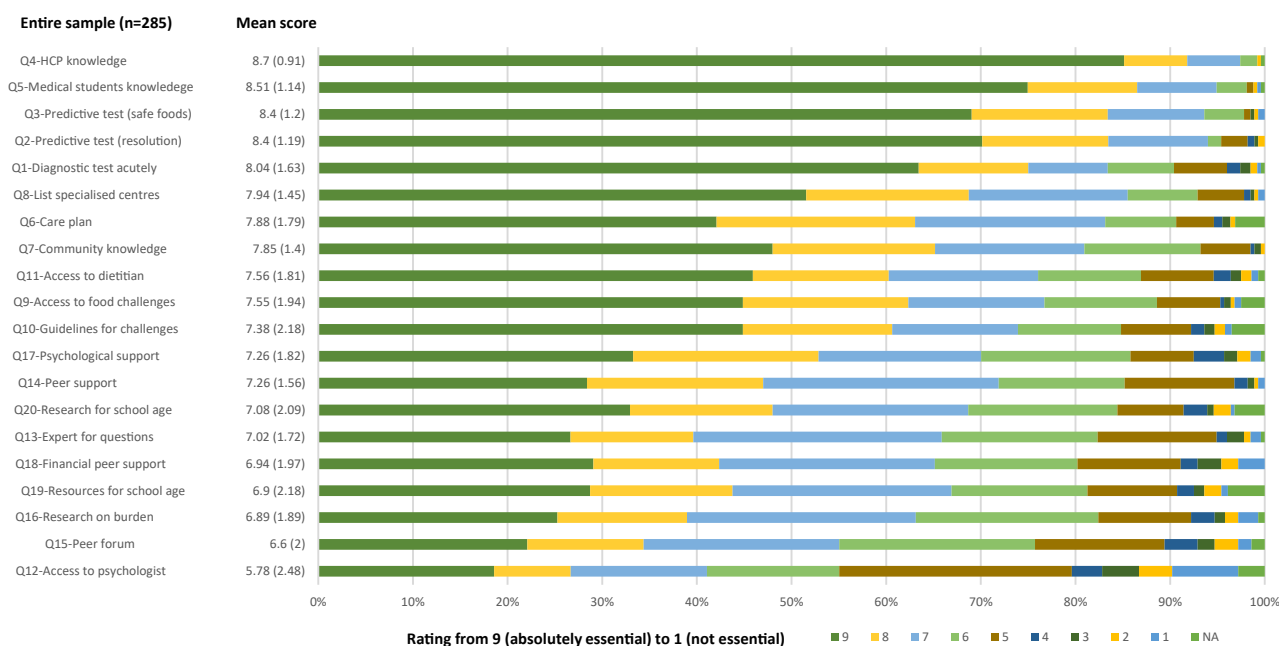


FIGURE 1. Rating of potential unmet needs by survey respondents (n = 285) from 9 (absolutely essential) to 1 (not essential).

rating for all questions in Figure 1, and further comparison between children and adults in Table E1. No differences were observed across countries (data not shown).

We conducted thematic analysis of the 132 comments from open-ended questions (106 from parents, 23 from adults with FPIES, 3 from parents who also had FPIES themselves). This resulted in 5 overarching themes emerging predominantly from parents; 3 related to challenges and 2 related to needs. Regarding challenges, respondents identified the “Anxiety and stress when managing FPIES,” including the lack of support from health care professionals and the lack of financial help. Fear of reactions and introduction of new foods were frequently cited as a source of anxiety, particularly by parents. A second theme concerned “Social restrictions and discrimination affecting quality of life.” This theme related to the difficulties in social situations such as eating out and the discrimination felt when trying to negotiate safe foods. Finally, respondents felt that “Lack of knowledge and support for FPIES” was a challenge. This included health care professionals, schools, and the wider community. Adults’ comments focused predominantly on the latter 2 challenge themes (see Table I). These themes clearly linked to the needs identified by respondents. Regarding needs, respondents wanted greater “Awareness, information, education and psychological support for FPIES.” This theme included education for health care professionals, teachers, and the general community as well as greater information for adult patients and parents in how to manage FPIES. Second, respondents wanted more “Research to improve knowledge regarding diagnosis and management of FPIES” including improved diagnostic methods and better food labeling.

To our knowledge, this is the first international survey exploring the challenges and unmet needs of children and adults living with FPIES from the parents’ and adult patients’ perspective. Better knowledge and awareness of FPIES among

health care professionals and medical students to avoid misdiagnosis was identified as the key priority to address. This is in line with the reported suboptimal satisfaction with care and previous reports of poor awareness among nonspecialists.⁷ Availability of diagnostic tests to avoid delay or misdiagnosis, as well as prognostic tests to identify safe food alternatives and tolerance development over time were perceived as key areas for future research. At least 25% to 50% of patients with FPIES react at challenge over follow-up and, despite no fatalities being reported in FPIES, anxiety due to fear of reactions seems a major concern for parents. Finally, improving clinical care including listing specialized centers, an integrated care plan and access to a dietitian, and appropriately supervised food challenges were also highly rated as essential areas. The FPIES’ profound impact on health-related quality of life is beginning to be unravelled.^{8,9} Our results help further understand the broad-ranging difficulties experienced by adults and parents/carers living with FPIES, from anxiety, social restrictions, and discrimination to financial pressure and lack of knowledge and support.

Regarding our study limitations, the diagnosis of FPIES was self-reported. Although most patients had been assessed by an allergist, whether the diagnosis of acute FPIES or chronic gut symptoms had been established by a health care professional was not determined. Our survey was disseminated in English through developed English-speaking countries only. As such, it may not reflect views from other regions or communities. Similarly, the survey was completed mainly by highly educated mothers of children with a relatively complex self-reported FPIES profile involving multiple foods, a persistent phenotype, and often both acute and chronic gastrointestinal symptoms. This may suggest selection bias (eg, patients/families with more complex backgrounds liaising with patients organizations) because such a profile is usually a minority in most clinician-reported FPIES series.^{3,4} Whether our findings reflect the challenges and unmet

TABLE I. Themes and subthemes emerging from the qualitative data thematic analysis of the 132 comments from the open-ended questions

Themes, subthemes, and quotes
Challenges
Anxiety and stress when managing FPIES
“Constant anxiety in fear of accidental exposure.” (mother)
“Travel on a plane.....field trips with school all bring anxiety.” (mother)
“The cost of the formula, her NG-tube supplies, hospital visits, medicines, and doctor care has been a huge stress.” (mother)
“It’s completely anxiety inducing for me as a mother every time we introduce new foods. All I do is stare at the clock waiting for that 2-hour mark after he eats to see what will happen.” (mother)
“High anxiety during food trials and reintroduction.” (mother)
“Keeping my toddler away from ALL foods is an exhausting challenge. Not only do I worry about acute exposure/reaction but high choking risk, as my child has never learned to chew from being on strict amino acid formula. It is a very sad, overwhelming experience and I generally feel unsupported.” (mother)
“Anxiety—Encountering food contamination anywhere but home. Embarrassment—vomiting in public/weddings/family events. Fear of trying new things.” (adult)
Social restrictions and discrimination affecting quality of life
“Because of trying hard to keep our child safe, we’ve had to withdraw from many social gatherings and from going out or getting away for a weekend or other trips.” (mother)
“Anywhere we go. Out to eat, holidays, school, etc all have to be planned and risk assessment [sic].” (mother)
“Frustration due to other children not understanding FPIES and not being able to participate in celebrations due to food restrictions.” (mother)
“Dining out is a huge challenge—people confuse rice allergy and assume gluten-free is what we need. Scary. This is where our social emotional well-being is affected most—parties, camp, school events, social events, and dining out.” (mother)
“Wanting to be polite and wanting to not appear to be picky.” (adult)
“Can’t—I can’t travel, can’t take my kids out for ice cream or anything, can’t go in a corn maze, can’t go to a movie theater (popcorn everywhere).” (adult)
“I actually lost out on a very good relationship because his mother was offended when I didn’t eat her food.” (adult)
“I appreciate that you’ve included psychological health in this survey. It took me a good 2 years to understand what having FPIES really means after my diagnosis, and looking back, the hardest part wasn’t the food trials or the appointments, it was accepting a new way of life and prioritizing my well-being.” (adult)
Lack of knowledge and support for FPIES
“Fighting with uneducated doctors, time and energy spent educating providers, having more knowledge than your providers on a diagnosis.” (mother)
“Nobody believed there was anything wrong with my baby. Was very paranoid for a long time until allergist confirmed the allergies and FPIES.” (mother)
“School was a nightmare. Sick so often had to homeschool. School gave him food that he can’t eat several times.” (mother)
“The lack of understanding from everyone. Doctors, family members, and friends who don’t fully understand leave our family with no support.” (mother)
“I think the lack of community knowledge and understanding and medical staff being aware [sic] of FPIES makes it a very long and lonely journey.” (mother)
“Need more hospitals/clinics that help to properly diagnose adults.” (adult)
“Seems like no one knows how to help me manage all the symptoms through diet. All they want to do is throw medications, which make things worse. I have had to do all the work. Very little from doctors.” (adult)
“Disbelief and lack of knowledge.” (adult who is also a parent of a child with FPIES)
Needs
Awareness, information, and education for FPIES
“ER providers need more education regarding FPIES.” (mother)
“ER doctors do not even know what we are talking about when we tell them about FPIES.” (mother)
“Educate nurses as well as doctors. They too need to know of FPIES and all of the symptoms that comes with it.” (mother)
“If we had a brochure to hand out to extended family to help them understand FPIES it would help.” (mother)
Research to improve knowledge regarding diagnosis and management of FPIES
“Think having a clear understanding that we can create a diagnostic tool and guidelines but knowing that every child is different and symptoms present differently just like the foods they can/can’t eat will be different from other FPIES kids.” (mother)
“A test to determine if she still has FPIES without a food challenge would really be invaluable. She doesn’t want to do a food challenge, and I can’t really blame her.” (mother)
“Really hoping more research is done soon to get diagnostic tools, more education to professionals and the general community, and just gain a better understanding of the disease.” (mother)

ER, Emergency room; NG, nasogastric.

needs of the broader spectrum of the FPIES community requires further study. Differences identified between parents and adult patients need to be interpreted with caution because numbers for the latter are limited. Six percent of respondents were adults or parents of children with chronic gut symptoms without evidence of profuse vomiting after eating the culprit food, which would not fall in the strict definition of chronic FPIES. Finally, the survey was conducted during the first stage of the coronavirus disease 2019 pandemic, when people were emerging from lockdown and isolation. The broad-ranging impact of this, including on mental health, may have influenced our results.

Our study provides a valuable framework to help codesign patient-centered clinical improvement and research strategies to help serve patients/families' needs and improve clinical outcomes. This should include early education initiatives on the presentation, diagnosis, and management of FPIES addressed to all stakeholders (health care professionals, patients, parents, caregivers, school staff, and the wider community) as well as strategies to help alleviate the high psychosocial burden associated with the disease.

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Conflicts of interest: J.M. and A.L.F. are cofounders and codirectors of the FPIES Foundation. R.K. has received research funding from Aimmune, National Peanut Board, Novartis, NIHR, Food Standards Agency. R.K. has received honoraria to give a conference presentation from DBV Technologies. R.K. is Chair of the Psychology Working Group of the British Society for Allergy and Clinical Immunology. M.V.O. has received honoraria to give a conference presentation from ALK, Diater, GSK and Leti. M.V.O. is chair of the Adolescent Working Group of the Spanish Society of Paediatric Allergy, Asthma and Clinical Immunology. Q.Y. serves on the medical advisory board for the FPIES Foundation, the scientific advisory boards for the Pareto Bio and the Infanant Health. Q.Y. has received funding from the Food Allergy Science Initiative (FASI). The rest of the authors declare that they have no relevant conflicts of interest.

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TABLE E1. Demographic and clinical characteristics, and rating of satisfaction with care received and impact of FPIES on well-being and family life in children (n = 264) and adult individuals (n = 32) with FPIES reported in the survey

Demographic and clinical characteristics	Entire sample (n = 296)	Children (n = 264)	Adults (n = 32)	P value
Respondent's age (y), mean $\pm$ SD	36.9 $\pm$ 8.2	36.5 $\pm$ 7.8	40.4 $\pm$ 10.7	>.05*
Respondent's sex: female, n (%)	279 (94.3)	253 (95.8)	26 (81.3)	.012†
Patient's current age (y), mean $\pm$ SD	6.8 $\pm$ 10.9	4 $\pm$ 3.3	41.1 $\pm$ 12.8	
Patient's age at FPIES onset (y), mean $\pm$ SD	1.8 $\pm$ 6.7	0.4 $\pm$ 0.5	19.1 $\pm$ 16.6	>.05*
Presenting phenotype, n (%)				>.05‡
Acute FPIES	135 (45.6)	120 (45.5)	15 (46.9)	
Chronic gut symptoms	18 (6.1)	13 (4.9)	5 (15.6)	
Acute FPIES + chronic gut symptoms	145 (49)	131 (49.6)	12 (37.5)	
Foods causing FPIES				
Single-food FPIES, n (%)	71 (24)	62 (23.5)	9 (28.1)	>.05†
Multiple-food FPIES, n (%)	225 (76)	202 (76.5)	23 (71.9)	
No. of culprit foods, median (IQR)	2 (1-4)	2 (1-5)	1 (1-2)	.002§
Specific culprit foods causing FPIES, n (%)				
Cow's milk	161 (54.4)	147 (55.7)	14 (43.8)	>.05†
Soya	104 (35.1)	99 (37.5)	5 (15.6)	>.05†
Gluten	58 (19.6)	56 (21.2)	2 (6.3)	>.05†
Nongluten grains	156 (52.7)	151 (57.2)	5 (15.6)	.003†
Vegetables	91 (30.7)	86 (32.6)	5 (15.6)	>.05†
Fruits	97 (32.8)	93 (35.2)	4 (12.5)	>.05†
Egg	73 (24.7)	70 (26.5)	3 (9.4)	>.05†
Shellfish	25 (8.4)	18 (6.8)	7 (21.9)	>.05†
Other	93 (31.4)	86 (32.6)	7 (21.9)	>.05†
Hospital admission due to FPIES, n (%)				>.05‡
Yes	106 (35.8)	97 (36.7)	9 (28.1)	
No	187 (63.2)	167 (63.3)	20 (62.5)	
Unsure	3 (1)	0 (0)	3 (9.4)	
FPIES "outgrown," n (%)				>.05‡
Yes	24 (8.1)	21 (8.0)	3 (9.4)	
No	199 (67.2)	172 (65.2)	27 (84.4)	
Unsure	73 (24.7)	71 (26.9)	2 (6.3)	
Allergic comorbidities, n (%)				
Other food allergies	77 (26)	70 (26.5)	7 (21.9)	>.05‡
Asthma	51 (17.2)	42 (15.9)	9 (28.1)	>.05‡
Rhinitis	50 (16.9)	38 (14.4)	12 (37.5)	>.05‡
Atopic dermatitis	79 (26.7)	70 (26.5)	9 (28.1)	>.05‡
No. of allergic comorbidities, median(IQR)	1 (0-1)	1 (0-1)	1 (0-2)	>.05§
HCP involvement, n (%)				
Primary care	155 (52.4)	138 (52.3)	17 (53.1)	>.05†
Emergency department	146 (49.3)	135 (51.1)	11 (34.4)	.01†
General pediatrician	151 (51)	147 (55.7)	4 (12.5)	.003†
Allergist/pediatric allergist	230 (77.7)	224 (84.8)	6 (18.8)	<.001†
Gastroenterologist/pediatric gastroenterologist	161 (54.4)	154 (58.3)	7 (21.9)	.011†
Dietitian	147 (49.7)	138 (52.3)	9 (28.1)	<.001†
Other	43 (14.5)	32 (12.1)	11 (34.4)	>.05†
No. of HCPs involved, mean $\pm$ SD	3.5 $\pm$ 2.0	3.7 $\pm$ 1.9	2.1 $\pm$ 1.9	<.001§
Satisfaction with care and impact on life				
Satisfaction with allergy or gastro specialist¶ (1-6), mean $\pm$ SD	4.1 $\pm$ 1.7	4.2 $\pm$ 1.6	2.7 $\pm$ 1.8	.001‡
Satisfaction with nonspecialist¶ (1-6), mean $\pm$ SD	3.5 $\pm$ 1.7	3.5 $\pm$ 1.7	2.3 $\pm$ 1.5	>.05‡
Satisfaction with FPIES Foundation¶ (1-5), mean $\pm$ SD	4.1 $\pm$ 1	4.1 $\pm$ 0.9	3.4 $\pm$ 1.2	>.05‡
Impact on family life# (1-5), mean $\pm$ SD	2 $\pm$ 1	1.9 $\pm$ 0.9	2.7 $\pm$ 1.3	.002‡
Impact on patient's well-being# (1-5), mean $\pm$ SD	2.4 $\pm$ 1.1	2.4 $\pm$ 1.1	2.7 $\pm$ 1.1	.044‡

	Entire sample	Parents/carers	Adults (nonparents)	
Ratings of potential unmet needs (1-9)** (mean ± SD)	(n = 296)	(n = 253)	(n = 21)	P value
Q1: Diagnostic test acutely	8.04 ± 1.63	8.04 ± 1.63	7.95 ± 1.9	>.05†
Q2: Predictive test (resolution)	8.40 ± 1.19	8.45 ± 1.1	7.67 ± 1.85	.034‡
Q3: Predictive test (safe foods)	8.40 ± 1.20	8.41 ± 1.16	8 ± 1.7	>.05†
Q4: HCP knowledge	8.71 ± 0.91	8.74 ± 0.83	8.19 ± 1.63	.003‡
Q5: Medical students knowledge	8.51 ± 1.14	8.53 ± 1.1	8.19 ± 1.57	.044‡
Q6: Care plan	7.88 ± 1.79	7.87 ± 1.83	7.71 ± 1.7	>.05†
Q7: Community knowledge	7.85 ± 1.39	7.87 ± 1.38	7.43 ± 1.69	>.05†
Q8: List of specialist centers	7.94 ± 1.45	7.95 ± 1.4	7.71 ± 1.8	>.05†
Q9: Access to food challenges	7.55 ± 1.94	7.53 ± 1.93	7.29 ± 2.39	>.05†
Q10: Guidelines for challenges	7.38 ± 2.18	7.35 ± 2.15	7.29 ± 2.9	>.05†
Q11: Access to dietitian	7.56 ± 1.81	7.56 ± 1.83	7.67 ± 1.7	>.05†
Q12: Access to psychologist	5.78 ± 2.48	5.63 ± 2.54	7 ± 1.79	>.05†
Q13: Peer support	7.02 ± 1.73	7.03 ± 1.69	6.67 ± 2.4	.043‡
Q14: Expert for questions	7.26 ± 1.56	7.24 ± 1.52	7.29 ± 2.3	>.05†
Q15: Psychological support	6.60 ± 2	6.55 ± 2.04	6.67 ± 1.9	>.05†
Q16: Online peer forum	6.89 ± 1.89	6.94 ± 1.84	6.14 ± 2.6	.04‡
Q17: Research on burden	7.26 ± 1.82	7.26 ± 1.82	6.86 ± 2	.038‡
Q18: Peer support on financial aspects	6.94 ± 1.97	6.94 ± 1.97	6.48 ± 2.2	>.05†
Q19: Resources for school age	6.90 ± 2.18	6.89 ± 2.17	6.19 ± 2.5	>.05†
Q20: Research for school age	7.08 ± 2.09	7.1 ± 2.06	6.76 ± 2.3	>.05†

HCP, Health care professional; IQR, interquartile range.

*t test used for comparative analysis.

†Fisher test used for comparative analysis.

‡χ² test used for comparative analysis.

§Mann-Whitney U test used for comparative analysis.

||Scale 1-6 from “very dissatisfied” (1) to “very satisfied” (6).

¶Scale 1-5 from “Not at all helpful” (1) to “Extremely helpful” (5).

#Scale 1-5 from “Extremely affected” (1) to “Not at all affected” (5).

**Scale from 1 (“not essential”) to 9 (“absolutely essential”).