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**Title:** APPEAL-1: A multiple country European survey assessing the psychosocial impact of peanut allergy

**Short Title:** APPEAL-1: Psychosocial impact of peanut allergy

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## ABSTRACT

### Background

Peanut allergy (PA) is a common, potentially life-threatening, and typically lifelong condition with a significant burden of illness. However, information is lacking on how persons with PA (PwPA) and their caregivers perceive the psychosocial impact of living with PA. The Allergy to Peanuts imPacting Emotions And Life study 1 (APPEAL-1) survey, conducted across Europe, investigated the experience and impact of living with PA. Here, we report data evaluating the psychosocial impact of PA on PwPA and their caregivers.

### Methods

APPEAL-1 was an online survey conducted in 8 European countries. Representatives of 8 patient advocacy groups and 5 healthcare-research specialists developed the survey. Eligible respondent groups included: adults diagnosed with PA (self-report); parent/nonparent caregivers (proxy-report for a child with PA); and parent/nonparent caregivers (self-report of PA impact on themselves).

### Results

Of 1846 total study respondents, 419 were adults with PA (self-report); 546 were parents/ caregivers (proxy-report) ; 881 were parents/caregivers (self-report). Most respondents reported lifestyle restrictions regarding food (84-93%) and additional domains including parties and socializing, holiday activities and destinations, and taking public transport (53-89%). Approximately 40% rated themselves as “very” frustrated and “very” stressed. Two-thirds (65%) felt socially isolated; 43% were bullied. Less than half felt confident in knowing when to use an adrenaline autoinjector. Several intercountry differences were observed such as high levels of uncertainty and stress in respondents from Ireland, highest rates of anxiety in respondents from Germany, and social exclusion and isolation most common in respondents from France.

**Conclusions**

PA imposes an adverse psychosocial impact on patients and caregivers, leading to frustration, stress, and isolation. Attention to the impact of PA is needed in research and clinical practice to improve PA healthcare and public education programs.

**Keywords:** Bullying, coping, daily life, peanut allergy, psychosocial impacts.

## INTRODUCTION

Peanut allergy (PA) is typically a lifelong and potentially life-threatening condition with an estimated prevalence of up to 2.8% of the general population in Europe.[1-3] A 2- to 3-fold increase in diagnosed PA over the last 2-3 decades has also been reported in the UK and US, although the reasons behind these rising prevalence rates remain unclear.[4,5] In most cases, PA persists into adulthood,[6-9] while allergies to milk, egg, wheat, and soy often resolve during childhood.[1] PA is also associated with higher rates of accidental exposures, severe reactions, and anaphylaxis than are other food allergies.[10-16] Most persons with PA (PwPA) have one or more comorbid nonfood atopic diseases (e.g. atopic dermatitis, asthma) and/or other food allergies.[17,18]

Standard of care for PA is the avoidance of peanut and use of rescue medication in cases of accidental exposures.[19-21] However, dietary avoidance itself can be a major source of anxiety, stress, uncertainty, and activity restrictions.[22-24] When allergic reactions occur, those having the reaction, parents, and healthcare professionals (HCPs) tend to underutilise adrenaline autoinjectors (AAIs)[25-28] in part because of confusion and misconceptions on exactly how and when they should be used.[26,29] This reinforces uncertainty regarding correct management, increases stress and may substantially impair health-related quality of life (HRQL).[30]

Although previous studies have shown that PA adversely impacts HRQL for PwPA and the parents/caregivers of children with PA,[20,22,31-33] many questions remain. These include understanding how individuals and families experience daily life with this condition and how they perceive current healthcare management of PA. Furthermore, there is little research on the psychosocial factors impacting HRQL associated with PA. Individual countries may have varying prevalence and awareness of PA, differing social attitudes towards it, and varying support systems for PwPA, in addition to the variety of healthcare systems across countries that can influence care for PwPA. These factors suggest that potentially important differences may exist in the impact of PA across countries and should be investigated.

The APPEAL-1 (**A**llergy to **P**eanuts Im**P**acting **E**motions **A**nd **L**ife 1) study was conducted to comprehensively assess the impact of living with PA on caregivers and PwPA across 8 countries in Europe. In this second of two articles describing the results of APPEAL-1, we report data collected directly to understand the psychosocial and HRQL impact of PA on PwPA and their caregivers. The data relating to the circumstances of diagnosis, severity of symptoms, comorbidities, management, and other clinical factors captured by APPEAL-1 are reported in an independent article published in this issue of *Allergy*.

# METHODS

## Study design

The design and methods used in developing the APPEAL-1 study and the survey are fully described in a companion paper appearing in this issue of *Allergy.* In brief, APPEAL-1 is a quantitative, cross-sectional, multidimensional, online survey study conducted in 8 European countries (Denmark, France, Germany, Ireland, Italy, the Netherlands, Spain, and the UK). The question items that make up the survey address key areas of concern (refer to survey format below) for PwPA and their caregivers, based on previous research in the field. Given that the range of topics planned for this study (from symptoms through to bullying and daily management) was far wider than is captured by any existing measure quality-of-life measure, it was decided to develop a novel, study-specific survey instrument. A formal scoping exercise with a broad range of stakeholders was implemented to ensure that goals and questions for this survey instrument were relevant. Representatives of 8 patient advocacy groups (PAGs) and a specialist panel, comprised of a mix of 5 specialists from various healthcare research fields, collaborated to develop the study and the questionnaire. The 30-minute survey was originally written in English and translated/back-translated into 6 other languages, including Danish, Dutch, French, German, Italian, and Spanish; all language versions were reviewed by the PAG representatives and piloted in test respondent samples. Ethical approval for this study was obtained from the Freiburg Ethics Commission International (Universitätsklinikum Freiburg; https://www.uniklinik-freiburg.de/ethics-commission.html).

## Respondent population

Participants were recruited via the PAGs or through a professional recruitment service for research studies. Two categories of participants reported on their own behalf (self-report): (i) adults with PA, and (ii) parent and nonparent caregivers who reported the impact of PA on themselves as caregivers. With regard to category ii, these parents/caregivers, hereafter referred to in this report as “caregivers”, were also invited to report the impact of PA on behalf of the individual for whom they were caring (proxy-report). Therefore, the total number of respondents exceeded the total number of participants.

### *Study inclusion/exclusion criteria*

Requirements for respondents recruited via PAGs:

- self- or caregiver-reported diagnosis of PA,
- 18 years of age or older,
- resident of one of the 8 designated countries, and
- able to provide informed consent, by self or by caregiver/proxy.

Exclusions for respondents recruited via the professional recruitment service:

- Participation in a market research study of PA during the previous 2 months
- Membership in a PAG

## Survey content and format

The survey consisted of questions in 4 main sections: (1) screening/inclusion criteria; (2) PA respondent characteristics and clinical history, including PA diagnosis and allergic reaction history, other concomitant allergies and medical conditions, and use of emergency medication; (3) psychosocial impact of PA (restrictions on choice, coping with/managing PA, relating to others, feelings and emotions); and (4) respondent sociodemographic information. The results for sections 2 (clinical history/characteristics) and 4 (sociodemographic data) are summarised in the paired report, which appears in this issue of *Allergy*. In section 3, in addition to rating their responses on a 5-point scale, respondents were given the opportunity to add free-text comments.

## Data analysis

Demographic, clinical, and survey response data were reported with descriptive statistics. Data were assessed with regard to: (1) total population (i.e. all countries and all respondent types); (2) individual country; and (3) respondent type (adults with PA [self-report], children with PA [proxy-report by caregivers], caregivers [self-report]).

# RESULTS

## Survey respondent population

The total study population was 1846 respondents, comprising 419 adults with PA (self-report), 546 caregivers who answered for the child with PA (caregiver proxy-report), and 881 caregivers of a child with PA, who answered regarding the impact of PA on themselves. The demographic and clinical characteristics and PA history of the study population are described in the companion report in this issue of *Allergy*.

## Impacts of PA on psychosocial parameters and quality of life

### *Restrictions on choice*

Restrictions on choice were reported by respondents in a wide range of contexts using a scale of "not at all," "a little," "moderately," "very," or "extremely" restricted and "don't know/not applicable." Most respondents reported that they felt restricted (rating ≥2) in choosing: where to eat out (89%, including who felt 58% "very" or "extremely" restricted); food options when eating out (94%; 62% "very" or "extremely"); shops where they can buy food (79%; 29% "very" or "extremely"); and buying food (84%; 38% "very" or "extremely") (**Figure 1**). Furthermore, respondents reported that they felt restricted in choices *not* directly related to food, such as choice of schools (55%), job options (37%), socialising (75%), and going to special occasions (89%) (**Figure 1**). A large majority (87%) said extra planning was needed for managing PA for "daily activities" and 89% said extra planning was needed for "special activities". When asked to rate their HRQL because of having to make extra plans, on a scale of 1 to 5 (where 1=excellent and 5=poor)[34], only 16% rated it as "excellent," although even fewer (3%) rated it "poor." Examples of the need for planning for PA as described by respondents are given in **Table 1**.

### *Feelings and emotions*

The psychological impact of PA was clearly evident in our findings. Respondents reported experiencing negative feelings and emotions due to the impact of PA on their lives on of 1 ("not at all," "rarely," or "extremely low") to 5 ("very" or "extremely"). Large majorities of respondents stated that PA impacts their daily activities (scores ≥2; 86%), 90% were frustrated, with 12%

"extremely frustrated" due to living with PA.With regard to frequency of these feelings, 91% of respondents were at least "somewhat frequently" frustrated (14% "very frequently"). Many respondents (89%) also stated they felt at least "some" uncertainty, and 90% reported feeling stress, with 40% at the upper end of the scale (i.e. scores of 4 or 5) for uncertainty and stress. Anxiety played a central role in the lives of a great number of respondents, with more than one-third of respondents reporting that they frequently (score of 4 or 5) felt anxious (36%) or frequently felt tense (30%). Only one-third (34%) rarely felt that "nothing bad will happen"; 30% stated they rarely felt calm (i.e. scores of 1 or 2).

With regard to specific contexts or settings, 92% of respondents said they worry about exposure to peanut on social occasions where food *is* involved, and more than half (54%) worry during occasions where food is *not* involved. Respondents worried about exposure to peanut in multiple other settings including at school/college/university (71%); on holiday (84%); on public transport (58%); and at hospital (60%).

### *Exclusion, isolation and bullying due to PA*

Difference, isolation, exclusion and bullying are feelings and behaviours that are part of everyday life for PwPA. More than three-quarters of respondents (77%) reported they had "been made to feel different" ("frequently" to "rarely") in a negative way because of PA, with 35% experiencing this frequently. Approximately two-thirds (65%) had experienced general feelings of isolation (23% "quite" or "very" frequently). Almost half of respondents (43%) said they had been excluded from social occasions where food *was* involved; 13% reported exclusion even where food *was not* involved (**Figure 2**). Of those who had been bullied (n=558; 43% of respondents), 10% said they experienced this behaviour frequently. Approximately one-third of respondents (both self- and proxy-reporting) described the impact of the bullying as severe (score of 4 or 5 on a 5-point scale) (**Figure 3**). A representative description of the social restrictions and impacts caused by PA is given in Quote 2 in **Table 1**.

### *Coping with PA*

The psychological impacts of PA presented above can influence the subjective experience of living with a condition, which can have a significant impact on psychological adjustment or coping and a major impact on chronic disease health outcomes.[35] Almost half of all respondents (45%) said they did not cope well when PA was first diagnosed (score of 4 or 5, where 1 is "extremely well" and 5 is "not at all well") (**Figure 4**). However, three-quarters of respondents (74%) said they now cope well with PA compared to how they did at diagnosis (score of 1 or 2) (**Figure 4**), implying an improvement over time in coping ability. Two-thirds of respondents (65%) said they were confident (score of 1 or 2, where 1 is "extremely confident") in their ability to recognise the symptoms of an allergic reaction, and 72% reported confidence in their ability to describe their symptoms to an HCP. However, rates of confidence were lower for knowing *when* to use an AAI (45%) and *how* to use one (59%). Potentially related to this finding, 87% worried about not having access to emergency services in case of peanut exposure. While 70% "would feel more anxious if they forgot to carry the AAI," 62% reported carrying their AAI with them "all the time." Quote 3 in **Table 1** describes a typical planning regimen for people with PA.

### *Understanding of PA among family, friends, and others*

Public knowledge and attitudes, sociocultural values, and interpersonal relationships are known to impact HRQL in chronic disease.[36] Respondents were asked to rate statements about how their family, friends, and other people understand and perceive an individual's PA, on a scale of 1 ("most true") to 5 ("least true") (**Figure 5**). Respondents gave both family and friends a mean score of "most true" for "*They have good awareness and understanding of peanut allergy,"* but said this was "least true" for other people. In scoring for *"They tend to be oblivious about the dangers of peanut allergy,"* respondents said this was "most true" of friends and other people. Yet respondents gave all categories of people (family, friends, other people) similar, moderate scores for "*They feel awkward when making allowances for peanut allergy"* and *"They believe there is too much concern over peanut allergy."* These findings are likely to reflect different categories of friends.

Respondents stated that they found it easiest ("always" easy) to discuss the impact of living with PA with HCPs, followed in order by family, friends, school teachers, and work colleagues. Yet, 25% of respondents stated they “rarely,” “very rarely,” or did not find it easy to discuss the impact of living with PA with their family, and 30% said they “rarely,” “very rarely,” or did not feel that way towards their friends (**Figure 6**). Only 5% of respondents said they were not at all confident when talking to new people about their PA, while 65% were either very confident (27%) or extremely confident (38%). Respondents gave both family and friends a mean score of “most true” for “*They have good awareness and understanding of peanut allergy,”* but said this was “least true” for other people. In scoring for *“They tend to be oblivious about the dangers of peanut allergy,”* respondents said this was “most true” of friends and other people. These findings suggest that although they are confident in their knowledge of PA and thus can discuss it if required, respondents were reluctant to do so, perhaps because of uncertainty about public attitudes (in general) to PA.[37] Quote 4 in **Table 1** briefly illustrates the kind of experience that people with PA and their caregivers may have with others.

### *Intercountry comparisons*

Although findings may reflect a response bias as well as differences in the recruiting process (e.g. age of respondents, recruitment through PAG versus the professional recruitment service), there were some differences in the patterns of responses among countries. In terms of reported restrictions on activities, the proportion of respondents found to have a “high level” of uncertainty and a “high level” of stress in Ireland (61% and 54%, respectively) was almost twice that of the Netherlands (31% and 26%, respectively). Respondents in Germany had the highest rates of frequently feeling anxious and rarely feeling calm (52% and 44%, respectively), while the Netherlands had the lowest rates for these responses (16% and 13%, respectively).

In Germany, 90% reported at least some restrictions for socialising and 86% for choice of holiday destinations, compared with 69% and 71%, respectively, of respondents in Italy reporting these restrictions. Feelings of social exclusion and isolation were most common in France where 86% of respondents reported that they had been made to feel different in a negative way versus 66% in Italy, and 74% of respondents from France reported feelings of isolation versus only 44% in Denmark. Rates of reported bullying ranged from 52% in the UK to 32% in Spain.

With regard to coping with PA at first diagnosis, more than one-quarter of respondents in Germany (29%) said they coped “not at all well” versus 9% of respondents in Denmark. The percentage of respondents who said they now cope “extremely well” with PA, compared to when it was first diagnosed, was highest in Denmark (55%) and lowest in Spain (20%). The Netherlands had the highest rates of respondents who were “extremely confident” in their ability to recognise allergic reaction symptoms (39%) and in knowing *when* and *how* to use an AAI (26% and 53%, respectively). In contrast, Germany had the lowest rates of respondents who were “extremely confident” in recognising allergic reaction symptoms (22%) and knowing *when* to use an AAI (12%, along with Denmark). France had the lowest rate of knowing *how* to use an AAI (14%).

See Supporting Materials for a video of results from APPEAL-1.

# DISCUSSION

APPEAL-1 is the first multidimensional, pan-European online survey study specifically designed to uncover the psychosocial burden of PA on the lives of both individuals and their families. The study was designed to provide a comprehensive examination of psychosocial health and quality of life, including novel aspects of emotional functioning and impact due to the impact of PA (frustration, anxiety, stress, isolation, and uncertainty). Furthermore, our findings showed that the experience of being bullied was prevalent among both children, as indicated in previous studies in children with food allergies including PA, [38-40]and adults. In addition to the biologically determined nature of PA itself, a variety of internal and external factors can influence the subjective patient and caregiver experience, which, in turn, can have a significant impact on coping outcomes.

Our findings showed that those living with PA not only face many restrictions on choice in their activities, but experience feelings of frustration, anxiety, stress, isolation, and uncertainty in their everyday lives. The APPEAL-1 findings are consistent with, and extend, our knowledge of the impact of food allergy in general and of PA in particular.[22,23,32,33,41] The findings also reveal a high unmet need for greater support, information, and education for allergic individuals and for the general public in living with and managing PA, and food allergies in general. For example, 40% of respondents said that they live with a high level of uncertainty, and 36% said that they rarely or never experience "the feeling that nothing bad will happen." Smaller sample and qualitative studies have previously shown that uncertainty and related anxiety, stress, and frustration are central themes in living with PA.[31,33,42,43] The identification and treatment of psychological issues impacting management, confidence, and quality of life should be seen as a priority and should be addressed by HCPs in coordination with governmental and nongovernmental organisations (such as PAGS).

The APPEAL-1 study also presents evidence of the problem across Europe of low confidence (and knowledge) in how and when to use an AAI. Our findings are consistent with global data showing unmet patient needs for AAI use training and anaphylaxis management across food and nonfood allergens.[44] Approximately one-third of respondents in the APPEAL-1 study were not "very confident" about recognising symptoms related to an allergic reaction, and less than half were "very confident" in knowing when to use an AAI. These findings add value to previous findings. A qualitative single-center study, for example, found that among 17 participating parents of children with anaphylactic reactions to peanut, almost all said that, at diagnosis of their child's PA, they had been given insufficient information on using an AAI.[42] Respondents also reported that the general population (people outside their circle of family and friends) have a poor understanding of PA.

Although responses were consistent across countries with regard to the burden of peanut allergy on psychosocial issues, the study also demonstrated some cross-country differences regarding the weight and type of that impact. We note here that these differences are likely due to interactions or modifiers across variables. Here we presented only descriptive data. For example, respondents from Germany expressed the highest levels of restriction of choice in activities, yet also reported the lowest rate of frustration among the countries, suggesting that the relationship is modified by other variable(s) such as level of general awareness or acceptance. In other findings, results provide a clearer picture, for example, in the case of respondents from the Netherlands reporting the highest rate for positive coping skills and the lowest rate for anxiety and for "rarely feeling calm," together with low levels of uncertainty and stress.

The strengths of this study include the large sample size, inclusion of participants across 8 countries, the multidimensional nature of the factors measured at one time, scope, and the diversity of the respondent groups. APPEAL-1 also included a quantitative examination of some novel factors such as AAI training, which may have practical healthcare implications. Previous studies have reported differences in HRQL for food allergy among residents of different European countries.[45,46] However, APPEAL-1 also identifies differences among the 8 participating European countries in areas of healthcare management of PA, which have not been previously reported and are of key importance (See companion paper in this issue of *Allergy*).

We acknowledge also the limitations of our design. The APPEAL-1 study findings may be negatively impacted by biases related to the self-selection recruitment methods. For example, individuals interested in participating in a study of the impact of PA on their lives might be those who feel the greatest impact, while those who feel less affected might be less likely to participate. Potential biases might also have been associated with each of the 2 recruitment methods used: respondents recruited through a PAG may have been more motivated to participate for emotional reasons related to PA while those who participated through the recruitment service may have been more motivated by incentive (since financial remuneration was offered). Other limitations include the absence of randomisation, and use of self- or proxy-reported data.

APPEAL-1 is the first multidimensional, pan-European online survey study specifically designed to uncover the psychosocial burden of PA on the lives of both PwPA and their families. The findings showed a strong burden of PA on emotional and psychosocial functioning in children, adults, and caregivers. The APPEAL-1 findings deepen our knowledge and understanding of the impact of PA on everyday lives, and show the importance of raising PA awareness in the general public, increasing support for managing this condition, and supporting inclusivity of those with PA. The study also underscores the unmet needs, such as unsatisfactory training for AAI use and low confidence among PwPA who use AAIs, and provides some signposts for clinicians and policymakers on how these may be addressed. Addressing psychosocial issues and constraints that impact management, confidence, and HRQL and providing meaningful support for patients and caregivers should be seen as priorities.

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## CONFLICT OF INTEREST STATEMENT

**ADG** reports lecture honoraria/consultation fees from Aimmune Therapeutics and research support from National Children's Research Centre, Our Lady's Children's Hospital, Crumlin, Dublin 12, Ireland.

**KB** reports consulting for Aimmune Therapeutics and Raptor Pharmaceuticals GmbH; research funding from Charite and Foundation for the Treatment of Peanut Allergy Patients (both Germany), speakers bureau for Aimmune Therapeutics, HAL, Meda Pharma, Nestle, Novartis, Nutricia, Thermo Fisher Scientific; and conducting clinical trials for Aimmune Therapeutics.

**FT** is chair of the EAACI Patient Organisations Committee and member of Team APPEAL; the national patient advocacy organisation has received honoraria from Aimmune Therapeutics.

**LR**, **SS, MP**, **AS**, **PC,** and **BH** are members of Team APPEAL and their patient advocacy organisations have received honoraria from Aimmune Therapeutics.

**MF** is a member of Team APPEAL and has received honoraria from Aimmune Therapeutics for advice; honoraria from Nutricia; research funding from NIAID, NIH, UK FSA, FARE, MRC & Asthma UK Centre, UK Department of Health through NIHR, National Peanut Board, Osem.

**RP** reports consulting for Aimmune Therapeutics.

**AV, RR** are employees of Aimmune Therapeutics.

**TL** was an employee of Aimmune Therapeutics at the time of study.

**MF-R** reports consultancies for Aimmune Therapeutics, DBV, Reacta Biotech, Schreiber Foods; research funding from European Commission, MINECO and ISCIII of Spanish government; speakers bureau for ALK, Allergy Therapeutics, Diater, Fundacion SEAIC, HAL Allergy, Thermo Fisher Scientific.

**HRF** is a member of Team APPEAL and reports honorarium from Aimmune Therapeutics.

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## Figure Legends

**Figure 1** Restrictions on choice: responses to question: "How RESTRICTED do you feel…" (N=1846: all respondents)
NA, not applicable.

**Figure 2** Responses to question: "Do you think you have ever been excluded from the following because of your peanut allergy?" (N=1300: all participants [adults with PA and caregivers answering for themselves])
NA, not applicable

**Figure 3** Responses to questions: A. "How would you describe the impact ON YOU of the bullying?" (n=558; adults who said they had been bullied); B. "How would you describe the impact ON YOUR

CHILD/THE PERSON YOU LOOK AFTER of the bullying?" (n=395: caregivers who said their child had been bullied)

**Figure 4** Responses to question: "How well would you say you cope with your peanut allergy now compared to when it was FIRST identified/diagnosed?" (N=1846: all respondents)

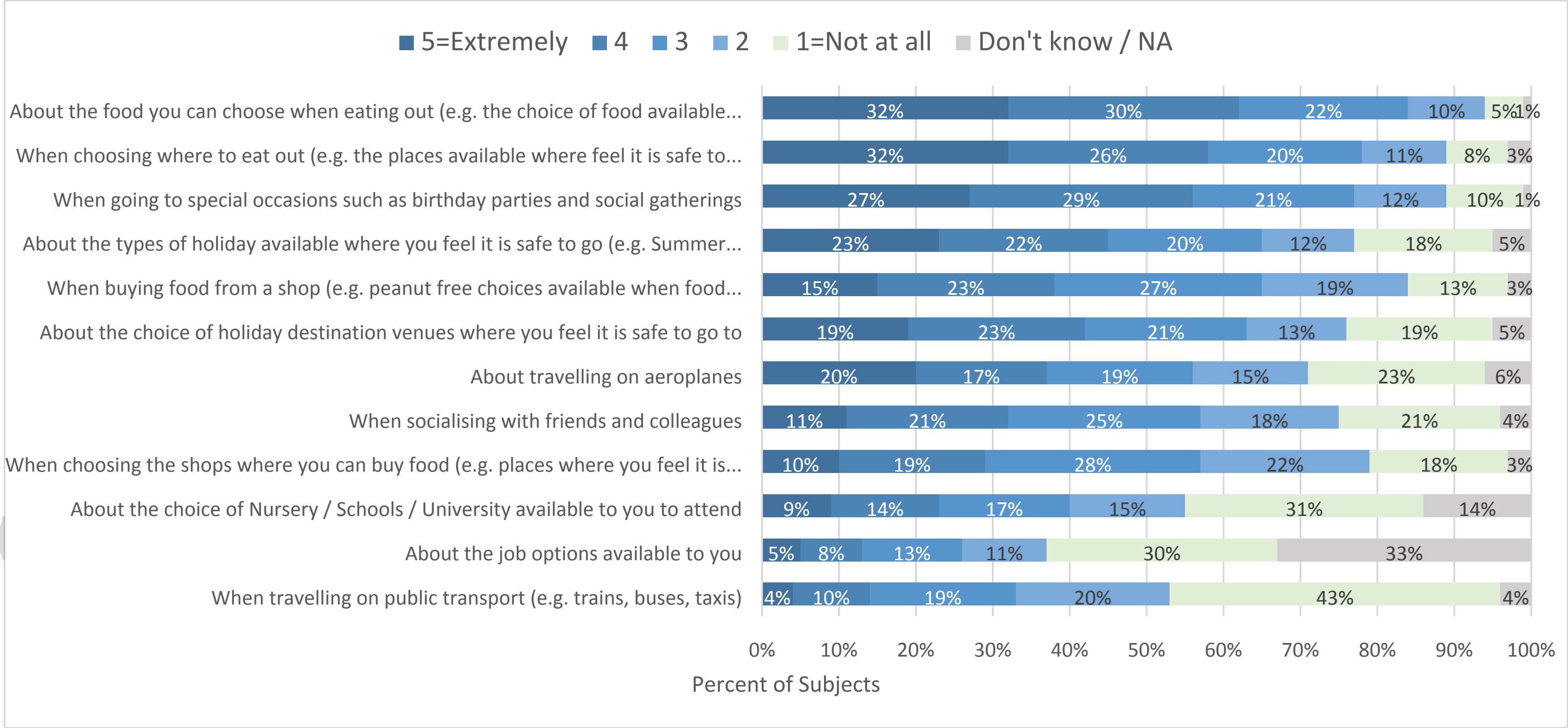
**Figure 5** Responses to question: "Thinking about your FAMILY/FRIENDS/OTHER PEOPLE: please rank the following statements in terms of what you think is most true about what they believe." (1=most true, 5=least true)

**Figure 6** Discussing the impact of living with peanut allergy: responses to the question: "Do you find it easy to openly discuss the impact of living with peanut allergy with family, friends, healthcare professionals, school teachers, and work colleagues?" (N=1846: all respondents)[a]

[a]Because of rounding, not all bars total 100%.

NA, not applicable.

**FIGURE 1**


5=Extremely
4
3
2
1=Not at all
Don't know / NA
About the food you can choose when eating out (e.g. the choice of food available...
32% 30% 22% 10% 5% 1%
When choosing where to eat out (e.g. the places available where feel it is safe to...
32% 26% 20% 11% 8% 3%
When going to special occasions such as birthday parties and social gatherings
27% 29% 21% 12% 10% 1%
About the types of holiday available where you feel it is safe to go (e.g. Summer...
23% 22% 20% 12% 18% 5%
When buying food from a shop (e.g. peanut free choices available when food...
15% 23% 27% 19% 13% 3%
About the choice of holiday destination venues where you feel it is safe to go to
19% 23% 21% 13% 19% 5%
About travelling on aeroplanes
20% 17% 19% 15% 23% 6%
When socialising with friends and colleagues
11% 21% 25% 18% 21% 4%
When choosing the shops where you can buy food (e.g. places where you feel it is...
10% 19% 28% 22% 18% 3%
About the choice of Nursery / Schools / University available to you to attend
9% 14% 17% 15% 31% 14%
About the job options available to you
5% 8% 13% 11% 30% 33%
When travelling on public transport (e.g. trains, buses, taxis)
4% 10% 19% 20% 43% 4%
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
Percent of Subjects

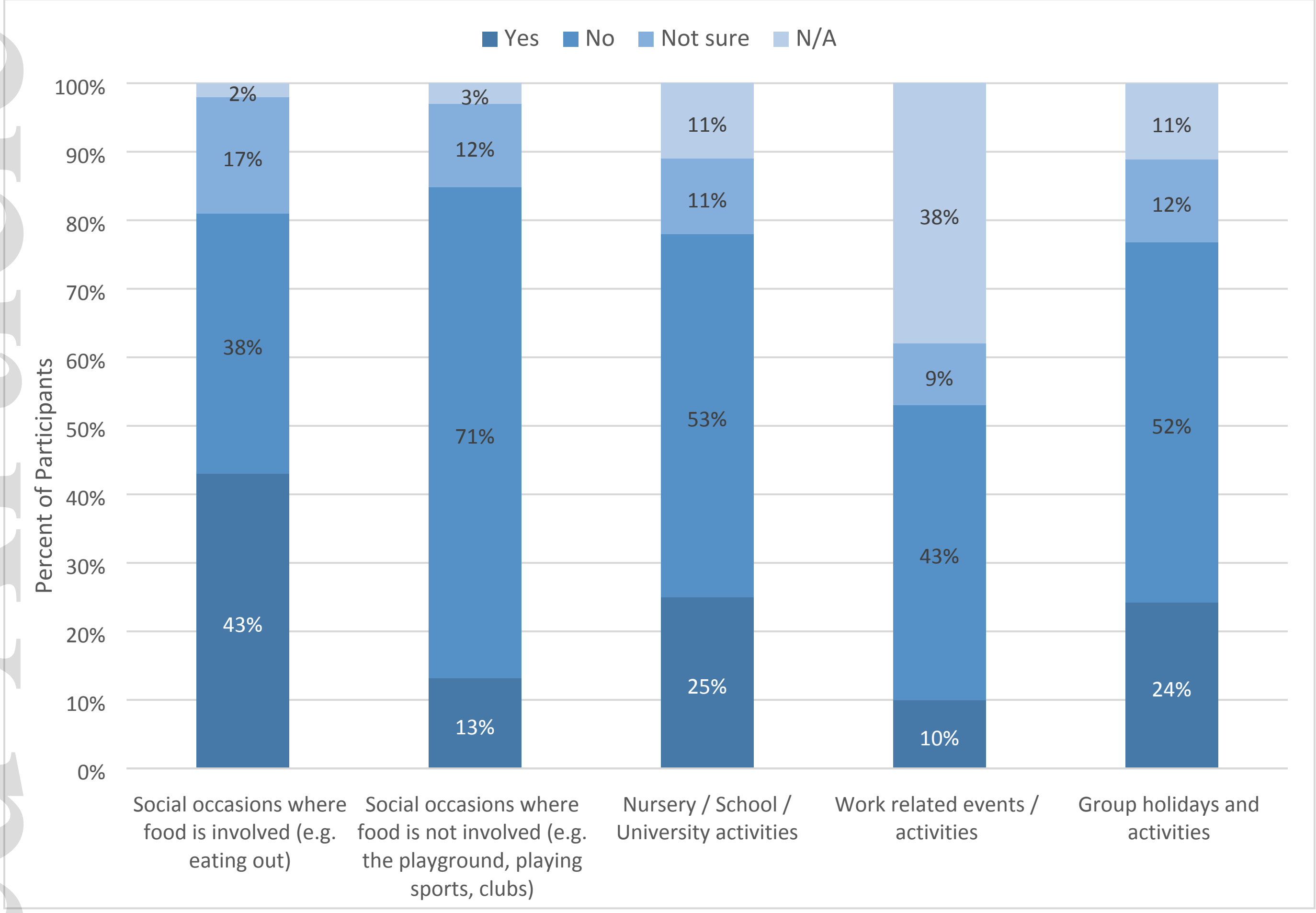
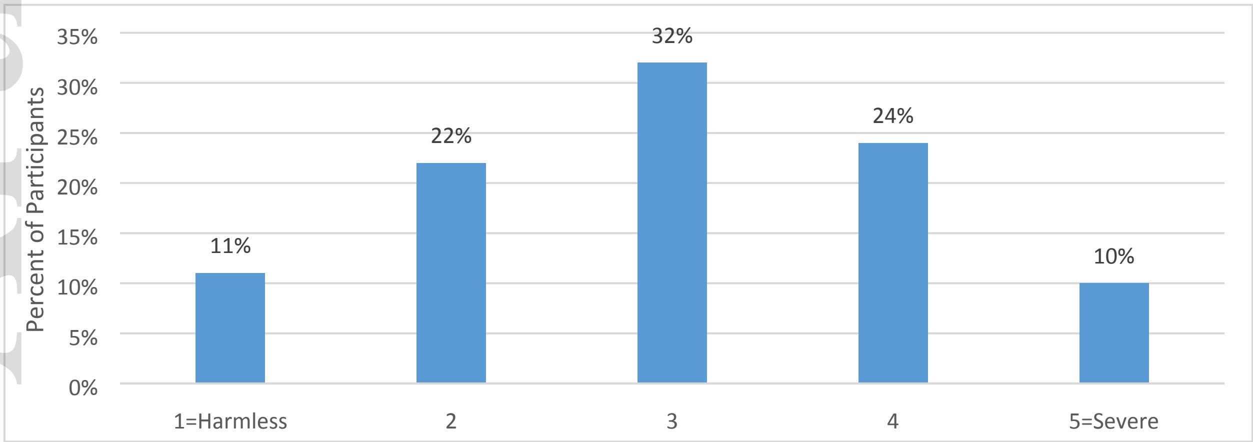

Yes
No
Not sure
N/A
Percent of Participants
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Social occasions where food is involved (e.g. eating out)
43%
38%
17%
2%
Social occasions where food is not involved (e.g. the playground, playing sports, clubs)
13%
71%
12%
3%
Nursery / School / University activities
25%
53%
11%
11%
Work related events / activities
10%
43%
9%
38%
Group holidays and activities
24%
52%
12%
11%

**Figure 2**

**A. Self-report**



**B. Proxy-report**

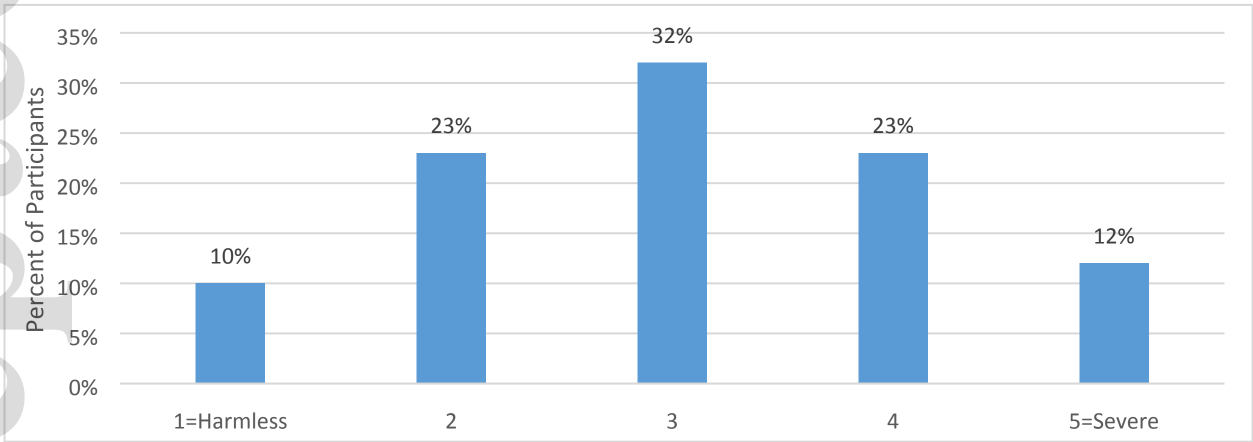


**Figure 3**

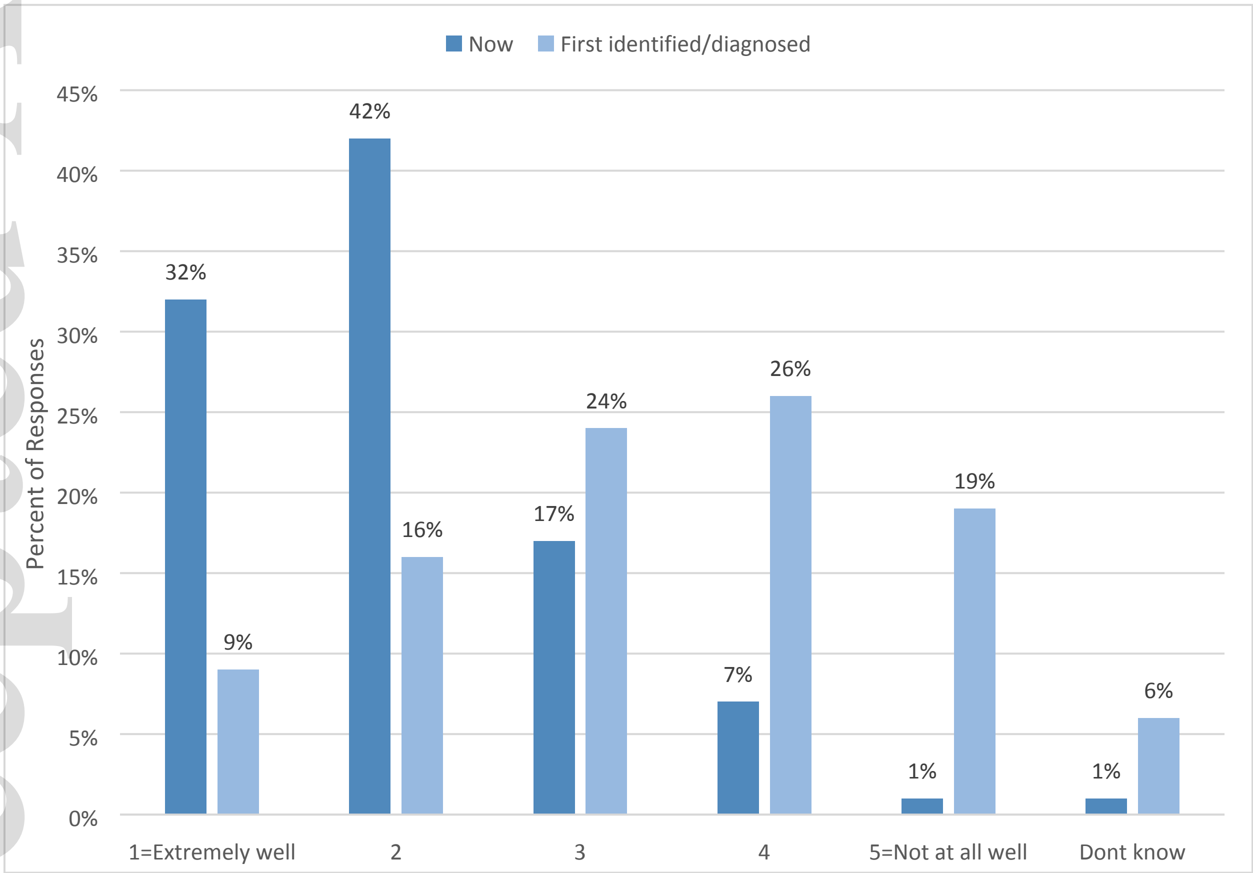
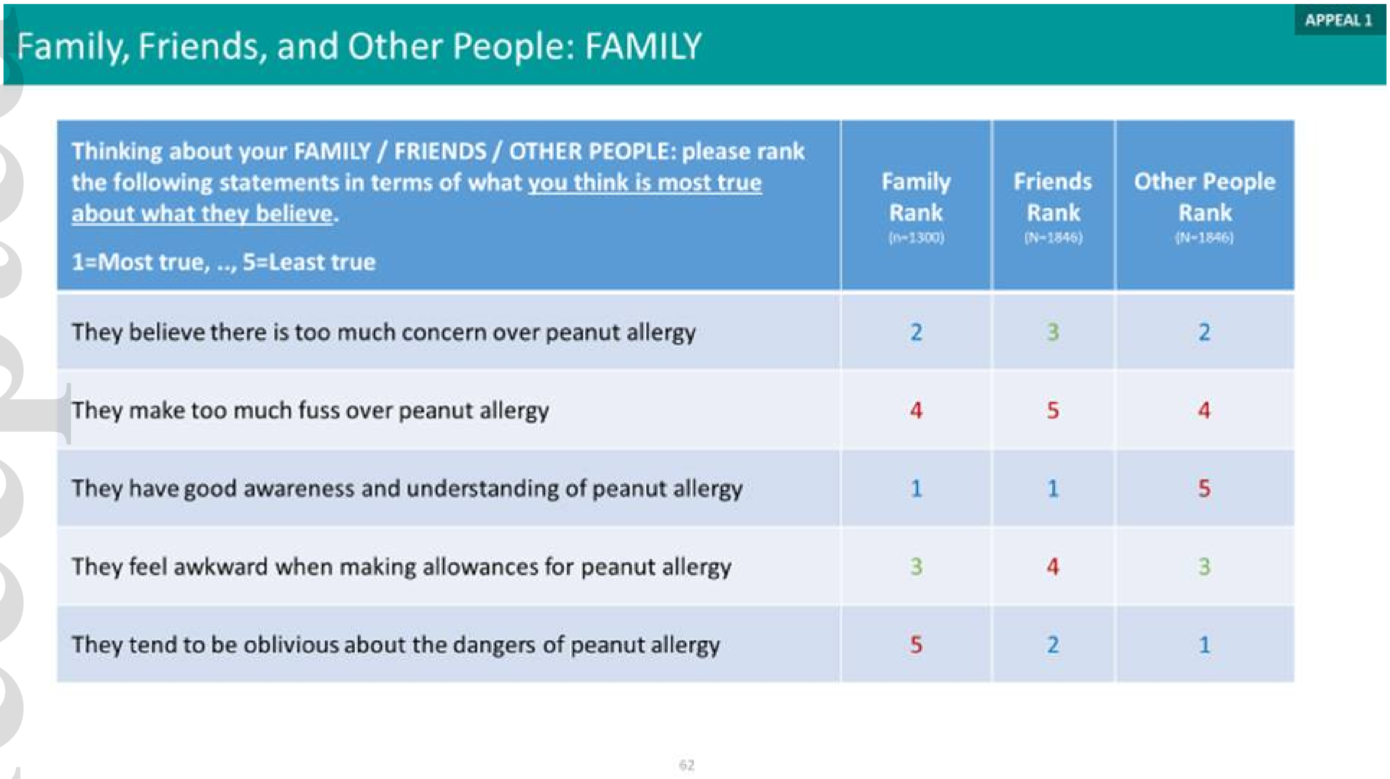

Now
First identified/diagnosed
Percent of Responses
45%
40%
35%
30%
25%
20%
15%
10%
5%
0%
32%
9%
42%
16%
17%
24%
7%
26%
1%
19%
1%
6%
1=Extremely well
2
3
4
5=Not at all well
Dont know

**Figure 4**



APPEAL 1

## Family, Friends, and Other People: FAMILY

| **Thinking about your FAMILY / FRIENDS / OTHER PEOPLE: please rank the following statements in terms of what <u>you think is most true about what they believe</u>.**<br>**1=Most true, .., 5=Least true** | **Family Rank** (n=1300) | **Friends Rank** (N=1846) | **Other People Rank** (N=1846) |
|---|---|---|---|
| They believe there is too much concern over peanut allergy | 2 | 3 | 2 |
| They make too much fuss over peanut allergy | 4 | 5 | 4 |
| They have good awareness and understanding of peanut allergy | 1 | 1 | 5 |
| They feel awkward when making allowances for peanut allergy | 3 | 4 | 3 |
| They tend to be oblivious about the dangers of peanut allergy | 5 | 2 | 1 |

**Figure 5**

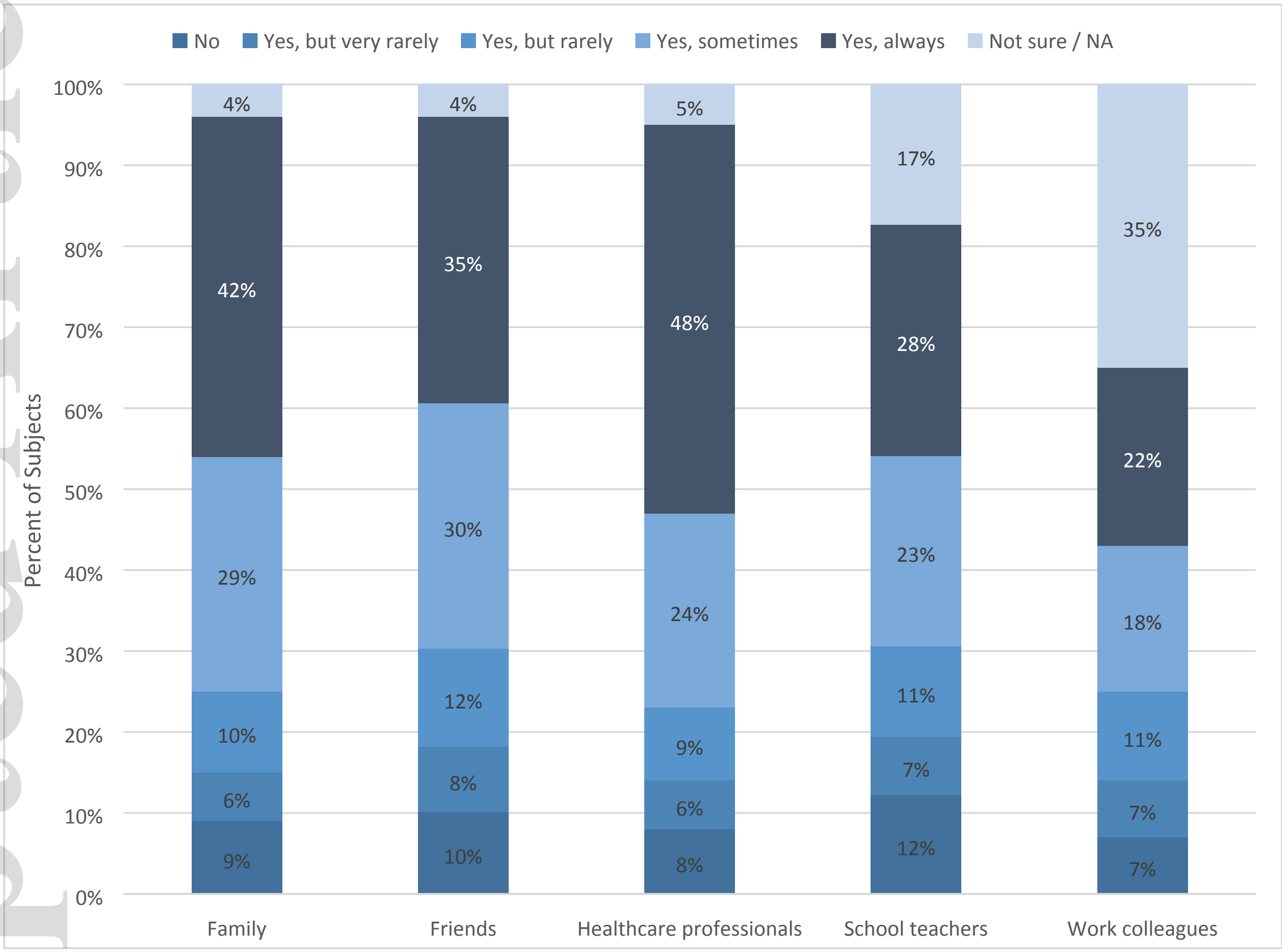


**Figure 6**

**TABLE**

**TABLE 1** In the words of survey respondents: impacts of peanut allergy on psychosocial parameters (free-text responses)

| |
|---|
| **Quote 1:** *My daughter avoids any foods if she is unsure they are safe, e.g. homemade cakes and biscuits, chocolate etc. We all carefully read packets whether it is at home or abroad and I now know the word for peanut and peanut oil etc in many different European languages so we can keep our daughter safe when we travel. However, I would not be happy to travel to Asia because of her allergy.* |
| **Quote 2**: *I don't like to go out with my friends as I never know where I can eat if it is a last-minute decision. I'm also concerned in case a boy has eaten peanuts and I don't know it and I kiss him.* |
| **Quote 3***: I have always had 2 rules: 1) Plan ahead, be firm and avoid nuts as far as possible, have EpiPen always, get son's friends to know what to do, have a care plan; and 2) See rule 1.* |
| **Quote 4***: I do find it annoying that restaurants like to "cop out." They say, "We can't guarantee that there are no nuts in the food–it's in the kitchen." I get cross and ask for the manager. I have* |

*watched as my daughter tries to handle waiters but they can be dismissive of a teenager who might then not eat with her friends. If adults are around, staff seem to be more helpful.*