

# Summary and Recommendations

## Willingness to Pay

National online surveys were conducted with adults who had a food allergy, food intolerance or coeliac disease or were parents/carers of children with one or more of those conditions.

The impact of food hypersensitivities on respondent's ( or respondents child's) health and quality of life were captured at the individual level via a number of generic and condition specific measures, including:

1. EQ5D-5L and EQ-VAS for adults
2. EQ5D-3L (proxy) and EQ-VAS for children
3. Condition-specific measures for food allergy, food intolerance and Coeliac coeliac disease for adults:
  - Food Allergy Quality of Life Questionnaire, FAQLQ (FAQLQ-PF/FAQLQ-PFT for children)
  - Food Intolerance Quality of Life Questionnaire, FIQLQ (FIQLQ-PF for children)
  - Coeliac Disease Quality of Life Questionnaire, CDQ (CCDUX for children)
4. Scoring of EQ5D-5L and EQ5D-3L (proxy) and EQ-VAS contingent upon their food hypersensitivity being removed.

These data represent the impacts of food hypersensitivities on health and quality of life. In addition, they are included in the WTP choice models to investigate if, and how, the value of removal of food hypersensitivities is affected by the severity of those conditions.

### 11.1 DCE Valuation Instrument

A stated preference valuation instrument was developed to allow estimation of WTP for a year's removal of the symptoms and limitations of a food hypersensitivity. The instrument was a DCE using a full factorial experimental design over two attributes: duration of FHS removal and cost.

A pill, taken once, was specified as the means of temporarily removing the food hypersensitivity. Attributes and their levels were represented graphically in the DCE to increase engagement and reduce cognitive load. The valuation tasks were tested and refined in five focus groups which yielded useful feedback but to a large extent validated the approach and the valuation instrument.

### 11.2 BWS Instrument

The condition-specific QoL measures (FAQLQ, FIQLQ, CDQ) comprise multiple impacts which people score, using Likert scales, to indicate how much each impact affects them. The FAQLQ, FIQLQ and CDQ indices constructed from those scores give an equal weight to each impact.

The relative importance of the impacts comprising the FAQLQ, FIQLQ and CDQ instruments were elicited by including them in a Best Worst Scaling (BWS) exercise in the survey. BWS involves presenting repeated subsets of the full set of 'items' (in this case, FHS impacts) and respondents select the impacts which have the greatest and least impact on their quality of life. The technique provides a ranking and estimates of how much more or less important those quality of life impacts are.

## 11.3 DCE Results

The extent to which respondents reject the premise of the valuation task is an important indicator of the validity of the valuation instrument and the economic values derived from it.

We find low levels of protest behaviour for those who complete the DCE choice sets. There are, however, larger numbers who decline even free removal of their FHS for periods up to 20 years and hence were not presented with DCE choice sets. These people require longer periods (> 20 years) of temporary removal, or permanent removal, or would decline even permanent removal of their (child's) food hypersensitivity. This is a new and important research finding.

For all conditions and in aggregate, for both Adult and Child models, we find statistically significant effects of duration of FHS removal and cost of removal on choice probabilities – this is consistent with most people making the trade-offs envisaged when designing the DCE.

Based on the analysis of the DCE results, the average WTP for the removal of an adult's FHS for a year, pooled across all conditions was £718. For models estimated separately by condition, the WTP values for food allergy, Coeliac coeliac disease and food intolerance were £1064, £1342 and £540 respectively.

Statistical tests were conducted to identify whether self-assessments of FHS impact (FAQLQ, FIQLQ, CDQ) affected WTP. In the adult allergy and intolerance models we find robust evidence of effects of condition severity on WTP – the higher people's FAQLQ and FIQLQ scores, the more they are willing to pay to remove their food hypersensitivity.

In these adult food allergy and food intolerance models the WTP values were only significantly different from zero when the condition severities (FAQLQ and FIQLQ scores) are sufficiently severe. For both conditions, the WTP estimates are significantly different from zero at the median FAQLQ and FIQLQ scores.

In contrast to the food allergy and food intolerance results, no effect of variation in the CDQ score on WTP to remove the condition was identified in the adult Coeliac coeliac disease sample.

The DCE choice tasks offered, at a cost, FHS removal for various durations (1 to 20 years). This was in part required because the focus groups indicated that a significant minority of people with a FHS would decline a single year of removal of their FHS, because of the 'cost' of having to adjust to their FHS returning one year later. The use of varying durations of FHS removal permitted testing for non-linearity in the value of additional years of FHS-absence.

These tests in the choice models estimated on the DCE data indicated that the value of additional years without the FHS declined in the adult Coeliac coeliac and Allergy models. There was no decline in the value of additional years in the adult food Intolerance model. The decline in the value of additional years free of their FHS could be the result of declining marginal utility or positive discount rates, or both.

In models estimated on DCE data from parents regarding their children's FHS conditions, the WTP values were: £27662902 for food allergy; £162811 for coeliac disease; £168995 for food intolerance. Parents' WTP for children with a food allergy is significantly higher than the case for

the other two conditions – this ordering is intuitive given the potentially fatal impacts of an allergic reaction.

**Table 11.1. WTP Results, in Aggregate and by Condition, for Adults and Children**

Models	Type of condition	WTP, Adults (£/year)	WTP, Children (£/year)
Aggregate Models	-	718	2501
Models by condition	Allergy	1064	2766
Models by condition	Coeliac	1342	1628
Models by condition	Condition	540	1689

The WTP for removal of a child's condition is greater than the corresponding WTP values for adults, in aggregate and for the 3 conditions separately, by a factor of between 1.2 and 3.1.

These differences in magnitude do not mean that the impacts of FHS are clinically more severe in children than adults. These WTP values are subjective valuations.

As with the adult samples, we test in the child models for the effects of FHS-severity on WTP and for declining value of additional years. In addition we test for the effects of the child's age on WTP – a plausible effect since younger children are less able to control what they consume and so may be regarded as more at risk of an adverse event.

In the child models we find evidence of WTP values being moderated by FHS- severity in only the coeliac model - the more severe the condition (as scored by the parent) the greater the WTP value of years of disease removal.

In the child allergy and intolerance models the FAQLQ and FIQLQ scores affect the degree of aversion to moving away from the status quo option – the more severe the condition impacts the less averse people are to taking the pill to remove their condition. But the FAQLQ and FIQLQ scores do not affect the WTP value.

We find no evidence of declining WTP for additional years without the condition for children. We do however identify an effect of the child's age on WTP in the child food allergy model – the WTP value declines with the child's age.

## 11.4 BWS Results

The BWS results indicate that people assign very different levels of importance to the impacts comprising the FAQLQ, FIQLQ and CDQ instruments. For example, in the adult allergy results on the impacts on quality of life, the most important impact included in the FAQLQ (the fear of an allergic reaction) is 8 times more important than the least important FAQLQ impact (the trouble from eating out less). This unequal prioritisation contrasts with the equal weighting used when constructing the FAQLQ, FIQLQ and CDQ measures.

Concerns related to eating out were top ranked for people with coeliac disease and ranked second for people with a Food Allergy. The trouble associated with reading labels was ranked least or near least important by people with food allergies and food intolerances.

The three impacts which were indicated to have the greatest impacts on people's quality of life, for each condition, are shown in Table 11.2. Embarrassment or fear related to eating out or /social situations feature in the top three impacts for all the conditions.

**Table 11.2. FHS impacts with greatest effect on quality of life, by condition, from BWS results**

### **Food Allergy**

1. The fear of an allergic reaction
2. the fear of an allergic reaction when eating out
3. the trouble from always being alert as to what you are eating

### **Coeliac Disease**

1. feeling afraid to eat out because my food may be contaminated
2. the concern that my long term health will be affected
3. the concern that this disease will cause other health problems

### **Food intolerance**

1. the worry that you experience physical distress because of symptoms during a reaction
2. the trouble from having to always be alert as to what you are eating
3. the worry that you will be embarrassed by the symptoms of a reaction in social situations

## **11.5 Limitations**

The sample sizes were sufficient for the estimation of statistically significant effects of duration of FHS-removal and cost. However, it should be noted that the sample of parents of children with coeliac disease was small (73 people) and not all of those completed the choice sets (having been filtered out because of their choice behaviour in the training or priced choice sets). The sample was recruited from 3 pools, and attempts were made to increase the sample size (by for example offering additional inducements) – this did result in increases in the sample, but the parents of children with coeliac disease proved hard to recruit. Further augmentation of that sample would further increase confidence in the results derived from estimation of choice models of the form presented here.

An evaluation of whether the samples are representative of the UK populations of people with food allergies, intolerances and coeliac disease is not possible because of the absence of UK data on the prevalence of those conditions. This is a limitation of the study. Reliable prevalence data would allow an assessment of representativeness and potentially the use of weights to aggregate from the sample to the population.

The estimated WTP values are for the removal of the condition (for a specified period). Respondents were not asked to mentally partition the value of pain, suffering and anxiety from other aspects, such as the savings (in time and money) that removal of their (child's) FHS would generate. As such, the WTP values estimated here are an aggregate value, including inter alia the expected financial savings.

## **11.6 Recommendations**

This research aimed to:

- A. estimate the economic value to people of removing the symptoms and limitations of their food hypersensitivities.
- B. identify the impacts of living with food hypersensitivity which most affect people's quality of life.

Regarding (A), the WTP models estimated have been designed to provide an estimate of the economic value to people with a food hypersensitivity of a year without their condition. The estimated WTP values encompass the pain, suffering, anxiety as well as the cost and inconvenience imposed by food hypersensitivities.

The magnitude of estimated WTP values seem plausible, as is the finding that the WTP of parents regarding their children was greater than the WTP of adults about themselves.

Confidence in the validity of the results is increased by the feedback in the focus groups, the low rates of rejection of the DCE valuation scenario and the assessment of the difficulty in understanding and making the choices in the DCE.

One of the motivations of the research was to provide WTP values which could be used to extend the FSA's Cost of Illness (COI) model from its current focus on foodborne disease to include the costs of food hypersensitivities.

The COI model currently includes the tangible (private medical expenditures and costs to the NHS, loss of earnings and costs to business) and intangible costs (pain, grief and suffering) caused by foodborne disease. It generates estimates of the annual burden to society from foodborne to facilitate assessment of cost effectiveness of food safety policy interventions, impact assessments and evaluation.

Extending the model to incorporate food hypersensitivity values requires an annual monetary value of the burden associated with FHS. The model can accommodate values disaggregated by the three conditions included in this study, and whether a 'case' is an adult or a child.

Identifying the appropriate WTP values to use in the COI model from the models reported above requires some explanation given that the estimated models:

- are based on a DCE in which the period of FHS removal ranged from 1 to 20 years.
- include a Status Quo ASC for which a WTP can be estimated in addition to the WTP per year of FHS removal
- include (in some preferred specifications):
  - declining marginal value of additional years without FHS
  - measures of FHS-severity
  - age of child

The use of varying levels of FHS removal in the DCE was necessary because of the finding from the focus groups (Section 6) that for important numbers of respondents the adjustment 'costs' associated with removing the FHS for a single year, and then having it return, were large enough to decline that one-year removal. Even at zero cost.

This preference to reject zero-cost removal of the FHS for short periods of time is a manifestation of the costs of adjustment (associated with short term FHS removal) exceeding the benefits of removal. Hence the DCE design included varying and, in some cases, long, durations (up to 20 years). Although choices will still be affected by respondents' perception of adjustment costs, an annual value can be estimated, partitioned from those adjustment costs.

That partitioning is achieved by the inclusion, in the models estimated to yield WTP, of the Alternative Specific Coefficient (ASC), associated with not choosing the pill.

In the models estimated people, on average, have a positive preference for the Status Quo (SQ). As such they have a positive WTP to avoid change – to avoid taking the pill to remove the FHS. This WTP can be estimated (See Appendix D).

This is not the case for the COI model. The WTP for the SQ represents the value associated with avoiding change in condition, whereas the COI model is concerned with costs of ongoing conditions. If, in contrast, one was interested in evaluating the market potential for a treatment that did indeed deliver relief from the FHS then this additional value should be included in the analysis, as it will modify the WTP value to transition from having, to not having, the condition.

Whereas for the COI model it is the economic value associated with the ongoing pain, suffering, inconvenience and cost that is relevant.

The preferred models (See Section 9) include:

- FHS-severity effects on WTP

For the COI model we recommend using WTP values evaluated at median values of FAQLQ and FIQLQ instruments.

- declining WTP for additional years of relief from FHS

For the COI model what is required is the WTP related to the current year. In cases of non-constant marginal utilities (adult Coeliac coeliac disease and food allergy models) we recommend using the WTP value estimated at a 1-year time horizon

- WTP varying with the age of the affected child.

In the child food allergy model, the WTP ranges from £3465 for a 1-year-old to £2197 for a 17-year-old. The choice of value to be used in the COI model should lie in this range but it is essentially arbitrary, and we have adopted the value for a 10-year old of £2766.

Based on these findings we recommend that:

- the WTP values presented in Table 11.3 be incorporated into the COI model as annual FHS cost values for children and adults with the three conditions and used for impact assessments and evaluations by the FSA
- additional work be undertaken to better understand the prevalence of the conditions among adults and children, particularly given widespread (potentially mistaken) self-diagnosis of conditions
- the FSA review the results of the BWS exercises as they are an indication of the priorities of people living with food hypersensitivities, disaggregated by the 3 conditions.

**Table 11.3. WTP Results, in Aggregate and by Condition, for Adults and Children**

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